

Cloaked representations of a cloaked disease:  
individualised experiences of dealing with genital  
chlamydial infection

Hilary Clare Piercy

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School of Nursing and Midwifery

University of Sheffield

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## **Abstract**

The aim of this study was to explore the impact of chlamydial infection from the perspective of the individual. One-off, unstructured interviews were conducted, either in the Genitourinary Medicine or the Family Planning Clinic, with 50 individuals (40 females and 10 males) who had contracted this sexually transmitted infection (STI). A grounded theory approach was used.

STI's have long since been associated with moral reprobation and social sanctioning, particularly in relation to females. They are diseases that other people get, associated with specific types and behaviours. This legacy has shaped their institutional management and it largely determined the individual and interpersonal responses of the study participants. However this effect was modified by the specific location of chlamydia within the hierarchy of STI's where ranking occurs primarily on the basis of curability and visibility. In these terms chlamydia was classed as a 'little' infection.

On an individual level, diagnosis of infection was strongly associated with a sense of discordance and a spoiled identity, commonly expressed as feelings of dirt and contamination. Some felt a need to feel clean following infection; the test of cure fulfilled this function marking the transition from liminality. Intentions to prevent re-infection centred on routine or relationship based strategies. Long term concerns were limited to possible female infertility.

On an interpersonal level, information control decisions were influenced by fear of disapproval and potential threat to social reputation. Notification of sexual partners, which is necessary to prevent re-infection of self and infection of others, was fraught with anxieties. It created opportunities for moral positioning and was associated with accusations of culpability and intent.

The health interface influenced responses to infection. The female experience commonly included management in primary care which was associated with insensitive management and inadequate information. The GUM clinic produced anxieties concerning usage but attendance was associated with confidence in contained and comprehensive infection management.

These findings are discussed in relation to policies and practices that focus disproportionately upon women, particularly the chlamydia screening programme.

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## **Chapter 1: Introduction and study assumptions**

### **1.1 Introduction**

*Chlamydia trachomatis* is currently the most commonly diagnosed sexually transmitted infection and therefore represents a significant health concern. Although its effects on the human body have been recognised for centuries, in some ways it might be considered a relative newcomer to the catalogue of sexually transmitted diseases because isolation of this organism and the development of reliable diagnostic tests proved difficult. One of the major characteristics of genital chlamydial infection is the high proportion of asymptomatic infection in both men and women, thus in many cases those who have chlamydial infection are unaware of the fact. In this respect the organism is aptly named as the word chlamydia derives from the Greek *κλαμος* (khlamus) meaning mantle or cloak.

My interest in this organism arose from my clinical background and is concerned with the wide-ranging effects that it has upon the individual. As a sexual health specialist nurse, my clinical work is in the contraceptive and sexual health clinics, also known as Family Planning Clinics. In this setting I witnessed a rapid increase in the amount of professional attention that genital chlamydial infection was attracting in the mid 1990's. At that time significant changes were occurring in this service. Whereas the role of the clinic had previously been confined almost exclusively to contraception and pregnancy, it expanded to incorporate the prevention and detection of infection and eventually also involved screening for infection in specific identified situations. This resulted in a steady increase in the amount of diagnostic testing for chlamydia in the clinics which in turn resulted in a significant increase in the number of female patients who were being diagnosed with this infection.

#### **1.1.1 Broaching the subject**

Contraceptive and Genitourinary Medicine services always have been and largely remain distinct from one another organisationally and structurally. As a result of this, it is relatively uncommon for members of staff, either nurses or doctors, working in the contraceptive service to have had previous or current experience of genitourinary medicine. Consequently, at that time staff working in the Family Planning Clinic (FPC) often felt ill equipped to deal adequately with the growing expectation that they expand their role to incorporate consideration of and investigation for sexually transmitted infections (STI's) and that they deal with the aftermath that occurred as a result of a positive diagnosis. The patients needed sensitive and appropriate care and this

required a depth of knowledge and a degree of confidence in discussing intimate sexual behaviours with which the staff were not necessarily equipped. On a personal level, my increasing knowledge and interest resulted in my increasing willingness to broach and discuss the topic with clients and I became acutely aware of the emotional impact that this infection appeared to have upon individuals who were diagnosed with it.

To discuss testing with these women was difficult because the vast majority had never heard of chlamydial infection and fewer realised that it was classified as an STI, with the consequent implications for treatment and management. It was not uncommon for women to say that they had heard the name but that they thought it was a wild flower. This general lack of awareness was confirmed by knowledge surveys conducted in the FPC and Genitourinary Medicine (GUM) clinics which also indicated high levels of misinformation and confusion (Piercy et al., 2000, Kellock et al., 1999). It was equally difficult to deal with those whose test results were positive because of the profound reaction and sense of horror that resulted and the inevitable questions which required adequate and sensitive responses.

### **1.1.2 The sexual health arena**

On a theoretical level, the amount of literature concerning chlamydial infection burgeoned as a result of the increasing number of diagnoses and the consequent increased level of professional interest. Much of this literature stemmed from the development of new testing techniques and was concerned with reporting initiatives to detect chlamydial infection in a variety of clinical settings. Other studies reported efforts to increase awareness of chlamydial infection and interventions to reduce infection. The missing component in all these was the patient whose perspective was remarkably absent on all counts. The effect of this, together with one-sided discussions of testing strategies and behavioural interventions, has been to objectify the person and present them as amenable to behavioural manipulation whilst failing to acknowledge the complexity of human behaviour and sexual relationships.

HIV has dominated the sexual health arena for the past twenty years such that it is difficult to contemplate any issue other than in respect of Human Immunodeficiency Virus (HIV). Consequently it has had a considerable impact upon the way that infections such as chlamydia are viewed and managed. HIV was responsible for the construction of an entirely new set of discourses. Sexual intercourse became a risky practice and concepts of safer sex were created. The condom, which had previously

been effectively obsolete, confined to the margins of contraceptive practices by the medically sanctioned contraceptive pill, emerged as the solution. It became the means by which to protect oneself from the unknown risk to which one was continuously exposed in the pursuance of sexual pleasures and gratification. Using a condom now came to be constructed as the only safe and morally responsible thing to do; the way in which to protect oneself and others.

As other infections forced themselves onto the public and professional platform as a result of increasing prevalence rates, the strategies that had been developed and energetically pursued in efforts to combat HIV were adopted and applied wholesale to these other infections. Exhortations to use a condom to protect oneself against HIV became the means by which to protect oneself against all STI's. The high degree of logic of this approach, given the commonality of transmission routes, makes it difficult to refute its validity. However this approach emphasises the similarities between infections whilst simultaneously failing to acknowledge the differences between them which arise from the characteristics of the individual infections and their specific social and cultural construction.

HIV led to the production of a vast multidisciplinary body of knowledge. The social sciences, for example psychology, sociology, anthropology, that had previously paid little attention to sexual health became fully engaged with the topic through the auspices of HIV. The result is apparent on the bookshelves of medical libraries where the sexual health section is dominated by diverse forms of HIV literature that considers the topic from every conceivable angle. It incorporates a multitude of approaches and represents the full spectrum of scientific disciplines from molecular biology, pharmacology and pharmacokinetics, sociology, psychology, anthropology, epidemiology and immunology, to name but a few. Other related but separate topics, such as other infections, have received attention within medicine but that attention has not expanded in any appreciable sense within the related disciplines that have embraced HIV. Consequently there is a considerable body of social science literature that deals with HIV but almost none that deals with any other sexually transmitted infection.

## **1.2 The aim of the study**

The overall aim of this study was to explore the impact of having chlamydial infection from the perspective of the individual. In particular I set out to consider the following key elements;

- The extent to which that experience was determined by the fact that this infection is sexually transmitted and how that influenced personal responses and interpersonal relationships.
- The extent to which that experience was shaped or modified by the specific characteristics of this particular infection.
- A wider consideration of the way that health policies and the consequent changes in service delivery impact upon the individual experience.

Its relatively recent categorisation as an STI together with the ease of treatment and the high proportion of asymptomatic infections would suggest that chlamydia constitutes a relatively minor health concern in some respects, although its potential impact upon long term health and fertility may be considerable. Although the process by which it is detected, a genital swab or urine sample, might be associated with embarrassment and consequent reticence, it is nevertheless a relatively easy and straightforward procedure and not highly invasive. The treatment is straightforward; at worse a course of antibiotics and a period of sexual abstinence, and has a very good rate of effectiveness. This infection might therefore be expected to represent a small and relatively insignificant episode in someone's life.

However this was not my clinical experience. My contact with those who had or had had chlamydial infection indicated that this infection episode was anything but insignificant. It was particularly traumatising at the time of diagnosis but subsequent frequent requests for re-testing suggested that it may be associated with an ongoing sense of vulnerability. I knew from clinical experience that a diagnosis of chlamydial infection commonly produced a range of questions. The women wanted to know what it was, where it had come from, how long they had had it and what it had done to them. These questions are clearly grounded in the social context of the infection, they arise from personal and social concerns and the possible answers must necessarily have personal and social significance. The sexually transmitted nature of this infection means that these questions are not a matter of simple curiosity. They are far-reaching, incorporating physical and social considerations, and possible answers have ramifications for self and others. I wanted to explore the way in which people managed the information that was available to them and the way in which they used it to make sense of their infection experience.

In 1998, publication of the CMO Expert Advisory report of chlamydia screening (DH, 1998) gave impetus to the already discernible increase in the detection and

management of this infection in primary care. In view of this I was anxious to examine the extent to which this increased involvement of non specialist clinicians impacted upon the experience of those with the infection and the role that specialist GUM services played in the process. One effect of the recommendations that came out from this report has been an increased focus of attention upon women and the development of opportunistic screening strategies that target women, despite the fact that this infection occurs equally in men and women. I was anxious not to perpetuate this gender bias that appeared to fail both women and men by placing undue emphasis upon the former and effectively ignoring the latter. Therefore, I determined to include men and women in this study as the means by which to represent the views, concerns and experience of both and to compare and contrast the gendered experiences of the infection itself and the testing strategies that were beginning to emerge. This mixed gender approach required me to make decisions regarding the use of collective pronouns in this study. As the majority of study respondents were female, the collective pronoun 'she' has been used other than when specifically referring to males when 'he' is used.

### **1.3 Study assumptions and terminology**

The history of sexually transmitted infection is punctuated by changes in the associated medical terminology. Venereal diseases (VD) were re-named as sexually transmitted diseases (STD's) and these were in turn replaced by sexually transmitted infections (STI's) and most recently sexually shared infections (SSI's). This reflected efforts to move away from connotations of sin that are implicit in the term venereal and connotations of culpability that are implicit in the term transmitted.

In this study the historical legacy forms a necessary part of the discussion because it plays a highly prominent role in forming and shaping understanding and experience. Whilst I have primarily used the term STI because it is the term in common usage today, other terms have been used when indicated by the historical context of the discussion. The move from disease to infection is significant because it reflected an effort to distinguish between the detection of a micro-organism and its bodily effect. In this respect use of the terms disease, illness and infection is important and merits consideration of their meaning and their interrelationship within the context of chlamydia. In the abbreviated terms STI's and STD's which are used throughout the text, I have inserted an apostrophe for ease of readability.

### **1.3.1 Disease and illness**

The concepts of disease and illness are inextricably linked in so far as recognition of one trades upon knowledge of the other (Dingwall, 1976). Whilst both terms centre round a specific problem, they do so from different perspectives. The term disease reflects a biomedical perspective and a reductionist approach in which the problem is configured as an alteration in biological structure or function (Kleinman, 1988) from which the individual is largely absent. Illness on the other hand is a label, a term that is attached to indicate that disturbances to the body and its normal functioning has occurred (Radley, 1997). However it is more than this. It is the human experience of those symptoms and encompasses the lived experience of monitoring bodily processes, and their appraisal as expectable, serious or requiring treatment. It incorporates the categorisation and explanation to others in the social group of those forms of distress that are caused by the pathophysiological process (Kleinman, 1988). Illness is an embodied experience expressed through the medium of symptoms.

Although the presence of disease is implicit in an illness, the two states are distinct and the relationship between them is far from simple (Calnan, 1987). Illness is fundamentally different from disease which is a medical label applied as a consequence of the recasting of the illness, viewed through the theoretical lens of medical practice. Disease is the problem viewed from the practitioner perspective, reconfigured as an alteration in function, either in a narrow biological sense or in a more expanded biopsychosocial context that recognises the interrelationships between the physical, psychological and social components (Kleinman, 1988). Disease in these terms would therefore expect to be preceded by the subjective self labelling of illness. It presupposes that the diagnosis of a disease always has to have its roots in the patient's experience of illness. It takes no account of disease in the absence of symptoms or the patient's experiences of symptom relief as a cure, even though the diagnosed disease is still present (Helman, 1995). However, the trajectories of the two are often at variance and the one may readily exist in the absence of the other. The presence of organic disease can and frequently does exist without any indication of bodily changes that may be identified as illness and similarly, a subjective assessment of being ill may readily exist in the absence of any identifiable biomedical evidence of disease. In a health arena that is increasingly populated by surveillance and monitoring techniques, disease may well be identified even though the individual concerned may have no indication of those elements that constitute illness.

The association between illness and infection is an area of further ambiguity. An infection state requires separate consideration, particularly when it is an infection that produces a variable bodily experience in terms of the identification of bodily changes. Consideration of an infection state is conceptually more difficult to grasp in a theoretical sense than an illness state because of its amorphous form. In some instances an infection may result in both disease and illness, however an infection may be present and produce no indication of its presence or it may produce symptoms that do not merit classification as illness. Someone may therefore have an infection without considering that they have an illness, either in the presence or the absence of symptoms. The infected state, when discovered may be sufficient to justify location within a disease category, however the extent to which disease, within the terms of the definition provided above, is present may not be clear.

This is of particular relevance in terms of chlamydial infection. In this situation, the relationship between the infective organism and the body to which it gains entry is somewhat problematic in so far as the manifestation of effect is variable. If symptoms are the marker of illness, then this commonly asymptomatic infection may or may not be equated with illness even though a diagnostic label has been applied. Similarly, the disease label is not inevitably attached at the point of diagnosis because infection in the absence of altered function or pathological change is also entirely possible, even though disease may become manifest at some time distant from the time of infection. Whilst I will primarily refer to an infection episode in this study, the terms illness and illness episode will also be used to reflect the fact that this infection produces emotional and psychological effects as well as physical body changes and is therefore intended to encompass the whole infection experience.

### **1.3.2 Sexual orientation.**

Although *Chlamydia trachomatis* is transmitted by both heterosexual and homosexual intercourse, this study considers chlamydial infection within the context of heterosexual relationships. This has occurred as a result of the study rather than being a pre-determined decision. It arose simply because all those recruited into the study described themselves and located the source of their infection within a heterosexual relationship. Consequently the findings of this study will be limited to heterosexual relationships and any reference to partners within the study will imply heterosexual partners.

### **1.3.3 The biographical details of participants**

It was necessary at the outset to decide what specific demographic data should be collected on all the participants. In an exploratory study of this sort it is particularly difficult to predict what personal details may or may not be relevant in relation to analysis of the emergent data. I decided to record age and gender alone. After consideration I decided not to collect data on social class. Social class is highly contested with a variety of categorisation systems, however occupation is central to the analysis of class and status and therefore is the basis upon which categories are formed (Scott, 1999). As this infection is most prevalent in those aged under 25, I anticipated that the majority of respondents would fall in the age range of 16-25 years. The expected variability in the educational and employment status, with some in full time education and others in employment, would have made it difficult to assess social class and for those who were in full-time education and economic dependents, it would have necessitated asking questions about the employment status of their parents. It was largely on this basis that I decided not to collect such information. I also decided at the outset to ask about the perceived relationship status. This proved to be somewhat more complex than I had anticipated and whilst it was clear cut and highly significant in some accounts, forming the basis of a number of explanations, it was considerably more ambiguous in other accounts.

Appendix I presents an overview of core details of the individual and their infection episode in a tabulated form for reference purposes as well as explanatory notes that identify the limitations of the information supplied. The names of the respondents are all pseudonyms and these are used throughout the findings section. The order in the table reflects the order in which interviews were conducted. Relationship status has been omitted from the table for the reasons stated above but will be incorporated within the findings.

The quotes in the findings section are the words of the respondents. The addition of other bracketed words has been kept to a minimum and used only where necessary to convey the sense of what was being said.

## **Chapter two: Background to the study**

### **Section One: A Historical overview of sexually transmitted infections**

#### **2.1 Introduction**

Sexually transmitted infections occupy a position in history that is derived as much from their social construction as from their position as pathologising conditions within the development of medical understanding. Their history belongs to the original venereal diseases of syphilis and gonorrhoea that came to be increasingly and inseparably associated with social attitudes and values, both in considerations of hygiene and as representations of morality, of sin and punishment, blame and retribution. With the passage of time they became increasingly associated with specific people and activities, becoming synonymous in the 18<sup>th</sup> and 19<sup>th</sup> centuries with women and more specifically with prostitutes such that these women came to be constructed as pathologised female and contaminated other (Spongberg, 1997). The power and persistence of this representation is such that it dominated public practice and policy efforts to control disease well into the 20<sup>th</sup> century both in relation to the traditional and the more recently recognised infections, and it continues to reverberate through personal accounts of these infections in the present time.

#### **2.2 The emergence of venereal diseases**

It appears that gonorrhoea has been known about since the earliest times. Descriptions of symptoms attributable to the disease are recognisable in Assyrian tablets that referred to cloudy and thick urine whilst Hippocrates described urethral strictures or strangury (Rosebury, 1972). The word itself is derived from its Greek name of gonorrhea meaning 'flow of seed' (Spongberg, 1997) which is further reflected in the Roman name of seminis efusio (Foucault, 1986). Although the disease was well recognised, it was generally considered a relatively minor condition of little consequence and exclusively a male condition. Galen considered it to be the involuntary discharge of sperm without erection of the penis, the result of paralysis of the spermatic vessels a shameful condition in so far as it represented a loss of virility (Foucault, 1986). By the thirteenth century the occurrence of gonorrhoea in men was attributed to impurities retained under the prepuce after exposure to an unclean woman (Rosebury, 1972, Worboys, 2004). This view persisted for centuries. In the 1860's, medical textbooks described it as a specific contagious disease whereby gonorrhoeal poisons were spread to men by healthy women as a result of sexual contact with their genital fluids (Worboys, 2004). This viewpoint reflected in part the largely

asymptomatic nature of infection in women, but was largely derived from and served to reinforce representations of the pathologised female body. The usual source of gonorrhoeal poison was considered to be that which had been deposited in the vagina of an 'unsound woman' by the man that she had previously had intercourse with. Other theories of the time considered prostitutes to be reservoirs of infection. Having become habituated themselves to its effect, they were not themselves harmed by it but they served as a source of infection to those men with whom they had sex (Worboys, 2004, Spongberg, 1997). Although there was a growing realisation in the 1870's that gonorrhoea caused infection in women, it received little serious attention until the late 1890's when the medical gaze shifted from externally located diseases towards internal conditions. This created conditions within which the pathologising effect of an infection that coursed its way through those internal structures of the female genital tract could be visualised (Worboys, 2004).

The origins of syphilis are contested. Whilst there are references in early writings to symptoms that could be attributable to syphilis, it made a significant appearance in the literature in the early to mid 1500's which suggests that it spread throughout Europe in epidemic proportions (Davenport Hines, 1990). From the outset its connection with sexual activity was recognised and provided facility to see it as the evidence of divine retribution. In his edict of 1495, Emperor Maximilian declared syphilis to be God's punishment for the sins of man (Andreski, 1989). Allen suggests that this fearful disfiguring condition spread through Europe on an epidemic scale producing widespread panic. The spread of infection caused increasing levels of fear and with it, blame (Allen, 2000). Blame was evident on a national and a personal level. On a national level it produced theories that explained the origins of this disease as located anywhere as long as it was other. One example of this is that it originated in America and was brought from the New World to Europe by Columbus. This explanation is attributed to the testimony of Ruy Dias de Isla who in his account 'Tractado contra el mal Serpentino' documented how he had treated a number of Columbus' sailors for this disease after they had returned to Barcelona in 1493 from Hayti (Abraham, 1935). Another example is found in the writings of the 16<sup>th</sup> century Venetian physician and poet Fracastoro. His lengthy poem in three parts, 'Syphilis sive morbus Gallicus' (Syphilis or the French disease) recounts how the disease was inflicted on the shepherd Syphilus as punishment by the Gods (Fracastoro, 1935). This title is attributable to the first definite evidence of syphilis in Europe which dates from the capture of Naples by Charles VIII of France in 1495 (Abraham, 1935). The poem, which was extremely well received in its time, not only gave rise to the name of the

disease but also gave support to the common practice of attributing it to another, the beginnings of a history that variously described it as a French, Italian or Neapolitan disease, as European pustules or the ulcer of Canton (Crosby, 1977). The labelling of syphilis as a foreigner's disease is considered to be a product of its abrupt appearance (Crosby, 1977), however it also represented the way in which disease was located in wrongness, conceptualised as archaically identical with the non-us, the alien. As a person judged to be wrong, a foreigner is regarded as, at least potentially, a source of pollution (Sontag, 1991).

On a personal level it was reflected in increasingly punitive measures that castigated and persecuted those afflicted with the disease, denouncing them from the pulpit, banishing them from settlements and refusing them hospital care and treatment (Allen, 2000). This approach was already well established in the treatment meted out to those with leprosy in which the outward decay of the flesh was considered a sign of inner promiscuity. Lepers were considered to be a moral and physical threat to the community and required to be separated from the rest of the population by ritualistic means (Turner, 1996). With the appearance of syphilis the focus of attention simply shifted to the syphilitic who adopted the social script that had been written for leprosy, as the visible and outward manifestation of inner corruption (Spongberg, 1997).

### **2.3 The feminisation of venereal diseases**

Gonorrhoea was subsumed in the interest that syphilis attracted. In the 16<sup>th</sup> century it became gradually entangled with and incorporated into treatises on syphilis which came to dominate considerations and representations of venereal disease. There was considerable and increasing confusion between the symptoms of one and the other. They came increasingly to be understood and presented as different manifestations of the same disease. Although this viewpoint was challenged by some, it was undermined in the 18<sup>th</sup> century by the ill-fated experiment of John Hunter who inoculated himself with a discharge diagnosed as gonorrhoea and subsequently developed symptoms of syphilis. Hunter was chiefly responsible for the persistence of the single disease theory which persisted until the mid 19<sup>th</sup> century, and for the gendered interpretations of the infection that stemmed from its understanding, chiefly in terms of the discharge that it produced. Gonorrhoea was considered to chiefly affect men, however even those who were infected were not considered a threat to others, on condition that they took trouble to remove all discharge prior to intercourse (Spongberg, 1997). This focus of attention on discharges caused all women to be viewed with suspicion (op cit). The source of danger was considered to be located in the woman's

discharge, vaginal secretions and menstrual fluids. Contact with any of these fluids was considered to produce urethral inflammation in men (Walkowitz, 1982). Women's bodies therefore came increasingly to be pathologised, viewed as innately diseased. Simultaneously however, it was considered that women could carry the disease without damage to themselves. They simply served as a source of contamination to men (Brandt, 1987).

In the eighteenth and nineteenth centuries, attitudes towards venereal disease largely reflected the decorums of class and gender, and were themselves reflected in the provision and availability of medical treatment. A disease that was considered an unfortunate but almost inevitable aspect of manhood was viewed as a source of disgust in women (Rizzo, 1996). To seek treatment was therefore considerably more acceptable for men and collusion by doctors to keep the infection secret from prospective and current wives was common (Stewart, 1996, Walkowitz, 1982). There was a dichotomous split in the portrayal of women, either as dangerous sources of infection or innocent victims of the infection i.e. the wives of those men who had been infected by the dangerous prostitutes. Whilst those women who had been infected by their husbands were expected to be submissive to male prerogatives, they were considered innocent victims and merited preferential admission for treatment in the venereal hospital, known as the London Lock (Williams, 1995). By contrast, the infection and consequent misery of prostitutes was regarded as morally deserved. This group of women came increasingly to be socially marginalised and ostracised. The establishment of the Lock asylum for penitent female patients in 1792 reflected the spirit of moral reform prevalent at the time, portraying the women as a danger to society. Treatment for venereal disease at that time was inseparable from moral reform, subject to sponsors of good character and contingent upon penitence (Williams, 1995).

#### **2.4 The Contagious Diseases Acts**

In the second half of the nineteenth century the Royal Commission into the health of the Armed Forces revealed alarmingly high levels of syphilis among soldiers in the Crimean War with morbidity rates that threatened the economic stability and the fighting capacity of the nation (Walkowitz, 1982). The findings of the Commission reinforced the idea that the female body was a reservoir for infection, and consequently that those women who were identified as the primary source of disease, the prostitutes, required careful monitoring to check the spread of the disease. In response to increasing pressure from civil and military authorities to introduce a system of

regulation the first Contagious Diseases Act was passed in July 1864 (Walkowitz, 1982, Spongberg, 1997). As the first piece of legislation pertaining to sexually transmitted infections, this Act represented a systematic attempt to prevent the spread of venereal disease among one specific group of people, the men in the Armed Forces, by the identification and containment of another specific group of people, women considered to be prostitutes. It applied specifically to eleven nominated naval ports and garrison towns and provided for the compulsory hospitalisation of any woman who was suspected of being a prostitute with a venereal disease. This was done on the evidence of one policeman who was required to stand before a magistrate and testify that a particular woman was a prostitute. This required her to submit herself to examination and, if found to be suffering from a contagious disease, she could then be detained for a period not exceeding three months (Spongberg, 1997, Keogh et al., 1913). The Lock hospitals and asylums that had been conceived as a place of refuge and healing for fallen sinners became places of imprisonment and punishment (Williams, 1995).

Amendments to the Act in 1866 extended the police powers and introduced two further elements; those of registration and fortnightly examinations (Roberts, 1993). This latter Act also provided opportunity for presumptive evidence in so far as the earlier Act required that a woman be charged with being both diseased and a prostitute whereas in the latter Act, the accusation of prostitution was sufficient to carry the presumption of disease (Keogh et al., 1913). Prostitution was taken as evidence of the existence of disease, and disease was taken as evidence of immoral behaviour. By this latter Act, disease and prostitution had become entirely synonymous. A third Act in 1869 extended the number of towns and cities to which the Act applied and was accompanied by a civil association set up with the aim of securing the application of the Act throughout the country (Roberts, 1993).

These punitive measures took place against a medical backdrop of poor and inadequate diagnostic testing, poor hygiene standards and subsequent cross infection. The treatment regimes that were available at the time were primarily based on mercury which was likely to be more harmful than the original disease. In the first two Acts, prostitutes were clearly seen as a source of contagion and therefore a danger from which the military men must be protected. In the third Act, the shift from primarily military measures to the wider limits of the Act extended its remit such that it increasingly served to increase the moral surveillance of the working class. As Roberts states

“If sex itself was dangerous, sex with a working class woman was more so; for she could serve as a channel through which the dirt, disease and immorality of the working classes could reach into the sanctity and purity of the middle-class home. Syphilis, the disease of immorality, summed up this fear of contagion by marking the whore as society's true enemy within. The Contagious Diseases Act could be rationalised as a means of dealing with this enemy.” (Roberts, 1993 p. 248)

The three Acts reinforced and extended the double standard of morality. For a man venereal disease at worst served as evidence of the excusable depravity that comes with keeping bad company. By comparison, infection in a woman was considered nothing short of criminal (Morton, 1971). Enforced containment of women was considered necessary to protect the men from the consequences of their depraved tendencies. The requirement that these women also wear yellow dresses for easy identification served to reinforce this double standard, making an invisible danger highly visible. With the broadening remit of the three successive Acts, police powers were extended with the arrest and registering of any woman deemed to be a prostitute who from that point onwards was labelled as a ‘common prostitute.’ The threat of registration discouraged working-class women from associating with prostitutes with the result that they became increasingly isolated and ostracized (Roberts, 1993).

Increasing opposition to the Acts gathered strength in the 1870's. This was primarily led by the National Anti-Contagious Diseases Act Association (NA) and the Ladies National Association (LNA) which had been formed under the leadership of the social reformer Josephine Butler. However whilst these two organisations attacked the Act, their position continued to support the idea that disease and prostitution were synonymous, in so far as the terms were used interchangeably by reformers. Although they did expose the implicit double morality by adopting a stance that primarily viewed prostitutes as victims of male lust, their primary opposition to the act lay in its ineffectiveness in stemming the flood of disease (Spongberg, 1997). In the face of opposition, the Contagious Diseases Acts were suspended in 1888 and repealed three years later in 1891 although coercive measures against women were once again instigated in 1916 and 1918 within the Defence of the Realm Act as a means by which to protect the Armed Forces from disease (Evans, 1992).

## **2.5 The Venereal Diseases Act and development of the clinic**

In the period immediately following the Contagious Diseases Acts there was little apparent state interest in venereal disease. Although there was treatment for the military, medical facilities for civilians was limited to provision of treatment by a few

voluntary hospitals and private practitioners (Evans, 1992). At the beginning of the 20<sup>th</sup> century, there were significant scientific developments in the diagnosis and treatment of syphilis. These provided an impetus to increasing calls for a Royal Commission on Venereal Disease. The causative organism was identified by Schaudinn in 1905 and led to the development of a diagnostic blood test for syphilis by Wassermann in 1906. In 1909, Erlich announced that he had discovered Salvarsan, the first effective treatment for syphilis. Against a backdrop of political unease about the social ramifications that reflected the legacy of the Contagious Diseases Acts, the government set up a Royal Commission in 1913. The membership and remit of the Commission was heavily contested in broad terms by the conflicting interests of the feminist movement and the medical profession. Despite feminist calls that it address the wider social causes of VD, the terms of reference of the Commission was limited to the prevalence and prevention of VD, and its activity was dominated by the medical profession who constituted the majority of the membership and the witnesses examined (Evans, 1992).

The Royal Commission reported in 1916 and, despite significant difficulties in determining the actual scale of the problem, concluded that VD was a major threat to public health and was responsible for considerable economic loss to the state. In relation to prevention of VD, the Commission reflected a two-pronged approach by making recommendations that addressed both education and medical treatment. The majority of the thirty five recommendations of the Commission addressed medical services and related to diagnosis and treatment reflecting their view that this was the most effective way to prevent disease. They recommended that local authorities were to negotiate with local hospitals to provide diagnostic and treatment services that were neither means nor residence tested. Additionally, General Practitioners (GP's) were to be provided with free supplies of Salvarsan. These recommendations opened the way to the establishment of those treatment facilities from which the present day GUM service is directly descended. Many of the original concepts are still apparent in the service structure today, particularly in the key areas of confidentiality and accessibility.

The Local Government Board issued the Public Health (venereal disease) Regulations of 1916. This paved the way for the establishment of clinics, the majority of which were attached to local hospitals. Legislation followed in the form of the Venereal Diseases Regulation (1917) which legally classified syphilis, gonorrhoea and chancroid as venereal diseases. It also provided members of the public with access to a specialist practitioner without an introductory letter from a GP. Attendance at the clinic was to be

voluntary. Despite considerable initial objection from hospital committees, the result was the establishment of clinics across the country with the numbers rising to 120 in 1920. Staffing was problematic due in part to the low status of the speciality. This caused considerable difficulties particularly in relation to recruitment with few of the medical or nursing staff reportedly working there by choice (Davenport-Hines, 1990). The appointment of full-time VD officers was recommended in 1918 and contributed to a situation where clinics were gradually equipped with specialist staff committed to the treatment of venereal disease (Morton, 1971).

## **2.6 Public efforts to control venereal diseases**

Public health education policies have featured prominently in STI prevention strategies since their formalised inception at the beginning of the 20<sup>th</sup> century. Public education consists of two separate but related activities. National information and propaganda campaigns are designed to convey simple health messages. Their reforming and pedagogic function is to raise public awareness of a health issue and produce attitude and behaviour change (Tulloch and Lupton, 1997). A second approach is the delivery of an educational package of instruction to an accessible and impressionable target population in order to increase their knowledge and inform their subsequent decision making.

In both Britain and America, education on venereal diseases was taken to be an essential public role; the target audience for instruction being military recruits. This represented a direct effort to reduce the alarmingly high rates of infection in this strategically important population at a time of war. Formalisation of teaching was justified on two counts. Firstly it was considered that families and communities had negligently failed to inform their young men of details of sex hygiene and venereal diseases. The task therefore fell to the Authorities and Government to rectify this deficiency. For this purpose the Social Hygiene Instruction Division was created in the USA whilst its British counterpart was the National Council for Combating Venereal Disease (NCCVD). Secondly, it was considered that formal education on these matters, conducted in a standardised and approved format, was preferable and more accurate than the less formal and more haphazard education gained through the home or on the streets. An increasing preference for the use of professionals such as physicians and social hygienists to deliver the lectures reflected a viewpoint that 'experts' were best placed to deliver such education which in a military setting was largely anatomical and practical rather than moralistic (Brandt, 1987).

Following demobilisation after the 1<sup>st</sup> World War, many of these military medical experts moved into the world of civil public education. Here they discovered that the pragmatic approach adopted within the military education programmes did not extend to those deemed appropriate for the civilian population. Public education included considerably more moral policing and a stronger emphasis was placed upon moral and social hygiene to the exclusion of alternative strategies, such as the use of prophylactic disinfectants which had been widely promoted by the military (Towers, 1980). With the advent of treatment centres, subsequent to the Venereal Diseases Act, educational programmes came to concentrate increasingly on the merits of attendance for treatment. The formation of The British Social Hygiene Council (BSHC) in 1925 occurred as a result of the amalgamation of the NCCVD and its rival organisation the Society for the Prevention of Venereal Diseases (SPVD). The activities of this new organisation were less overtly moralistic, however the title reflects the way in which these diseases continued to be considered as socially, morally and personally contaminating.

The 2<sup>nd</sup> World War and the emergent concerns over levels of venereal disease saw a repetition of earlier practices in both Britain and the USA. Education was once again targeted at the military with lectures and educational films, although the emphasis had changed somewhat to reflect the availability of effective treatment and condoms (Brandt, 1987, Hall, 2001). On the home front, the BSHC had been replaced by the Central Council for Health Education, reflective of a greater commitment to a preventive rather than a moral approach in the propaganda campaigns. However the change of emphasis did little to redress the social perspective of venereal disease with its portrayals in advertising leaflets and educational campaigns of the dangerous loose women who 'looked clean but....' (Brandt, 1987). These served not only to sustain the double standards of sexual morality but to perpetuate perceptions of present venereal disease in terms of social hygiene.

## **2.7 Conclusion**

The historical legacy of these diseases is therefore one that grounds them firmly within a moralistic context. The development of medical techniques and treatments provided the means by which to accurately identify and effectively eliminate the organisms from the bodies of those who had become infected. This was the basis upon which the medical treatment centres were established. However, a venereal disease represented a threat not only to the physical body but also to the moral self because they were taken to be indicators of immorality, sin and depravity, particularly for women as a

result of their synonymous association with prostitutes. This presented a considerable challenge to their treatment and informed the structure and organisation of treatment centres from their inception.

## **Section two: Sexual Health Services**

### **2.8 The early days of Genitourinary Medicine**

The establishment of the public treatment centres led to the development of venereology as a medical speciality. However, the centres and their patients were similarly subjected to marginalisation and treated as outcasts. Confined to the out-of-the-way corners of the hospital, with inadequate and substandard facilities, the centres were largely ignored and banished from public and professional thought. This was reflective of prevailing social and moral attitudes to venereal diseases and those who contracted them. The development of effective treatments and the decrease in incidence both in the inter-war period and after the 2<sup>nd</sup> World War resulted in an overall lessening of policy interest that further contributed to their medical marginalisation (Hall, 2001, Evans, 2001). Although their incorporation into the National Health Service (NHS) consolidated their position, and subsequent social and demographic changes altered their profile, the overall policy was one of benign neglect. By the early 1970's the previous problems of poor conditions, overcrowding, and difficulties in attracting staff to this low status area were clearly evident (Evans, 2001). It took the emergence of HIV in the early 1980's to bring STD services centre stage. In 1988 a review of the service was commissioned by the Secretary of State for Social Services (the Monk Report) with a remit to examine current and predicted workloads, and to recommend action needed regarding manpower, training, resources and accommodation (DH, 1988). This, together with the volume of ring fenced HIV funding that was directed into the service, resulted in a massive transformation of the 'Cinderella' service that had existed for seventy years.

### **2.9 The current structure and organisation of GUM services**

Two current advisory publications reflect current thinking on the delivery of genitourinary medicine services. These documents were developed by the Association for Genitourinary Medicine, an organisation recently subsumed within the British Association for Sexual Health and HIV (BASHH). 'Service standards in genitourinary medicine' (BASHH, 2001b) is an advisory document for purchasers and clinical governance leads. It outlines key organisational aspects that address the fundamental principles of the service. 'Basic Considerations for a GU service' (BASHH, 2001a) offers a brief overview of physical and staffing needs for the provision of basic core services in GU medicine at any site, and draws heavily on the Monk Report (DH, 1988) and Health Services Building Notes HBN 12 (Genitourinary Medicine). They provide a comprehensive framework for what is considered to be best working practice in this

area. The fundamental principles of a genitourinary medicine service are identified as follows:

- Open access without need for referral
- Free treatment at point of access
- Confidential service
- On-site diagnosis of common conditions
- Partner notification and health education available to all attenders.

Collectively they contribute to the unique service provided within a GUM clinic. The first four principles have been in place since the clinics were established as a result of the 1917 Venereal Diseases Act. They were established in recognition of the social context within which the diseases were located, the vilification of those suffering from them, and the consequent necessity of reducing barriers to access. The fifth principle developed from the 1940's onwards, being slowly adopted by clinics across the country.

### **2.9.1 The principle of open access**

The GUM clinic fulfils the traditional role of acting as a referral service for general practitioners and other services such as family planning and gynaecology. However, in common with contraceptive services, it is also accessible by self referral. This opportunity to access specialist services directly, bypassing the normal route of referral via a GP, is a unique feature within the NHS and limited to these two specific aspects of sexual health care.

An individual who chooses to access GUM services directly may do so for a number of reasons. They may see it as a means by which to reduce delays in access to care. Alternatively they may wish to detach care for STI's from their GP medical services, perhaps because they have confidentiality concerns, because they want to keep that part of their life separate, or because they have reservations about discussing sexual matters with their general practitioner. Others may view it as a specialist service which is likely to provide high quality care, and choose to access it directly for this reason. In a qualitative study by Evans and Farquhar (1996), service users identified that they wanted a service that was anonymous, confidential, non-judgemental, caring, expert and more convenient than GP services. For some, the ability to self refer to the clinic thereby avoiding general practice does appear to be extremely important, to the extent that they may not have sought assistance if an alternative to their GP had not been available (Dixon-Woods et al., 2001).

Direct access does not always equate to immediate access. Organisational structures vary between clinics. In the majority, there is a mixed approach with pre-booked appointments and immediate access, although some clinics operate an appointment only service, and a small number offer a walk-in only service (Djuretic et al., 2001). Rapid treatment for STI's is considered essential in terms of both the individual and the social control of these infections which can be rapidly and effectively transmitted within a population. However the current high levels of demand for the service have produced lengthy delays in appointments across the country and are a matter of considerable concern (Djuretic et al., 2001, Leenars et al., 1994, Foley et al., 2001, Select Commons Committee, 2003).

In order to access clinics directly, one needs to be aware of their existence and of the direct referral facility. At the time of their development GUM clinics were mainly established in acute hospitals, although this has extended in recent times to the usage of community hospitals and other sites. As the clinics were often tucked away in hard-to-find corners of the hospital their location, together with a marked reluctance on the part of the clients to ask for directions, resulted in these clinics being hard to find. Also, it was common to name the clinic using acronyms, for example the prototype clinic set up at St Georges Hospital, London, was named 'Lydia' (Davenport-Hines, 1990). The purpose of this practice, which persists in a modified form to some extent today, was to disguise the identity of the clinic in an attempt to reduce the embarrassment felt by clients when asking directions. However it perpetuated an assumption that a name that described the function of the clinic was not in itself a suitable label by which the clinic could and should be known. Calls for standardisation suggested that the adoption of a common name would make it easier to talk about the subject, improve its public profile and prevent misunderstanding of function (FitzGerald et al., 1994).

The purpose of using titles that do not explicitly describe the purpose of the clinic is to make the service more acceptable to the public. As a result, people who do not know about the clinic are reliant upon others in order to find out about the existence of this specialist service. There are three identifiable information sources namely, lay referral, 'insider knowledge' usually from a health professional, and contact tracing or referral from a health professional (Dixon-Woods et al., 2001).

The use of anything other than an explicit title contributes to the creation of privileged knowledge. The true function of the clinic is known only to those who have information

that enables them to make the link between the pseudonym and the function. This contributes to a situation where a significant proportion of people are not aware of the existence of the function of the GUM clinic (Leenars et al., 1994). However there is limited evidence to support the practice of using a non explicit title. In a questionnaire survey of GUM attenders, the majority favoured a non-descriptive name (Sonnex et al., 1995). However, those participating in this survey were a privileged group. As a sample of GUM attenders, they were by definition aware of both the existence and the function of the clinic. Consequently their views cannot be taken to represent the views of those who do not have first hand knowledge of the existence of the clinic and who are therefore reliant upon others for this information.

### **2.9.2 Free treatment at the point of access**

Free treatment at the point of access has three purposes. Coupled together with on-site diagnosis of common conditions it enables diagnosis, prescribing, and dispensing to occur at the same time. Firstly, it is considered important from a public health perspective because of the role that prompt treatment plays in reducing spread of infection. Secondly, it removes the cost implications of prescription charges that may act as a deterrent for some individuals in obtaining the medication. Finally, if coupled together with on site dispensing it also minimises the number of personnel that the client needs to interact with, by negating the necessity of visiting a hospital or community pharmacy. Collectively these measures are intended to increase the probability of compliance with the treatment regime. A comprehensive example of this is seen in relation to chlamydial infection. When the treatment of choice is a single dose of azithromycin, the clinic's role in relation to treatment is commonly extended further to incorporate on-site administration of medication. Thus the client may attend the service with a presumptive chlamydial infection, and leave having received the complete treatment regime for the infection.

### **2.9.3 Confidentiality**

All staff are subject to the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 which form part of the 1977 NHS Act. These current directions, which have been modified over time to reflect the changing organisational structure of the NHS, apply only to England and impose an obligation on the members and the employees of both NHS Trusts and Primary Care Trusts to secure that information obtained about sexually transmitted diseases should be treated as confidential. The directions state that

“Every NHS Trust and Primary Care Trust shall take all necessary steps to secure that any information capable of identifying an individual obtained by any of their members or employers with respect to persons examined or treated for any sexually transmitted disease shall not be disclosed except:

- a) for the purpose of communicating that information to a medical practitioner or to a person employed under the direction of a medical practitioner in connection with the treatment of persons suffering from such disease or the prevention of the spread thereof, and
- b) for the purpose of such treatment or prevention.”

(NHS Act, 1977)

Interpretation of this legislation in the GUM setting, and a recognition of the key role that robust safeguards to protect confidentiality have played in making this service acceptable to individual attenders, has led to the development of accepted working practices in GUM which are synonymous with the specialty. Thus patients attending the clinic have records that are specific to that clinic, produced and maintained entirely separate from other hospital records. “It is custom and practice that GUM notes are kept secure within the unit and separate from main hospital notes” (BASHH, 2001a p 4). Additionally the unique code identifier generated for each client attending the GUM is also used as a means of identification in relation to all communications between the service and others such as transport of laboratory forms. This ensures adherence to the legal direction by preventing the disclosure of any information capable of identifying an individual who has attended the clinic to be examined or treated for any sexually transmitted disease. In essence any identifying information relating to the client who attends GUM is contained within that unit. Any information flow that is required in order to collaborate with other services such as laboratories is strictly controlled by encoding. Written communication with the patient’s GP will only occur in response to a formal referral in the majority of cases.

#### **2.9.4 On-site diagnosis of common conditions.**

At first attendance comprehensive testing is offered for all sexually transmitted infections. This includes venepuncture for syphilis and HIV as well as genital swabs and possibly urine samples for other infections. The availability of on-site microbiological facilities in GUM clinics means that slides can be prepared and examined immediately after samples are taken. This enables some diagnoses to be made during the course of the visit which can then be treated. This does not however extend to all conditions. Blood results and some swab results, including chlamydia, are currently laboratory based. This situation results in a delay between investigation and diagnosis and will often necessitate a return visit.

### **2.9.5 Partner notification and health education.**

Genitourinary medicine has a clear remit to perform a public health role as well as providing care and treatment for individuals. This extends to the statutory obligation to return statistical data to the Department of Health on the KC60 return form, a requirement since 1917. The content of the return has undergone several revisions since its inception, the most comprehensive in 1988 as part of the revision of government statistics following the Korner report. Collation and analysis of the data was delegated to the Public Health Laboratory service (PHLS) communicable disease surveillance centre in 1996 and subsequently to the Health Protection Agency (HPA). This data forms the primary dataset for STI statistics in England and Wales. In relation to Chlamydial infections, codes C4 A-E are assigned, covering uncomplicated and complicated chlamydial infections, Chlamydia ophthalmia neonatorum and the epidemiological treatment of suspected chlamydial infection.

The second public health role of the GUM clinic is that of partner notification, the identification and notification of the sexual contacts of those with infections, for the purpose of offering them treatment, and reducing the spread of infection in the wider population. The system was first introduced in England in an experimental scheme in Tyneside in 1945. A team of contact tracers who were based in the GUM clinic undertook to question patients, and then to locate and visit their contacts in order to persuade them to visit the clinic (Wigfield, 1972). The role became more defined in the 1950's and evolved further from the 1980's onwards with the development of standards for practice, originally by the Society for Health Advisors in Sexually Transmitted Diseases in 1995 (SHASTD) and subsequently by the Society of Sexual Health Advisors (SSHA). Notwithstanding this, the process of partner notification in England in peacetime has always been and remains a voluntary process in regard of all STI's including HIV (Chippindale, 2002, Robinson and Rogstad, 2003).

Since their introduction, Health Advisors have traditionally been based in the GUM clinic and employed by the clinic. Although there is a significant amount of outreach work, and liaison with other disciplines and agencies within the role of the Health Advisor, it is the organisational structure within the clinic and the network links between clinics that enable the role to be fulfilled. The NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 provide the legislative framework within which contact tracing is carried out; this legislation therefore fulfils a dual role. It protects the confidentiality of those examined and treated for STI's by securing of information, but it simultaneously enables disclosure of information 'in connection with

the treatment of persons suffering from such diseases or the prevention of the spread thereof.'

Although nearly one hundred years have elapsed since the introduction of GUM clinics, many of the features that were instigated from the outset are still apparent today. Their primary aim to make the clinic an acceptable place to visit by ensuring that it was discrete, confidential, and contained remain the primary requirements of the service today (Evans and Farquar, 1996, Dixon-Woods et al., 2001). However, the geographical and linguistic cloak that has traditionally covered GUM services in order to ease entry through the clinic door has paradoxically hidden it from view and confounded attempts to increase public awareness of structure and function. The systems that ensure the anonymity and confidentiality aspects of the service are demonstrably important for the personal experience of those that use the service. However, insofar as they emphasise the public persona of GUM as a service separate and apart from others, they serve to perpetuate the social stereotyping of STI's as infections that need to be treated and managed through services that are separate and distinct from all other branches of healthcare.

### **2.10 The development of Young People's Sexual Health Services**

Sexual behaviours and practices became the focus of considerable attention as a consequence of concerns about the emergence and possible spread of HIV infection. A major result of this was the commissioning of the First National Attitudes and Lifestyles survey in 1987 which was undertaken in 1990-1991 and published in its entirety in 1994. Data from this survey indicated a decreasing age of first intercourse, a high proportion of young people who have first intercourse prior to age 16 years (approx 30%), and high levels of first intercourse without contraceptive provision (approx 50%) (Johnson et al., 1994). It consequently brought sexual practices, particularly those of young people, under considerable public scrutiny. The inclusion of sexual health as one of the five areas for targeted health action that were contained within the 'Health of the Nation' document of 1992 represented the national response to this information. The Health of the Nation set targets for the reduction of STI rates, in particular gonorrhoea, and for a reduction in teenage pregnancy rates. The effect of this, which was accompanied by the availability of targeted funding, was the development of services and initiatives that sought to achieve these targets. This resulted in the establishment of large numbers of specialised young people's services across the country within both Community Trusts and General Practice.

### **2.11 Proposals for Sexual Health Service convergence**

The 1994 Cairo conference on Population and Development represented a perceptible shift from macro concern with population growth to individual rights in sexuality and reproduction (DeJong, 2000). It recommended that Family Planning Services be expanded and that they give more attention to the prevention and treatment of sexually transmitted diseases (Fox et al., 1995).

Arising from this, a national conference of the main medical groups involved in providing sexual health services in England produced a consensus statement which summarised the future direction for service development. Key recommendations of this unpublished document were the greater convergence of the various sexual health services. This would ensure that those using the services had access to an appropriate range of care at one visit. It was envisaged that this would reduce multiple attendances and maximise the effective use of resources.

In a few cases this produced the creation of comprehensive sexual health services 'under one roof' (Dawson et al., 2000, Steadman and Elstein, 1995). More generally, it heralded a perceptible move towards the acceptance of managing STI's within Family Planning and Reproductive Health Care Services. This has been evident in the development of service provision. In many areas of the country contraceptive services have embraced the detection and management of STI's, albeit in a limited capacity within the specialist Young People's Sexual Health Clinics.

These service developments and the consequent need to educate and train staff for this expanded role has been reflected in a perceptible increase in cross disciplinary training in medical and nursing post registration education (FFPRHC, 2002, University of Sheffield, 1998). A notable example of this is the Sexually Transmitted Infection Foundation (STIF) programme developed by the British Association of Sexual Health and HIV (BASHH) and currently being run at venues all over the country, both as a stand-alone programme and as a compulsory component of the Diploma of the Faculty of Family Planning.

### **2.12 The Sexual Health Strategy and proposed changes to service delivery**

Published in 2001 the First National Strategy for Sexual Health and HIV stated that its aims were to:

- Reduce the transmission of HIV and STI's
- Reduce the prevalence of undiagnosed HIV and STI's

- Reduce unintended pregnancy rates
- Improve health and social care for people living with HIV
- Reduce the stigma associated with HIV and STI's

(DH, 2001a p. 3)

In addressing these aims, it considered the two key elements of prevention and service provision. In terms of prevention it identified the educational elements of public information as crucial both in formalised settings, particularly schools, and through the mass media. Media coverage was primarily through the organisation of public information campaigns. The strategy set out to reduce the number of newly acquired HIV infections, to reduce the levels of unsafe sex, and to raise awareness of services. Specific targets for the reduction in HIV and gonorrhoea rates were set as a means by which to measure effectiveness.

The Strategy identified considerable variability in the quality of sexual health services across the country and particularly a lack of co-ordination between services. As a response to this it proposed a service structure with three identifiable levels of provision. Level one provision should be available in every General Practice and should provide the following:

- Sexual history and risk assessment
- STI testing for women
- HIV testing and counselling
- Pregnancy testing and referral
- Contraceptive information and services
- Assessment and referral of men with STI symptoms
- Cervical cytology screening and referral
- Hepatitis B immunisation.

Level two provision should be available within each Primary Care Trust or Primary Care Group. It should be provided either by a Primary Care Team with a special interest in sexual health, or by local FPC's and GUM clinics working in conjunction with General Practices. It should include the following:

- Intrauterine device insertion
- Testing and treating STI's
- Vasectomy
- Contraceptive implant insertion
- Partner notification

- Invasive STI testing for men (until non-invasive tests are available).

Level three provision should be provided by specialist clinical teams who also have responsibility for resource planning including health needs assessments and quality aspects of service delivery such as clinical support and clinical governance. The specialist services provided will include:

- Outreach for STI prevention
- Outreach contraception services
- Specialised infections management, including co-ordination of partner notification
- Highly specialised contraception
- Specialised HIV treatment and care.

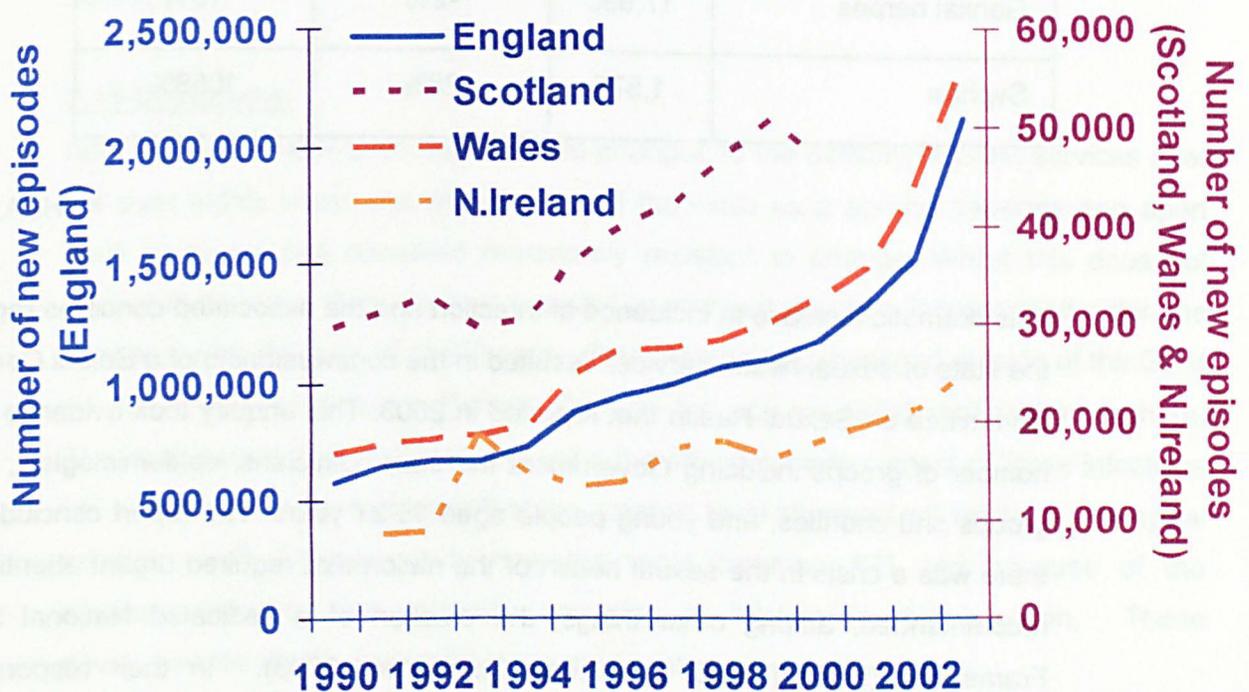
(DH, 2001a pp. 23-25)

There are several aspects of this proposal that merit consideration. The gendered implications of categorising STI testing in men are striking. The testing of men for STI's merits a distinction between invasive and non-invasive techniques. By implication therefore swab taking in men is considered an invasive technique. There is no similar distinction in the testing of women and the assumption therefore is that speculum examination of women is not considered invasive. There is also a lack of detail as to what some of the terms mean. For example, what constitutes highly specialised contraceptive provision? Whilst a number of the functions identified for each of the service levels are already part of their remit, for example cervical cytology and pregnancy testing in level one provision, and are therefore unlikely to be problematic, other aspects appear considerably more problematic. Of particular relevance in terms of this discussion is the identification of STI treatment and partner notification as level two service provision.

These functions, and particularly that of partner notification, are synonymous with GUM clinics. The mechanisms through which they have been managed have evolved out of the clinic structure and organisation, and are therefore largely dependent upon it. Effectively the strategy moves a significant part of the GUM workload into Primary Care to be managed within level one and two services. As such it represents a major shift in the way that STI services are to be managed, both on an individual level and within the wider Public Health context.

### 2.13 The size of the problem.

One of the primary factors driving the movement of STI management into Primary Care is the increasing amount of infection that is being detected and its impact upon the workload of the GUM service. This was evident in the Sexual Health Strategy, however it has received further impetus as a result of increasing concerns and increasing political pressure. The extent of this increased activity is illustrated below. As this data from the HPA indicates, the number of new episodes of STI's seen in GUM clinics in England has risen steadily and steeply over the past thirteen years and the rate of increase shows no sign of abating.



(HPA, 2004).

The incidence figures of all STI's have risen over the period of time although the rate of increase has varied from one infection to another. As the table below indicates, the increasing number of diagnoses of both chlamydia and syphilis is particularly striking. Some of that related to chlamydia may be attributable to improved testing techniques which are more sensitive. Also an increased number of requests for testing will mean that a higher proportion of the existing asymptomatic infection is being detected. It is difficult therefore to determine how much of this activity is due to a true increase in prevalence. Other figures such as those for gonorrhoea and syphilis are less amenable to such explanations and diagnoses for these conditions may therefore be taken to more accurately reflect increases in the number of individuals infected.

**Number of new diagnoses of selected STIs, GUM clinics, England, Wales & Northern Ireland, 2003**

	Number	% change	
		2002-2003	1995-2003
Chlamydia	89,818	9%	192%
Genital warts	70,883	2%	27%
Gonorrhoea	24,309	-3%	139%
Genital herpes	17,990	-2%	15%
Syphilis	1,575	28%	1058%

(HPA, 2004)

This dramatic increase in incidence of infection and the associated concerns regarding the state of sexual health services resulted in the commissioning of a Select Commons Committee on Sexual Health that reported in 2003. This enquiry took evidence from a number of groups including Government ministers, clinicians, epidemiologists, patient groups and charities, and young people aged 15-21 years. The report concluded that there was a crisis in the sexual health of the nation that required urgent attention and recommended, among other things, the creation of a dedicated National Service Framework (NSF) (Select Commons Committee, 2003). In their response the Government did not take up this recommendation, instead clearly indicating that they considered the Sexual Health Strategy as central to improvements in sexual health (DH, 2003).

**2.14 The implications for Primary Care**

It would appear therefore that there is a clear expectation that much of the medical care and treatment associated with STI's will take place outside of the GUM service. This clearly has considerable implications both in terms of the extra workload in primary care and the need for clinical expertise in order to successfully implement these changes. A few studies have been published that report the feasibility of this approach. In one of these which took place in a specialist contraceptive service, a

number of staff already had extensive GUM experience (Evans et al., 2004). A second study reported the expansion of services in a specialist youth service which used outreach staff from the GUM clinic to manage the process (Beddard et al., 2003). Whilst it was successful, it would clearly not be possible to provide this level of specialist support on a large scale in primary care settings. Other studies are underway, in particular the nationally funded Chlamydia Screening Study which has examined the feasibility and effectiveness of full management including partner notification in primary care (Low et al., 2004). The findings of this have yet to be reported but are likely to be highly influential in informing this process. The effects of any changes are likely to be far reaching both for staff working in primary care and for the large number of patients whose infections will be managed in their entirety in this setting.

### **2.15 Conclusion**

Although there have been considerable changes to the delivery of GUM services over the past eighty years, the organisation of the clinic as a service separate and apart from all others has remained remarkably resistant to change. Whilst this does not appear to be under threat there is a clear Government intention, incorporated within the Sexual Health Strategy, that STI care will be increasingly managed outside of the GUM service and be provided in Primary Care by the non specialist staff that work there. The impact upon Primary Care and upon the effective management of these infections will be profound. It is inevitable that the greatest level of impact will relate to chlamydial infection, both because it is now the most common STI and because of the developments that are currently occurring in relation to this infection. These developments will be discussed in the next section.

## Chapter 3: *Chlamydia trachomatis*

### **3.1 The emergence of chlamydia as an STI**

*Chlamydia trachomatis* has a relatively short history as a recognised sexually transmitted infection, although human diseases caused by this organism have been recognised since antiquity. Trachoma was described in Egyptian papyri (Schachter, 1999a) and medical reports of the 18<sup>th</sup> century contain descriptions suggestive of Lymphogranuloma venereum, a condition caused by a serovar of the organism (Williams, 1995). However genital tract infections and neonatal ophthalmia caused by *Chlamydia trachomatis* were not recognised as such until it was possible to distinguish them as distinct from gonococcal infections, even though from the 1940's onwards a group of newly recognised diseases were diagnosed with increasing frequency. These were collectively referred to as non-specific genital infections and initially attributed to an organism labelled as Bedsonia virus (Catteral, 1967).

The organism was first visualised in 1907 and first isolated from the genital tract in 1959, however accurate diagnosis was dependent upon testing techniques which developed through the early and mid 1960's and led to a body of knowledge that emerged from the early 1970's onwards (Schachter, 1999a). This charted a catalogue of increasing links between this organism and its pathophysiological effects, which in women was primarily associated with pelvic inflammatory disease. Genital chlamydial infection was added to the list of diseases recorded by the GUM clinic as part of the KC60 in 1989 (Steadman, 1998).

### **3.2 The characteristic of the organism**

*Chlamydia trachomatis* is an obligate intracellular bacterium which resides within the host cell in one phase of its life cycle and is dependent upon that host cell for metabolic processes. There are 18 distinct serotypes of which serotypes D to K cause sexually transmitted infections. The organism has a two phase life cycle and exists in two forms; as a metabolically inactive elementary body and a metabolically active inclusion body which is taken up into the host cell by endocytosis. The elementary body attaches to and invades epithelial cells. Within 12-18 hours after invasion the elementary bodies develop into metabolically active reticulate bodies. These have the ability to divide to produce a form called a chlamydial inclusion. This forms into elementary bodies approximately 18 – 30 hours later. Lysis of the infected cells causes release of these infectious elementary bodies approximately 48 – 72 hours post infection. The first chlamydial genome was sequenced in 1998 (Stephens et al., 1998)

and led to increasing understanding of the complex processes of the life cycle and the host-organism interaction.

### **3.3 Presentation of the infection**

The infection often goes undetected for a variable length of time due to the fact that it frequently does not produce symptoms in the affected person. This situation is more common in females than males. The proportion of asymptomatic infections in women has been estimated to be up to 80% although close and specific questioning indicates that a proportion of those women may have had mild and disregarded symptoms (Hopwood and Mallinson, 1995). Symptomatic infection in women is characterised by intermenstrual and post coital bleeding, purulent vaginal discharge, dysuria, lower abdominal pain and dyspareunia (CEG, 2002). There is considerable discrepancy in estimations of the amount of asymptomatic infection in men which are due in part to the sensitivity of tests available. Whilst it has been proposed that the majority of men affected with *Chlamydia trachomatis* do have symptoms (Hay et al., 1994) the proportion of asymptomatic men has been estimated in later studies to be between 50% and 90% (Hicks, 2001, DH, 1998). In men symptomatic infection is characterised by dysuria and penile discharge (CEG, 2002).

### **3.4 Complications of Chlamydial infection**

Despite the frequent absence of symptoms this is not an inconsequential infection as the potential sequelae of infection may be considerable. The organism can ascend to the upper genital tract and infect the epithelial cells of the salpinx. Infection of these cells at the mucosal surface is characterised by inflammation which has been shown to be mediated through the development of pro-inflammatory cytokines at the mucosal surface (Rasmussen et al., 1997). This inflammation is exacerbated upon re-infection ultimately leading to tissue damage and scarring. Chlamydial infection therefore can lead to pelvic inflammatory disease (PID) and the association between the two has been clearly demonstrated, particularly when the cervical barrier has been breached (Qvigstad et al., 1983, Westergard et al., 1982). Pelvic inflammatory disease may result in morbidity as a result of chronic abdominal pain, more commonly however chlamydial infection of the fallopian tubes is asymptomatic or sub clinical (Paarvonen and Eggert-Kruse, 1999). It would seem logical to assume that the longer the infection persists, as a consequence of non-identification and lack of treatment, the greater the opportunity for ascending infection to occur. This assumption is supported by the findings from a programme of identifying, testing and treating chlamydial infection in

women which was demonstrated to be effective in reducing the incidence of pelvic inflammatory disease (Scholes et al., 1996).

Tubal infertility is a known consequence of pelvic inflammatory disease. A single episode of PID is calculated to carry a 10% risk of tubal factor infertility. The risk doubles with each successive bout to almost 40% after three or more episodes (Westrom et al., 1992). The proportion of asymptomatic PID suggests that silent infection is the most common cause of tubal factor infertility (Paarvonen and Eggert-Kruse, 1999). Clearly then the infection may be producing a trail of damage even though there is no indication of its presence and the consequences of that damage may not become apparent for some considerable time when attempts to conceive prove unsuccessful.

Chlamydial infection is also a causative factor in ectopic pregnancies. In one study women with a history of PID were six times more likely to be admitted for an ectopic pregnancy than controls (Buchan et al., 1993). In Sweden, the introduction of a national screening programme and a subsequent decrease in the incidence of chlamydial infection rates was associated with a decrease in the ectopic pregnancy rates (Egger et al., 1998).

In relation to pregnancy, Chlamydia has been implicated as a cause for preterm labour on the basis of serological testing for IgG antibodies as evidence of prior or persistent infection (Claman et al., 1995).

Evidence relating to the role of Chlamydia in the development or promotion of cervical intraepithelial neoplasia (CIN) is unclear. One study found no difference in the incidence of chlamydial infection in patients with CIN and those with normal cervical smears (Takac and Gorisek, 1999, Buchan et al., 1993) whilst other evidence suggests that chronic chlamydial infection is very commonly associated with cervical hypertrophy (Markowska et al., 1999).

The likelihood of complications occurring are associated with the length of time from infection to treatment which may be significant, particularly if the primary infection does not produce symptoms, or if there is a significant delay between infection and presentation of symptoms. An increased likelihood of complications is also associated with repeated infection. Males do not escape its effects either with potential complications including orchiditis and epididymitis (DH, 1998) and there is a suggested

association between chlamydial infection and unexplained male infertility (Greendale et al., 1993).

### **3.5 The scale of the problem**

The main source of information regarding STI infection rates comes from the KC60 returns that are provided by GUM clinics and therefore reflect the activity in this setting. The reported incidence of genital chlamydial infection has risen steadily over the past ten years and it is now the most commonly diagnosed sexually transmitted infection in GUM clinics in England and Wales (HPA, 2004). In England, Wales and Northern Ireland diagnoses of uncomplicated chlamydia infection in men rose from 13, 497 in 1995 to 39,977 in 2003. In females it rose from 17, 297 in 1995 to 49,841 in 2003. This represents a 196% and a 188% increase in males and females respectively which has occurred as a result of an approximate 10% year on year increase in diagnoses. The highest burden of infection falls upon young adults. In 2003 the highest rates were detected in 15-19 year old females and 20-24 year old males whilst 79% of all female diagnoses occurred in those under the age of 24 years and 87% of all male diagnoses occurred in those under 35 years. There is regional variation in the levels of reported infection. In England the highest rates in males and females were in London (271/100,000 and 273/100,000 respectively) but high rates were also reported in other regions of the country, in particular Yorkshire, Humberside and the North West (HPA, 2004).

This data requires careful interpretation. Whilst the considerable year on year increase in figures has been interpreted as an absolute rise in prevalence there has been a considerable increase in the amount of testing and screening as a result of increased public and professional awareness. As a result, part of the increase may be due to tapping further into the reservoir of undiagnosed infection that is an inevitable aspect of an asymptomatic infection. An additional consideration is the tests used and the relative proportion of false negative results. As tests that are more sensitive gradually replace their predecessors (a situation that will be discussed in full later in the chapter) the increase in sensitivity will be reflected as increased incidence of infection.

A more useful indicator of the scale of the problem is prevalence figures which provide a snapshot of the amount of infection in a given population at a given time. A number of prevalence studies have been undertaken in a variety of settings and with a variety of populations although the vast majority of activity, particularly in health care settings has focussed largely or exclusively on women. A meta-analysis of recent studies

demonstrated considerable differences between population prevalence rates and those associated with specific health care settings, particularly those settings where testing was more likely to be associated with specific sexual health consultations. Rates were highest for those under 20 years of age and decreased with increasing age. In those under 20 years, population prevalence rates were estimated to be 5.0% as compared to 8.1% in GP practices, 10.0% in family planning clinics, 12.2% in youth clinics, 12.6% in antenatal clinics, 12.3% in termination of pregnancy clinics and 17.3% in GUM clinics. There was insufficient data to estimate prevalence rates in men (Adams et al., 2004). On the basis of this information it is evident that a significant proportion of the young and sexually active population have chlamydial infection.

### **3.6 Looking for and finding the infection**

The microbiological test by which chlamydia is detected and the body sample that is required for testing have been a focal point in the Public Health response to this infection as the characteristics of this intracellular organism have created specific challenges in the development of a test that is both sensitive and specific. At present the diagnostic process is dominated by two types of tests; enzyme Immunoassay (EIA) which represents the older and currently more commonly used type of test and the more recent Nucleic Acid Amplification Tests (NAAT). In order to maximise the likelihood of detecting infection when it is present, it is essential that the sampling technique is correct. The EIA requires an endocervical swab sample from women and therefore necessitates a speculum examination and a competent swab-taking technique. However testing from the endocervical site alone results in 5–30% of infections being missed because they are in the urethra only and consequently not detected (Hay et al., 1994). Best practice in relation to women therefore involves taking an endocervical and a urethral swab although in reality urethral swabbing is considered more painful and staff in non-specialist settings are more reluctant to undertake this practice; consequently it is not routinely carried out in Primary Care. For men, the EIA test requires either a urethral swab or a first void urine sample. Personal communication with colleagues in primary care indicates similar concerns with regard to taking urethral swabs in men.

The EIA test is recognised as having a low sensitivity, estimated to be as low as 60% (Schachter, 1999b) with the result that there are a significant proportion of false negative results associated with this test. Advances in molecular genetics have led to the development of amplification techniques whereby DNA segments can be replicated in a short time producing multiple copies. The amplification of chlamydia specific DNA

segments has revolutionised testing for this infection in two ways. Firstly the NAAT tests are highly sensitive with estimated sensitivities of approximately 90% with male urine and female cervical specimens (Schachter, 1999b). Secondly it is possible to perform this test on a variety of samples such as cervical swabs, vaginal and urine samples.

The availability of non invasive testing has been heralded as a major advance in the detection of infection. The opportunities that it affords for self collection of samples has resulted in a range of innovative projects that have taken testing further into the social spaces (Low et al., 2004, Rogstad et al., 2001, LaMontagne et al., 2004). This approach is endorsed in the Select Commons Committee Report (2003) which recommends testing outside traditional health service settings and identifies school based services, night clubs and social clubs as possible suitable testing sites. The acceptability of such approaches is unclear although the low uptake rates from postal studies which used home collected samples (Rogstad et al., 2001, Low et al., 2004) indicates that there may be resistance to such practices in some settings.

### **3.7 The management of chlamydial infection and the test of cure**

The management of any sexually transmitted infection has two aims. The first addresses the health of the individual in whom it has been detected by reducing the impact of infection. In relation to a curable infection this is achieved by prompt and effective treatment in order to eliminate the organism and minimise the possibility of long term pathological damage. The second aim is the Public Health activity of reducing the prevalence of infection within the population. Some activities of the GUM clinic such as the collection of epidemiological data clearly relate to one function rather than the other. Other activities serve both functions. Thus prompt treatment addresses the first by reducing the effect of the infection on the individual and simultaneously addresses the second by reducing the possibility of infection transmission.

Clinical effectiveness guidelines for the management of *Chlamydia trachomatis* genital tract infection have been developed by the clinical effectiveness group of the British Association for Sexual Health and HIV (BASHH) (CEG, 2002). The interpretation and implementation of these guidelines varies to some extent from one centre to another, in accordance with organisational considerations and clinical decision making. Of particular relevance to this discussion is the situation with regard to undertaking retesting subsequent to antibiotic therapy. The policy to offer a retest in the study site

was a key element in this study in terms of the recruitment strategy and it constituted a significant aspect of the illness event for many of the respondents. To this effect it merits specific consideration as an aspect of infection management.

Retesting after treatment can serve several functions. Treatment failure can occur for three main reasons. Firstly, the causative organism may be drug resistant (a particular concern with gonorrhoea). Secondly, the drug of choice may have a low effective cure rate, for example erythromycin which is the drug of choice for chlamydial infection in those who are or may be pregnant. Thirdly, poor compliance with the drug regime may result in insufficient medication being taken to effect a cure. This is a consideration with a course of therapy but much less so with single dose therapies that are commonly administered in the clinic. A test of cure (TOC), undertaken after a therapeutically determined time interval, will determine whether treatment has been ineffective on any of these three counts. Re-infection may occur in the time interval between treatment and retesting if a partner has not been treated and unprotected intercourse has taken place. This will also be detected on the retest although technically it is a test of re-infection (TOR).

Retesting originates from the management of gonorrhoea and has been part of clinical recommendations for clinical management of this infection for many years (CDC, 1979) for the reasons identified above. However it is acknowledged that the cause of a positive result at the time of retest is most commonly re-infection rather than treatment failure, particularly as single dose treatments dispensed in the clinic largely eliminate issues of poor compliance with treatment. Despite the propensity of the gonococcus to develop resistance to antibiotics, the effectiveness of current treatments and clinic workload are the basis on which the retest has been removed as a routine part of post treatment assessment from the most recent guidelines for the management of gonococccal infection (Bignell, 2004).

Although re-infection is clearly the predominant issue and TOR would be a more accurate term, both guidelines and literature favour the term TOC even when they are clearly describing reinfection (Elaward and White, 2001, Lewis et al., 1999). In its literal sense the term 'test of cure' in this situation could be argued to be accurate given that those who are reinfected are not yet cured of the infection, in the sense that they are not infection free. However the terminology implies non clearance of infection rather than re-infection and as such is confusing and potentially misleading. The reason for inaccurate use of terminology is unclear. Although it may in part be due to

custom and practice, it may also be considered more socially acceptable to justify a test on the basis of ensuring that infection has been eliminated rather than suggesting re-infection, given that re-infection at the time of retesting indicates non adherence with the advice supplied at the treatment visit.

Retesting has traditionally been a common activity in GUM clinics in relation to other infections, to the extent that reduction of the amount of retesting is recommended as a means by which to reduce clinic activity (Robinson and Rogstad, 2003), a change that is evident in practice as identified previously in relation to the management of gonorrhoea. In the clinic in which this study took place, management of chlamydial infection at that time included a retest approximately four weeks after treatment. The advice that accompanied treatment was to abstain from sexual intercourse until the return visit or, as a minimum, to abstain for at least one week after commencement of medication with protected intercourse until the return visit. The purpose of this was to prevent both onward transmission of infection and re-infection. Both primary treatments (Doxycycline and Azithromycin) have high effectiveness rates and there is no documented problem with resistance. Although there may be some compliance issues with Doxycycline (Augenbraun et al., 1998), this is not an issue with Azithromycin which has a single dose regime. Overall therefore it is unlikely treatment will fail. On this basis the current National Guidelines for clinical management of chlamydial infection do not recommend a retest other than subsequent to treatment with erythromycin (CEG, 2002).

However, a follow up visit is recommended for the following purposes:

- Following up partner notification
- Reinforcing health education
- Providing reassurance
- Assessment of treatment efficacy/exclusion of re-infection

(CEG, 2002)

The sole purpose of the recommended follow up visit is therefore Public Health, with the patient attending in order to provide information and receive advice. It seems unlikely that this would provide sufficient incentive for attendance and a test of re-infection is commonly offered by GUM clinics "as a demonstrably effective method of encouraging patient attendance for follow up" (Dale et al., 2001 p 207). The test therefore acts as an incentive and justification for a return visit that enables

achievement of the public health objectives. As such it occupies a central position in enabling the GUM to conduct its other duties as listed above. Although it is referred to as a test of cure by both staff and patients it is most probably a test of re-infection and is offered whether or not re-infection is an issue as an incentive to clinic re-attendance. Its function therefore is largely as a tool of surveillance. From the perspective of the clinic this means that the retest is largely dispensable, a desirable although not essential aspect of infection management. It is perhaps not surprising therefore that this procedure appears to be rapidly disappearing as part of the service response to managing increasing demands upon the clinic.

### **3.8 Current efforts to tackle chlamydial infection**

#### **3.8.1 The key documents**

The current national situation with regard to the diagnostic testing and screening for chlamydial infection derives from two key government documents, namely the Chief Medical Officer's (CMO) Expert Advisory Group Report on *Chlamydia trachomatis* (DH, 1998) and the National Strategy for Sexual Health and HIV (DH, 2001a). It is also informed by two nationally funded screening studies: the Dept of Health funded opportunistic screening study (Underhill et al., 2003) and the Chlamydia Screening Study (CLaSS) funded by the National Technology Assessment Programme of the NHS (Low et al., 2004). The national rollout of screening that has occurred subsequent to the opportunistic screening study as part of the Sexual Health Strategy has further shaped the current situation at an operational level.

#### **3.8.2 Testing and screening**

Prior to consideration of these documents it is necessary to clarify the terms testing and screening as they represent two separate strands in the clinical approach. Although the two are separate concepts with different epidemiological, psychological and ethical implications there is commonly confusion between them and the terms are used interchangeably due in part to the vague and non-specific nature of the symptoms associated with chlamydial infection.

Screening involves testing someone for the infection in whom there are no clinical indicators that suggest the presence of infection. The UK National Screening Committee offers the following definition:

"A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its

complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications.”

(DH, 2001e p. 6)

Diagnostic testing relates to testing for infection in those in whom clinical indicators suggest the presence of disease. The client identifies a problem and initiates the process of diagnostic testing by presenting him/herself to a health professional with a history of symptoms in order that the cause can be identified and the symptoms alleviated by appropriate treatment. Alternatively it may result from a clinical picture that emerges during a consultation and examination. For example, examination of the cervix whilst taking a smear may reveal cervicitis which is suggestive of chlamydial infection and prompt investigation for infection.

### **3.8.3 The Expert Advisory Group on *Chlamydia trachomatis***

The Expert Advisory Group which reported in 1998 was convened by the Chief Medical Officer in 1996 against a background of increasing concern about the rising levels of genital chlamydial infection and a growing body of evidence that clearly linked the infection with its sequelae of pelvic inflammatory disease, tubal infertility and ectopic pregnancy. It recognised that there was no clear professional consensus about approaches to this infection. Its remit was to review the current evidence and to make recommendations in relation to effective management, particularly with respect to screening. The group considered three possible approaches to screening and testing. Firstly, diagnostic testing in those presenting with symptoms suggestive of infection and in those considered at high risk. Secondly, a systematic and widespread call/recall system of register based screening, and thirdly opportunistic screening of specific target populations.

### **3.8.4 Testing for chlamydial Infection**

The Expert Advisory Group recommended that diagnostic testing should occur in response to the following clinical presentations:

- Women with acute PID
- Women with mucopurulent discharge
- Women with lower abdominal pain
- Women with vaginal discharge
- Women with post coital or intermenstrual bleeding
- Men with urethral discharge

- Men with NSU and epididymitis
- Men with reactive arthritis
- Infants with ophthalmia neonatorum or neonatal pneumonitis and their parents.

(DH, 1998 p. 11)

### **3.8.5 Screening for chlamydial infection.**

The Expert Advisory report made a number of recommendations with regard to screening for infection. In relation to generalised screening, the group rejected a widespread call/recall approach on the grounds of the inability to identify those who were sexually active and the consequent high level of inappropriate screening that would result.

It recommended that screening should be considered in:

- couples undergoing investigation for infertility
- women undergoing procedures requiring instrumentation of the uterus.

Additionally, it favoured the introduction of offering screening to those populations considered to have high prevalence rates as listed below

- All GUM attenders and their partners
- Women seeking termination of pregnancy and their partners
- Asymptomatic sexually active women aged under 25, especially teenagers
- Asymptomatic women aged over 25 who have had a new sexual partner or had two or more partners in a year.

The first two of this second list are definable populations in so far as they are either attending a specific service, the GUM, or undergoing a specific procedure, namely a termination of pregnancy (TOP). In this respect it would appear relatively unproblematic to instigate a testing policy in these areas and indeed this has been common practice for some considerable time in the area in which this study was conducted although extending testing to partners, particularly in a TOP service is considerably less straightforward.

The second two identified populations represented a considerably greater challenge posing questions such as how, when, where and how often this population were to be tested. To address these questions the Department of Health funded the chlamydia opportunistic screening study. Based in two centres, Portsmouth and The Wirral, this study which ran between 1999 and 2000 set out to assess the feasibility and acceptability of opportunistic screening in a range of health care settings, both primary

and secondary. The urine based screening using an NAAT test focused on sexually active young people (16 – 24 years) attending testing sites. Screening was focused on women on the basis that they used health services more often and were therefore more accessible. It was offered to women in primary care and specialised services, and additionally to males attending GUM clinics and sexual health clinics (Pimenta et al., 2000). 50% of the eligible female population in the target age range were tested and the study reported the highest infection rates to date for this infection with an overall prevalence of 9.8% and 11.2% in Portsmouth and The Wirral respectively in 16-24 years old females (DH, 2001b).

A key aspect associated with the process of opportunistic screening which came to light as a result of this study was the question of re-screening and re-infection. Any screening programme requires consideration of the re-screening interval which is ordinarily based upon the natural history of the disease. In the case of infection, re-infection can and does occur at any time. Thus it is possible to be treated one day and become re-infected the next or to test negative on one day and test positive a week later. Short re-infection intervals have been reported with chlamydial infection (Hereika et al., 2001) and a re-infection rate of 8% in the Dept of Health study adds further support to the view that is a significant problem. The approach taken in this study was to invite everyone in the target population to participate in the study every time they attended a study site. Perhaps it is not surprising that individuals found this a source of irritation and a number of them interpreted it as an indication that health professionals considered them promiscuous (DH, 2001c).

The persistent focus of attention upon women has been criticised in terms of its effect upon both men and women and in the messages that it conveyed, of women as vectors of infection (Hart et al., 2002, DH, 2001c). The pragmatic justification that is commonly cited is the difficulty in accessing males who are considered to rarely attend medical health facilities (DH, 2001a, DH, 2001b). However, data from the screening study which demonstrated that 55% of young men had visited their GP within a six month period and 72% had done so within a 12 month period effectively undermines the assumptions upon which these decisions are based. This lends weight to increasing calls for a mixed gender approach to screening although an increasing indication that chlamydia is a possible cause of infertility in men (Idahl et al., 2004) may be construed as a more persuasive reason.

### **3.8.5 The National Chlamydia Roll out Programme**

On the basis of the findings from the opportunistic screening study the Department of Health outlined a phased roll out of chlamydia screening in the implementation plan of the National Sexual Health and HIV Strategy. In the first instance, ten community sites were selected. Protocols have been developed for screening of males and females aged 16-24 years which have been largely implemented in conventional Primary Care health settings although outreach activities in less conventional sites such as University campuses and health fairs are encouraged. NAAT tests were used for the screening and samples were largely self-collected. These consist of urine samples from men and either urine samples or vulvo-vaginal swabs from women (LaMontagne et al., 2004). The programme is currently being expanded in stages with a second set of ten sites recruited in 2004. It is expected that national coverage will be achieved by 2007 which should ensure national use of NAAT testing on non-invasively collected samples by that time.

The volume of work generated by the considerable increase in the number of diagnoses has necessitated exploration of alternative infection management approaches. Several of these have been the focus of the Chlamydia Screening Study (CLaSS) which was completed in 2004 and has yet to report substantive findings. Best practice is currently considered referral to GUM for those diagnosed in primary care. However this is unlikely to be achievable in the current climate when GUM services are overstretched. Median waiting times for an appointment at GUM were reported in 2003 as 12 days with some as long as 6 weeks (Select Commons Committee, 2003), a position that is more likely to have deteriorated than improved in the interim. The expectation that a significant amount of STI management and particularly that relating to chlamydial infection will be managed in primary care is explicit in the three tiered service structure identified in the Sexual Health Strategy service structure (DH, 2001a). To this effect alternative models of management, including those pertaining to treatment and partner notification, feature in the CLaSS study.

### **3.9 The human factor**

#### **3.9.1 Professional awareness of chlamydia**

The effective implementation of any health practice which represents a significant change from previous practice is dependent upon those practitioners charged with that task. Their willingness or resistance to undertaking the task will influence the extent to which new policies are adopted and this in turn is influenced by a number of personal

and organisational considerations. If Primary Health Care staff are to take over the management of this infection it will require that they are sufficiently knowledgeable and comfortable in undertaking sexual health consultations that require them to take detailed sexual histories. Current evidence suggests deficits in their knowledge and comfort levels that will require addressing. Surveys of both GP's and Practice Nurses (PN's) demonstrate variability in perceived levels of expertise and comfort between staff and with different groups of patients (Temple-Smith et al., 1999, Stokes and Mears, 2000, Temple-Smith et al., 1996).

### **3.9.2 Knowledge levels of staff**

The training requirements of staff have been identified as a matter requiring attention (Matthews and Fletcher, 2001, DH, 2001a). As a response to this the British Association of Sexual Health and HIV (BASHH) have developed the Sexually Transmitted Infection Foundation (STIF) programmes which are now widely available across the country. These are aimed at Primary Care providers, particularly GP's and provide a grounding in the clinical management of STI's. This is a positive response to the challenge although their impact on practice is as yet unknown.

As a parallel service staffed by professionals who have specialised in sexual health, one might expect Family Planning (FP) nurses to be knowledgeable about a common STI such as chlamydia. However the findings from the single reported study that examines the knowledge level of this professional group are a matter of some concern. Myers (2004) assessed the knowledge level of 124 nurses, midwives and health visitors qualified in FP/contraception and currently practising FP/contraception in dedicated contraceptive services. Although she found some aspects of genital chlamydia being universally known, others were poorly known with apparent knowledge gaps, particularly in relation to transmission, risk factors, signs and symptoms and aspects of management. This study does not claim to be representative of the underlying population, however the mode of recruitment through conferences suggests that this population is likely to be more rather than less knowledgeable and motivated rather than the underlying population (Myers, 2004). These findings about a group of sexual health specialists raise serious concerns about the state of knowledge of other practitioners working in sexual health in non-specialist settings, and often with non-specialist training and qualifications who will be required to undertake much of the screening and infection management in Primary Care.

### **3.9.3 Attitudes of staff**

A further consideration is the extent to which those in Primary Care will embrace this expanded role. The current amount of testing and screening in Primary Care appears to be highly variable and strongly associated with the interest and expertise of practitioners in sexual health (Shefras et al., 2002, McNulty et al., 2004). Their willingness to undertake partner notification is also variable with reports of little or no efforts in this area (Cassell et al., 2003, McNulty et al., 2004) and a preference for this activity to be conducted by the GUM service (Joshi and Dixon, 2000).

Smear taking has been identified as an appropriate time to undertake chlamydial screening (DH, 2001a, Underhill et al., 2003, McNulty et al., 2004, Armstrong et al., 2003), presumably on the basis of convenience and opportunity. Personal communication from a number of practitioners together with the literature (Devonshire et al., 1999, Piercy et al., 2000, Kellock et al., 1999) suggest that this is the time when PN's outside of the screening roll out programme are likely to offer opportunistic screening. However this increased activity and increased surveillance of the female population would appear to have had little effect upon infection detection rates; an unsurprising finding given that smears are undertaken on those over 20 years and chlamydial infection is most prevalent in those aged 16-19 years.

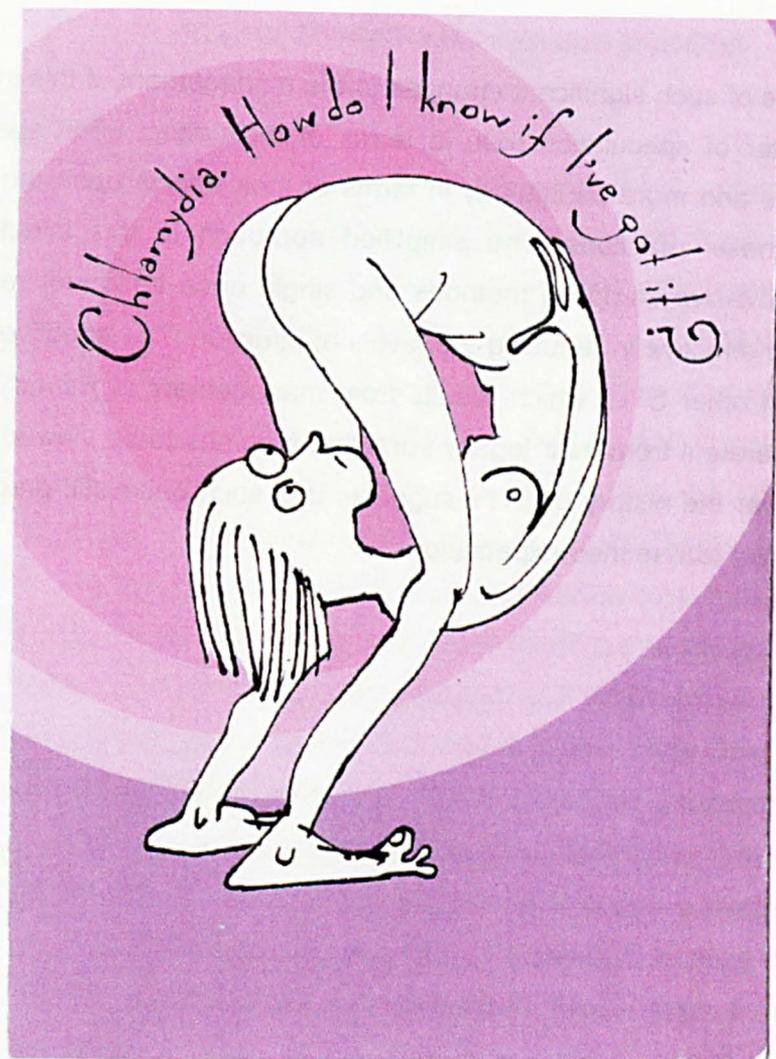
On the basis of the evidence it is apparent that any move towards management of this infection in Primary Care faces considerable challenges and a significant level of ongoing commitment from Primary Care staff. In order to be effective, screening will need to be offered to those considered to be at risk of infection on an ongoing basis. Considerable investment will therefore be required to prepare and maintain a workforce in Primary Care who are able and feel able to take on management of the infection.

### **3.9.4 Public awareness of chlamydia**

The willingness of individuals to submit themselves to testing for an infection depends on a number of factors. As a minimum they need to have some understanding of what it is, why they are being offered the test and be convinced that it is of benefit to them to be tested. The CMO Expert Advisory Report identified lack of public awareness of this infection as a major cause of concern in the effectiveness of any testing policy basing their comments upon evidence which demonstrated that a sizeable proportion of the population had not heard of the infection and a larger proportion knew very little about it beyond having heard the name.

The National response was a public awareness campaign using posters and leaflets which concentrated on providing key facts and used captions and pictorial representations to draw attention to key facts. Two examples of these are given overleaf. The "Who's Chlamydia" campaign of 1999 drew on the assumed lack of familiarity with the name of the infection whilst the subsequent set of postcards drew attention to the asymptomatic nature of the infection by asking "How do I know if I've got it?"

Personal communication with School Nurses suggests that they too have risen to the challenge by including chlamydia as a key element in their input into secondary school sex education in recent years. Overall, the increased amount of discussion, media coverage and testing activity have collectively contributed to a situation where significant increases in awareness have been reported in conjunction with the opportunistic screening study (DH, 2001c). Whilst it is difficult to conceive of this as anything other than a desirable situation, it is likely to impact upon the demand for testing in a programme that does not at present have a re-screening interval and where any interval that is set may be difficult to defend in a consultation situation when individual circumstances become a matter of consideration. Whether it becomes a matter of concern to practitioners and funding bodies alike is likely to be determined by the extent to which demand for testing rises and the resultant impact upon infection prevalence rates.



## 'Who's Chlamydia?'

When Claire's boyfriend told her that he had Chlamydia, she got the wrong end of the stick.



### **3.10 Conclusion**

The consequences of such significant changes to the management of this infection are at present a matter of speculation both in terms of their effect upon specialist and generalist services and more particularly in terms of their effects upon those patients diagnosed with these infections. The simplified approach to this infection that is afforded by non-invasive sampling methods and single dose treatment regimes may prove to be highly effective in reducing the levels of infection. The effective separation of chlamydia from other STI's which results from management in Primary Care may also serve to separate it from their legacy such that it comes to be viewed as a minor nuisance. However the history of STI's suggests that such optimistic predictions and 'magic bullets' rarely realise their expectations.

## **Chapter 4: Methodology and method**

### **4.1 The focus of enquiry**

The focus of this study is the subjective experience of a personal and embodied encounter with a micro-organism which enters the body and has an effect upon it. That effect is meaningful in a physical sense. The somatic effects wrought by the inter-relationship and the interaction between the human and bacterial organism create an experiential import of physicality through which the experience is understood, delimited and confined in a biomedical sense. However the actual and lived or potential and anticipated physical bodily changes force themselves upon the conscious being and produce social action. The experience is at one and the same time embodied and interactional. It is socially constructed with significance that impacts not only at an individual and an interpersonal level but also within the wider social context within which it is located. It reflects the internalisation and resolution of multiple social and cultural influences to which one has become exposed over time and which have shaped and formed views and attitudes. When something unexpected and unwanted happens, it causes a challenge to self perception, particularly if that occurrence has moral agency. My clinical experience told me that this was a matter of considerable concern to many of those with this infection. I wanted to explore how and why this was, what matters were of greatest concern and the way in which these concerns were resolved or managed.

### **4.2 Methodological decisions**

Qualitative research stems from a Kantian model of human rationality which proposed that perception is more than seeing, that knowledge is based on understanding and consequently cannot be independent of the knowing subject (Denzin and Lincoln, 1998). It derives from an ontological position that people's knowledge, understandings, interpretations, and interactions are meaningful properties of the social reality that is to be explored. It follows from this that meaningful data can be best generated by interacting with people, listening and talking, observing and gaining access to their accounts and interpretations. Qualitative studies therefore set out to actively construct knowledge about the world using a set of analytical techniques with which to understand and explain social actions and meanings (Gerson and Horowitz, 2002). The mixed origins of qualitative research in both sociology and anthropology and the subsequent evolution and development has resulted in a considerable degree of diversity under this broad heading, both in the collection of theoretical and methodological presuppositions and in the methods that have been developed.

I determined to use a grounded theory approach because I had chosen an unexplored area of study. The individual experience is complex. It is the product of personal and embodied considerations but is also shaped and formed by interpersonal interactions and the social meanings which are so dominant in relation to sexual health. I considered that this method would enable me to achieve in-depth analysis of the data and generate a theoretical account that was grounded in the data and located within the dominant social constructions that contribute to the creation of the individualised experience. A major consideration in this decision was the flexibility that it afforded me to produce an account that reflected something of the complexity of reality, that was not confined to any one pre-determined philosophical stance, but which enabled me to work within and between multiple perspectives and paradigms.

I arrived at this decision having considered other possible methodologies; primarily phenomenology and ethnography.

#### **4.2.1 Phenomenology**

Phenomenology was first developed by Husserl and spawned a movement that included Heidegger, Gadamer and Merleau Ponty. Its core is the study of phenomena, those objects of human experience, its purpose being the elucidation of those phenomena to which people attach meaning (Crotty, 1996). It arose as a formalised research approach initially in psychology and has subsequently been widely used in nursing research. Its purpose is variously described as the exploration of subjective or lived experiences. By creating conditions within which accounts of specified phenomena are verbalised, the meaning that they hold for individuals are described (Whitehead, 2004, Smith, 1997, Lemon and Taylor, 1997, Kvigne et al., 2002). This approach is therefore based on the proposition that individuals are the vehicles through which the essence of a phenomenon can be accessed and subsequently described (Priest, 2002). However, this premise is contested because it fails to explicate the meaning of phenomena or the relationship between phenomena and experience (Crotty, 1996).

#### **4.2.2 Husserl**

Husserl sought to describe and structurally analyse consciousness separate from the conceptually bound and theoretical constructions within which and through which they are understood and described (Ray, 1994). In the phrase 'back to the things themselves' Husserl encompasses the intention to characterise phenomena, the objects of consciousness, precisely as they are given in experience. In order to

describe the essence of phenomena he proposes the phenomenological method which requires that we 'bracket' or suspend beliefs and abandon the 'natural attitude' that takes the world for granted instead adopting the transcendental attitude. This process is a pre-requirement to eidetic reduction, the process of pure perception through intuition (Husserl, 1964, Smith and Woodruff-Smith, 1995). Husserl's position was one of transcendental idealism, where the transcendental subjective process, the knowing ego reflecting on itself, seeks to attain the genuine and true form of the things themselves (Ray, 1994).

#### **4.2.3 Heidegger**

Derived from the work of Husserl, Heidegger's primary point of divergence was from transcendental idealism, the seeking of a reality through consciousness. His position was primarily ontological as his objective was to seek the meaning of Being and his starting point was that because Being is the Being of entities, then enquiry must of necessity start with the entities as they are understood (Mulhall, 1996). Heidegger focused his attention on Dasein which signifies humans who comprehend Being on the basis that Being manifests itself through humans and it is therefore the way to grasp Being itself (Crotty, 1996). For Heidegger, our understanding of the world is reached through 'being-in-the-world' and Dasein makes sense of the world from within his existence, in his relations with himself and with other things in the world. He considered that human being manifests an implicit capacity for an understanding of an entity which is the means by which he can interact with an entity. He rejected the concepts of bracketing and eidetic reduction and identified the role of hermeneutics as the process by which we unfold that understanding and make explicit that which is implicit thereby grasping the meaning of Being itself (Mulhall, 1996).

#### **4.2.4 The application of phenomenology to nursing research**

In exploring the use of phenomenological methodologies, I discovered a multitude of procedures and techniques which seemed distant from the philosophical concepts and their appropriation, and a heavily contested debate about the justification of doing so. Existing studies predominantly reflect philosophical lineage, from the transcendental idealism of Husserl through to the hermeneutic interpretive tradition of Heidegger and subsequently Gadamer. Whilst many studies claim a specific philosophical stance (for example Pascoe, 1996, Crist and Tanner, 2003, Kvigne et al., 2002), others embrace a mixed lineage either implicitly (Corben, 1999) or explicitly (Miller, 2003) even though fundamental differences between them would seem to render this deeply problematic.

A number of these studies claim a phenomenological method, particularly in conjunction with Husserl although in practice they appear to comprise a set of principles, commonly labelled as bracketing, analysing, intuiting and describing, which are then used as staged processes in the research method (Lemon and Taylor, 1997, Baker et al., 1992, Priest, 2002, Kvigne et al., 2002). This has been criticised on a number of points including misrepresentation of the term bracketing (Paley, 1997) although the techniques have been justified on the basis that they are conducted within the context of psychological rather than philosophical phenomenology (Beech, 1999), a position that supports the claim that research endeavours have spawned a new form of phenomenology, far removed from its philosophical origins (Crotty, 1996).

The way that data are produced and used is also questioned. The derivation of themes that are then brought together to produce description is problematic in terms of the structure that the process imposes (Beech, 1999, Crotty, 1996). Husserl asserted that we cannot move beyond the point of description, a stance that does not appear to support the construction, interpretation, and analysis involved when one person describes the experience of another or the cumulative description from a group of individuals (Paley, 1997, Priest, 2002) failing to acknowledge the construction, interpretation and analysis by both parties in the process of producing the account.

This seems to produce fundamental difficulties in the application of Husserl not only as a method but also in methodological terms. The methods of Heidegger which both questioned the notion of non positional knowledge and explicated the notion of positional knowledge (Todres and Wheeler, 2001) appear more compatible with social research in so far as they are founded upon the interpretative process (Mulhall, 1996), however they remain highly individualised and therefore problematic as a basis of justifying the production of shared meaning derived from data. Additionally, my purpose was not to focus exclusively upon the meaning of phenomena but also to explore the way in which that experience was socially and culturally created and the extent to which those constructions constrained or determined the personal and social responses to the infection state. Phenomenology as the sole methodology therefore appeared inadequate.

#### **4.2.5 Ethnography**

The GUM clinic constitutes a key aspect of the infection experience. It is the site within which meaning of the infection is realised and detailed, both in terms of its structure and function. Although some of these functions are undertaken elsewhere, it is the

primary site within which the practical aspects of the infection are managed, in an individualised way through diagnostics and therapeutics, in the interface between the patient and the professional, and in a wider social sense through its focal position in the associated public health activities. It is also a location which is so closely associated with the historical development of the social construction of sexually transmitted infections that in a structural sense it both defines and is defined by the social meaning of these infections. A consideration of an ethnographic approach was merited on the basis that an examination and exploration of the clinic site might be expected to provide insights into the infection experience.

Ethnographic methods including observation, opportunistic and formalised interviewing derive from anthropological fields of enquiry. They are most commonly used in conjunction with one another with the collective purpose of describing a group or culture (Fetterman, 1998) although as an effect of critical reassessment, they have come to focus more fully upon demonstrating the relationships between forms of heterogeneous action in a specific setting rather than attempting to represent a culture as a whole (Baszanger and Dodier, 1997). Observational data collection as a cyclical process that moves between the micro and macroscopic elements of the study field provides breadth and depth of observation whilst verbal accounts and explanations gathered through interviewing fulfil a range of functions. They both explain and contextualise that which is observed, as representative or comparative means of elucidating common group beliefs as well as identifying those values that inform behaviour (Fetterman, 1998). Observational techniques provide the means by which to collect direct information about individuals and organisations, as well as an opportunity to observe how they explain their behaviours, whilst interviewing creates a structure within which to collect people's perceptions, motives and accounts of their experiences and actions (Gerson and Horowitz, 2002). Arguably therefore ethnography provides the means by which to get closer to social reality than any other method (Hammersley, 1992) although the product is necessarily a social construction that reflects the assumptions and practices of the researcher who produced it and needs to be recognised as such (Gerson and Horowitz, 2002).

To date, ethnographic examination of the GUM clinic has been confined to the work of Pryce (Pryce, 2000, Pryce, 2001, Pryce, In press). This work has been valuable in describing the way that sexualities are realised and managed within a setting that is a primary site where the discourses of sex and medicine interpenetrate. In so doing he not only identifies the significance of the site in this respect but also draws attention to

the absence of previous work in this area. Those aspects that fell outside the remit of his study; the clinical encounter and the exploration of specific diseases consequently remain unexplored. However, I consider that the aim of my study differed from that achievable by an ethnographic approach in terms of what constituted the focal point. In this study where a specific disease was the central issue of concern, the focus of enquiry within an ethnographic approach would necessarily have been the clinical encounter, and whilst it would undoubtedly incorporate the experiences of the patients, it would be as one part that contributes to a composite picture constructed from a variety of perspectives. Additionally, it would not allow opportunity to effectively consider aspects of the infection experience that were constructed, either partially or wholly in settings other than the GUM clinic.

My purpose was to take the individualised experiences of infection as the focal point. I wished to examine the aspects of the GUM encounter, the role and function of the other players and the structures and processes as they were interpreted and represented by the individual as one part of their whole infection experience. I elected therefore to use interviews with those who had had chlamydial infection as my data source, as the best means by which to access personal experiences and understanding is through the words of the individuals themselves. In a field where the medical discourses are so dominant and largely unchallenged, I needed an approach that provided me with a structure within which I could analyse the data in relation to theoretical frameworks that reflected the meaning embedded in them, rather than in terms of those assumed by my own preconceptions, which as a health professional were heavily influenced by the dominant hegemony.

#### **4.3 Grounded theory**

Originally developed by Glaser and Strauss, the purpose of Grounded theory is “the discovery of theory from data that has been systematically obtained from social research” (Glaser and Strauss, 1967 p. 2). Coming from the Chicago school of sociological thought it has its roots in symbolic interactionism where the empirical starting point is the subjective meaning that individuals attribute to their activities and environment. A grasp of their viewpoint provides the means by which to understand interaction, process and social change (Strauss, 1987). The term grounded was coined by the authors as a contrast to ‘grand theory’ which is created from logical assumptions and speculations in order to emphasise the way in which the theory produced derives from the data. The central concept is comparative analysis, the constant movement between existing theoretical material and the data which both informs and is informed

by the analytic process that results in the development of theory. It is this which forms the basis of the other core concepts of theoretical sampling, theoretical sensitivity and theoretical saturation and which guides and directs the conduct of the study itself (Glaser and Strauss, 1967).

Grounded theory was conceived as encompassing multiple methods and multiple theories in the generation of theory and as such appears to support its categorisation as a method that uses a systematic set of procedures (Strauss and Corbin, 1990). The considerable flexibility and variability that this framework provides has contributed to its widespread adoption in a range of disciplines and a number of different theoretical orientations (Strauss and Corbin, 1990). In the process, inevitable evolutionary development and modification has occurred which emanates in part from the divergent stances of its co-developers which was apparent to their students (Stern, 1994) but became increasingly evident through those texts that followed 'The discovery of grounded theory' (Strauss, 1987, Strauss and Corbin, 1990, Glaser, 1987). The primary point of contention was the extent to which the original concept of emergence was replaced by a densely codified and 'structured'<sup>1</sup> operation that was most apparent in the 1990 text that Straus co-authored with Corbin and resulted in the proposition by Glaser that the Glaserian method should be called grounded theory whilst the Strausserian method should be renamed as conceptual description (Stern, 1994). Melia (1997) identifies how the Strauss & Corbin text has largely become synonymous with grounded theory, not least because of its comprehensible description of procedural stages that can be readily followed. Her concerns that this preoccupation with procedures may have occurred at the expense of theory reflect the primary criticism of Glaser (Melia, 1997). This does not deny the practical role that these books play in guiding a novice researcher through the stages of the process; however it does necessitate a return to the original text and the core concepts upon which it was constructed as a basis upon which to make procedural decisions with regard to the conduct of the study.

One of the key characteristics of a grounded theory approach is the joint collection, coding and analysis which occur concurrently throughout the process from beginning to end (Glaser and Strauss, 1967) enabling the processes to inform one another. Coding of data therefore commences at the outset as a means by which to effectively fracture the data and force the researcher to consider the data in terms of explicit concepts and

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<sup>1</sup> The term stricture is that of Stern, a pupil of Glaser's and is indicative of the degree of divergence that had occurred between the Glaserian and Strausserian schools.

their relationships rather than in a descriptive way. Constant comparison between the categories that are assigned and those that have already been assigned generates the theoretical properties of a category, its dimensions, conditions, and its relation to other categories. Whilst Strauss details this in considerable detail in his earlier text 'Qualitative analysis for social scientists' this structure is presented in a simplified format in the later account, suggesting that rigidity of structure is not the central tenet. Rather it is the developing depth of analytic process that occurs in tandem with increasing theoretical sensitisation. It is the process of comparative analysis, oscillation between data and theory, that informs both the generation and the development of categories and may necessitate recoding as new insights enable one to realise the significance of events and descriptions that had previously been overlooked (Strauss and Corbin, 1990).

The point of divergence between Glaser and Strauss lies in the way that the coding process is conducted, which is reflective of differences in the fundamental questions that one is asking of the data. Strauss' approach to coding is highly detailed and requires minute examination of the text line by line and word by word through the sequential processes of open, axial and selective coding. This enables the assignment of category labels which designate the characteristics of a concrete entity rather than simply labelling the entity itself (Strauss, 1987, Strauss and Corbin, 1990). Strauss effectively stops at every word of the data to ask the question 'what if?' Glaser by contrast adopts a broader focus of approach, more concerned with the data as a whole. He keeps his attention on the data and in asking the question 'what do we have here?' he is concerned to allow the data to tell their own story (Stern, 1994).

#### **4.3.1 Theoretical sensitivity**

Theoretical sensitivity refers to an awareness of the subtlety of meaning in the data. The effect of theoretical sensitivity is to provide insight into and understanding of what is going on, as well as the capability to discern what is pertinent and what is not. In part it comes from the knowledge base the researcher brings from the outset. This is necessary in order to generate the questions that occur in the process of constant comparison. However, it is also an ongoing process which is itself informed by data collection and analysis. The generation of theory which is rooted in the data requires comparison with extant theory that further informs the identification of subsequent literature and leads the researcher into diverse bodies of existing theory that touch upon aspects of the emerging theory (Glaser, 1987). In so doing it expands and strengthens the theoretical construct on which the theory is based whilst ensuring that

it is grounded in the data by encompassing concepts that were not apparent at the outset of the study but which have only become so as a consequence of the analytic process. It is essential therefore that as a method that sets out to develop new theory rather than test pre-established principles, review of the literature should occur alongside data collection and analysis (Strauss and Corbin, 1990).

My theoretical sensitivity which developed over time came primarily from two sources. Firstly my clinical expertise in a related area of sexual health provided an experiential perspective that drew on knowledge and experience acquired in a professional capacity. This developed further as a result of close and ongoing contact with both patients and fellow professionals. Secondly I explored an increasingly wide and diverse range of literature. My exploration of the theory started in the burgeoning expanse of biomedical literature that pertains to this infection but gradually expanded into related biomedical arenas and increasingly into the sociological literature that I came to see as essential for providing a sociocultural grounding within which to understand and explain the emerging concepts.

As I gained greater understanding and insight into the associated issues through theoretical exploration and the early stages of data analysis, I became more expert at elucidating sexual histories in a clinical context and at facilitating a greater depth of discussion in the research setting. My increased confidence and competence resulted in clients and participants alike being more willing to disclose the intimate details of their sex lives and to articulate the attitudes and values that underpinned their interpretation of events and their decision making. Consequently the quality of data increased as a result of theoretical sensitisation which enabled the uncovering of data that might otherwise be overlooked (Glaser, 1987).

#### **4.3.2 Theoretical sampling**

The emergence of concepts that have proven theoretical relevance to the evolving theory (Strauss and Corbin, 1990) provides the basis of theoretical sampling, the decisions that determine what data to collect next and where to find them. The central consideration in this process is the concept rather than the person. Whilst this may conceivably involve different groups and different locations in the process of data collection (Glaser and Strauss, 1967) the extent to which it can be realised is likely to be constrained by logistical considerations. In many circumstances sampling is determined on the basis of those to whom one has access. However, as Strauss and Corbin identify, this does not preclude the possibility of theoretical sampling. It may

simply increase the amount of time required and the amount of data that needs to be collected before processes and variation are adequately uncovered and the requisite degree of density is achieved (Strauss and Corbin, 1990).

In the conduct of a grounded theory study it is not possible to predict either the amount of data that must be collected or from where it should be collected to best effect, as the determining factor is the achievement of theoretical saturation, a requisite in the production of conceptually adequate theory (Strauss and Corbin, 1990). Saturation occurs when no additional data are being found that can further contribute to the development of the categories and it is therefore dependent upon theoretical sampling as the means by which that development occurs. In practical terms the achievement of theoretical saturation for any one category becomes evident when similar instances are seen or reported time after time, although in order to feel confident that this state has been achieved it is necessary to ensure as great a diversity as possible within the study group and this aspect of the process therefore also relies upon concurrent data collection and analysis (Glaser and Strauss, 1967).

#### **4.4 Study sites**

The primary study site was a GUM clinic based within a medium sized District General Hospital in the Midlands area of England. This clinic runs seventeen doctor sessions per week and serves a diverse, although largely indigenous, population of approximately 370,000. The unit is small with a permanent nursing staff of 7 which includes one health advisor and a small team of medical staff headed up by 2 part-time consultants. The small number of individuals with whom to negotiate, and the positive and enthusiastic attitude of the senior nursing staff, contributed significantly to the feasibility of conducting a study on sensitive issues, where considerations of confidentiality are paramount, and access to patients is carefully restricted by staff who function as highly effective gatekeepers.

In keeping with the requirements of grounded theory I determined to follow the principles of theoretical sampling. The use of an opportunistic recruitment approach, which was the only realistic approach available to me, represented a constraint to this process. This is an acknowledged difficulty that can largely be overcome when it is not possible to use more than one site by continuing to collect data for a sufficient length of time (Strauss and Corbin, 1990). Many of the emerging categories could be adequately explored by continued data collection. However sole use of this site was limiting in so far as it did not enable me to access the experiences of those with

infections who had not attended the GUM clinic, or those for whom the infection was not a very recent occurrence. I felt therefore that it was necessary to access participants via a separate second study site. I explored a number of options including community networks and structures and alternative health care settings. The logistical difficulties associated with the former appeared to be considerable. Preliminary requests for recruits within a sub sample of a University student population yielded no volunteers and the time and cost constraints associated with attempting to recruit from a wider pool of young adults appeared prohibitive.

I elected therefore to use the FPC in the same geographical area and therefore theoretically serving the same population as the GUM clinic for this second site. The FP service provides for this population through one main town centre site, which provides clinic sessions six days per week, and a number of satellite clinics which run one session per week in order to provide a service in the outlying areas. I elected to confine recruitment in this second site to the main town centre clinic. This was firstly because of the wide geographical spread of these satellite services and secondly because involvement of the satellite clinics would have necessitated inclusion of large numbers of sessional staff in the recruitment process which was anticipated to be problematic on the basis of previous experience (Piercy et al., 2000).

A significant and steadily increasing amount of testing for infection takes place in the Family Planning service, either by patient request or on presentation with symptoms. Whilst it was anticipated that most of those diagnosed in this setting would have attended the GUM clinic for treatment, it did provide a means by which to access those who had not done so. It also provided a way in which to reach those for whom infection was a less recent occurrence and therefore to explore the effects of the passage of time. Several participants were recruited through this second site during the second half of the study.

#### **4.5 Considerations of credibility**

The standard by which a grounded theory study is judged needs to be appropriate to the realities of qualitative research and the complexities of social phenomena (Strauss and Corbin, 1990). Glaser and Strauss identify the three criteria of assessment as credibility, plausibility and trustworthiness and propose that they should be judged on the detailed elements of the strategies used for collecting, analysing and presenting the data. From the researchers' point of view, credibility comes from their conviction that their conceptual framework forms a systematic study which derives from prolonged

immersion in the study and the continued comparative process (Glaser and Strauss, 1967). This needs then to be effectively communicated to others with provision of sufficient detail of the process and the relevant theoretical and logistical considerations in order that it can be assessed. My claim to credibility in this study lies not only in the theory that is presented as the product of the process, but also in the rigour of the process presented through reflexivity and transparency of decision making.

#### **4.6 Interviewing in sexual health research**

Asking a person questions about their sexual behaviour, their personal experience of a sexual health matter, or the way in which they make sense of a sexual illness experience represents a potentially useful way of eliciting information, and has been widely used as the primary source on which to base theoretical findings in this field. However what is asked, how it is asked, and the meaning that is attributed to the answers received, is largely determined by the ontological perspective and the epistemological stance within which it occurs and is bounded within a set of assumptions. This is the case in any research, but particularly in sexual health research where personalised information may well be intensely private and sensitive. Acknowledgement and consideration of the major assumptions is therefore essential to the process of understanding the data and the interpretation that it generates.

##### **4.6.1 Sex surveys and the associated problems**

Sexual attitudes and behaviours are commonly explored by means of quantitative surveys. Within these, there is an emphasis upon data collection methods such as self completion questionnaires and techniques such as telephone and computer assisted interviewing. Their perceived advantage is that they reduce the necessity for face to face discussion as well as allowing for the sampling of large numbers of people. This approach is founded upon the recognised difficulties of asking and answering questions about this most private and personal aspect of life. However whilst surveys have utility in empirical terms, in counting and measuring the extent to which individuals report involvement in specific behaviours, its dominance as the foremost approach in sexual health research is problematic on a number of counts.

##### **4.6.2 The problem of reliability**

The sampling methods and scale of operation in surveys lead to claims of generalisability. However these claims are based on the assumption that the respondents represent the population from which they are drawn and that the information that they provide accurately reflects their own reality. Although it is

possible to achieve high response rates that are comparable with other survey studies (Johnson et al., 1994), there are concerns as to the extent to which non response is attributable to the topic of enquiry. It is probable that those who do not respond are likely to be those with the most sensitive information to report (Tourangeau and Smith, 1996) and therefore the claim of representation is questionable.

The survey method has been shown to be associated with significant underreporting of sexual activities and infection rates (Tourangeau and Smith, 1996, Catania et al., 1996, Melnick et al., 1993) and may also be associated with over-reporting, particularly in relation to socially normative behaviours. It is also likely that there are gender differences in relation to specific aspects of sexual behaviour such as number of partners (Catania et al., 1996). It has been proposed that self-administered methods reduce social embarrassment and therefore enhance honest reporting (Catania et al., 1990) with computer assisted self-administered systems further enhancing the effect (Tourangeau and Smith, 1996). However whilst this may produce changes in report rates that are interpreted as increased honesty, they are of themselves founded upon an assumption of understanding in relation to the wording of the questions.

#### **4.6.3 The problem of language**

The survey approach is founded upon methodological assumptions which produce difficulties in relation to many topics of enquiry, but particularly in relation to sex research. A core assumption is that as long as they are presented in the same way, words will have the same meaning for different people and their responses can be collectively analysed on the basis of this assumption (Hollway and Jefferson, 2000). Making this assumption produces variable degrees of difficulty. Much language is privileged; it is educationally influenced and socially and culturally determined. Therefore common understanding and shared meanings cannot be assumed. This is a particular concern in relation to sexual behaviour. It is rarely spoken of in public and the associated vocabulary is both impoverished and inappropriate with a wide diversity of language styles. Vernacular, biblical, romantic, euphemistic, scientific and lay terms are all in common usage and often used interchangeably within a conversation (Johnson et al., 1994). This represents a considerable challenge to any research, whatever approach is used. In surveys and particularly self completion methods of data collection where the reliability of the data is founded upon an assumption of common understanding of the questions asked this is clearly problematic. Language that is commonly used by researchers and considered to be easy to understand and unambiguous is not universally understood by respondents. For example, in one

survey of sexual activity, researchers identified a lack of comprehension of the terms vaginal intercourse and anal intercourse which produced significant problems for a proportion of the study respondents (Binson and Catania, 1998). The achievement of an acceptable level of shared understanding is dependent upon a considerable amount of preliminary work in determining both the language to be used and the degree of explicit explanatory information required (Johnson et al., 1994).

To interpret answers and responses that have been decontextualised by the process of interviewing is intrinsically problematic because the responses that people give emanate from their sociocultural background of meaning. It is this background within which they hear and interpret the question and within which the meaning of their answer is embedded. The set of assumptions and presumptions that are imposed by the researcher create an alternative context through which the process of interpretation occurs (Mischler, 1986). This is a problem with any topic of enquiry, however with something such as sexual health where ambiguities and assumptions abound it is especially so. Therefore to explore the personal experience of a sexual health matter and how people make sense of it, requires not only that we ask questions but that we do so in a way that allows the answers and the explanations to be heard within the context of the sociocultural embedding within which they have been constructed.

#### **4.7 Unstructured Interviews**

Unstructured interviews provide an alternative solution that addresses many of these concerns. They create space and opportunity for the participants to tell their own story, to offer an account that reflects what was relevant to them, both in terms of the specific areas of concern and their relative magnitudes. They also provide a structure within which both interviewer and interviewee have the opportunity to clarify what is said. They are therefore consistent with an inductive method of enquiry such as grounded theory. My own clinical practice had provided me with experience of dealing with clients at various stages of the infection experience, those concerned about possible exposure to infection, clients at the point of diagnosis and those who expressed residual concerns subsequent to treatment. This was the primary means by which I had been alerted to the fact that for many of them this was a significant event. However, whilst my own insight was extremely valuable to the process, I was anxious to ensure that my pre-conceptions did not lead to assumptions. I determined therefore to use a minimal pre-determined structure that was confined to an opening question and then topic prompt areas (see appendix IV). This provided the basic framework for the interviews, however it was modified and expanded to some extent during the course of

the interviewing process in order to incorporate those concepts into the later interviews that emerged during preliminary analysis. An example of this is presented in section 4.13.

When people are asked questions, the context within which they are asked has a considerable degree of influence upon the answers that they give. The absence of a predetermined content of enquiry and rigidity of structure characterises the unstructured, in-depth or narrative account. The lack of tightly managed structure and content provides facility for the individual to use their own voice, to exercise a degree of determination and control over what is said and how it is said. It enables a discussion that is reflective of the perspective of the respondent rather than being constrained by the researcher's own perspective and pre-conceptions (Parr, 1998). This approach allows us access to the narratives that people create for themselves, that help them to understand who they are (Mathieson and Stam, 1995). With the loss of predetermined structure and format there is greater opportunity for recounting of narrative, a constructed account that creates meaning by telling stories about an experience, which encompasses within it both the actor who has lived through that experience and the teller of the story.

“it is through narrativity that we come to know, understand and make sense of our social world and it through narratives and narrativity that we construct our social identity” (Somers, 1994 p. 604).

#### **4.7.1 The power of narrative**

Narratives are created in response to life events because the process of creating an account provides a means by which to order thoughts and construct meaning. It is the disruption to ordered life events and the chaos that ensues that requires us to restore some order and make sense of the experience through narrative reconstruction, a telling of events which provides not only explanation of events but also acts of interpretation (Williams, 1984). As a process that inevitably accompanies significant life events, narrative provides a rich source through which to try and understand the interpretation and meaning that people attribute to objects and events (Plummer, 1995). As such it has been widely adopted as a method by which to chronicle and understand major life events that produce biographical disruption, in particular chronic illness (Mathieson and Stam, 1995, Kleinmann, 1988, Bury, 1982, Frank, 1995). The applicability of this approach, as a means by which to generate personalised accounts of a significant health events, such as chlamydial infection, appeared to me therefore to

be the most appropriate way to examine how and why this infection produces biographical disruption.

Through the process of interviewing we aim to gain access to and achieve an understanding of someone else's experience (Riessman, 1993), through their thoughts, ideas and memories conveyed in their own words (Reinharz, 1992, Gerson and Horowitz, 2002). In this way it provides a means by which to develop understanding of the social processes that define and determine identified events and experiences. We need to listen carefully to what people are saying and why and how they are saying it, in order to understand the social and cultural context of events as well as the events themselves (Parr, 1998). It is acknowledged however, that we can never have direct access to the experience of another person, only that we can hope to deal with an ambiguous representation of it derived through and mediated by the processes of talk, text, interaction and interpretation each aspect of which shapes, constructs and constrains the end product (Riessman, 1993).

The account that is produced tells of past events but it does so selectively in terms of present concerns and values (Skultans, 1999). Its power therefore lies in its ability to reflect those aspects of an experience that are of greatest significance to a teller, although these are inevitably temporally defined, not fixed but moderated over time. In its creation and its recounting, it provides a means by which to reconstruct a sense of order from the fragmentation created by life events (Williams, 1984). As such it is more than a simple explanation of events. It is actively created in the telling, incorporating not only reconstruction but also present understanding and future speculations (Mattingley and Garro, 1994). In this respect the process of providing an account is a conspective act, the means by which an individual can rehearse past actions, evaluating the role of self and others and consider alternatives and redirective actions. As such it serves a number of psychosocial functions. Centred primarily on the self, it develops and maintains a sense of identity in so far as it provides a means by which to define, assess and reassess self and to present ourselves to others (Kuhn, 1962, Viney and Bousfield, 1991, Plummer, 1995).

#### **4.7.2 Researcher and researched**

A key aspect of this unstructured type of approach is the opportunity that it affords for greater connectedness between researcher and researched. An interview that imitates conversation provides opportunity for mutual listening. In so doing it reduces the boundaries between knower and known and creates opportunity to ground knowledge

in concrete social contexts and experiences (Oakley, 2000). The widespread adoption of this approach as a means by which to generate useful knowledge comes in part from the opportunity that it affords to develop intersubjectivity and non hierarchical relationships between researcher and participant (Maynard and Purvis, 1994, Kelly et al., 1994, Oakley, 1981). Much of this is predicated upon establishing a relationship between interviewer and interviewee, recognising the contribution of the respondents and treating them as an equal partner in the relationship rather than simply as an object from which to extract information.

As a contrived event within the research process any interview situation is in itself a social act, an interactional process (Kuhn, 1962) and its product, the data that is produced, can only ever be the outcome of a socially situated activity where the responses are passed through the role-playing and impression management of both the interviewer and the respondent (Dingwall, 1997). However the account that is produced is not purely the product of one person's deliberations. What is said and the way in which it is said, as well as what is left unsaid, will also be influenced by the person to whom it is said as the teller creates a self, a representation of how they wish to be seen (Riessman, 1993, Goffman, 1990). The product of the interaction is the creation of shared meaning as both interviewer and interviewee interact through the process of verbal exchange. A question in this context might be thought of more as part of a circular process through which meaning is created rather than as a stimulus with a predetermined and shared meaning that is intended to elicit a response (Mischler, 1986). The meaning that emerges is processual, created in the telling through the construct of accounts and events that enable meaning and significance to be constructed (Mason, 2002, Mattingley and Garro, 1994).

The process must therefore be viewed as a co-operative activity and its product as a composite of the participating individuals and the relationship between them. Whilst this position does not discount the possibility of obtaining a knowledge of the world by means of that interaction (Miller and Glassner, 1997) it is clearly necessary to consider and acknowledge the dominant influences and contemplate the ways in which they have contributed to the production of the account. A number of considerations arose in this study. In part these related to the set of assumptions associated with the process of interviewing, the setting within which the interviews took place and the context within which the narrative was constructed. More specific considerations arose in relation to the sensitive nature of the topic of enquiry and the choice of approach that included both males and females.

### **4.7.3 The sensitivity of the topic**

Questions relating to sexual behaviour are considered to produce a greater degree of unease in research participants than almost any other topic (Lee, 1993). The personalised and sensitive nature of the information that one is attempting to elicit in sexual health research relates to intensely private and intimate activity. To ask detailed questions that probe into someone's sexual behaviours is therefore a potential source of considerable embarrassment and distress. It is often considered highly problematic within the context of a clinical encounter (Ross et al., 2000, Temple-Smith et al., 1999) and might be expected to produce as great or greater difficulties in a research situation where it may be construed as intrusively sensitive (Lee, 1993) although the extent to which this situation is realised is not necessarily clear cut.

This has clear implications for a qualitative method of enquiry that requires face to face contact and utilises an unstructured interview which provides less theoretical safety for either interviewer or interviewee. There is no structured interview schedule for either to hide behind which provides opportunity for the one to ask pre-determined questions and the other to provide superficial answers that reveal little of oneself. However the lack of linguistic barriers that produce this vulnerability also create a situation within which personal perspectives and concerns can be conveyed, in the individual descriptions and insights of the participant (Melia, 1997) without the predetermined constraints and pre-conceptions of someone else. The process of in-depth interviewing provides a means by which to gain access to and achieve an understanding of someone else's experience. Whilst there is no way in which that experience can be accessed directly and the best one can hope to deal with is an ambiguous representation of it (Riessman, 1993), nevertheless creating the space within which an individual can tell their story provides the best form of access to that experience, acknowledging and embracing the ambiguities and contradictions that are commonly integral to emotionally charged accounts (Brannen, 1988)

### **4.8 Considerations of the interview process**

The sensitivity of the topic contributes to the balance of power and control within the interview situation in relation to both structure and content. Although in style it may approximate to a conversation, an interview situation is nevertheless an artificially contrived situation brought about for the purpose of discussing and gathering information on a specific topic. Similarly it is a fractured account (Miller and Glassner, 1997) partial in length and with a focus that is guided and steered by the researcher's agenda which exercises a degree of control over the process. As a social interaction,

the interview is a situation within which power and control exist and operate influencing in turn the outcome of the interaction, the interview data.

The extent to which this can be minimised by the creation of a non-hierarchical relationship is a debated point. Any interview that occurs is a product of the researcher's agenda. She has planned and prepared for it. This creates considerable potential for a marked asymmetry of power within the interview itself although it does not necessarily reflect the whole picture. As the one who chooses whether to not to participate, what they do or do not elect to disclose or divulge in the interview situation, what they choose to emphasise and what they elect to downplay, the participant also has the potential to exercise a considerable amount of power (Reynolds, 2002, Mauthner and Doucet, 1998).

#### **4.8.1 Presentation of the researcher self**

Unstructured interviews provide a structure within which the interviewer's role is not necessarily limited to eliciting information but within which she invests her own identity by being prepared to contribute personal information including sharing of feelings (Fontana and Frey, 1998). Indeed the sharing of personal information and being prepared to honestly answer questions is considered by some to be a condition and moral imperative for interviewing within a feminist methodology (Oakley, 1981, Finch, 1984). It is also a natural process in a relaxed interview situation where encouraging discussion of sensitive issues can lead the researcher to reveal her own values and opinions (Wilde, 1992).

In considering the conduct of feminist research, Oakley (1981) proposes that recognition of the shared gender socialisation and critical life experiences comes from a researcher's willingness to contribute personal information to the interview. This provides a means by which to reduce social distance between female interviewers and interviewees thereby increasing intimacy and diminishing the hierarchical relationship in the interview. It is this commonality that is the basis of rapport, that sharing of a common language such that there is congruity between the frames of reference within which the communication is conducted (Kuhn, 1962). However to propose that social distance can be so readily reduced denies the impact of other structural differences such as race, class, professional status and age (Reynolds, 2002, Holland and Ramazanoglu, 1994, Parr, 1998) and fails to consider the impact of cross gender interviewing.

The proposition that an interviewer shares personal information derives from an expectation that there are experiences to be shared and that the sharing of them is of benefit to the interview and the individuals contributing to it. The hierarchical relationship that the interview automatically creates can make it highly problematic (Bowler, 1997) and several authors have questioned the relative merits of doing so (Miller, 1998, Parr, 1998, Mauthner, 1998). The extent to which one is prepared to invest one's own identity, and in particular the willingness to share personal information, is a matter that requires individual consideration. It may not feel comfortable sharing personal information and unsolicited proffering of personal opinions may not necessarily be acceptable to the participant. Although one may aspire to a non hierarchical situation and adopt a conversational approach, an interview is nevertheless a contrived situation and any information that is supplied will contribute to that situation. In some instances this may be beneficial both to the interviewee, to the relationship and to the quality and depth of subsequent discussion. However its influence upon what is said and the extent to which it creates an expectation of specific responses cannot be discounted (Parr, 1998).

The way in which the research is presented to and perceived by participants impacts upon what is voiced in the interview (Miller, 1998). The location of the interviews and the status of the researcher will inevitably contribute to this. Undertaking the interviews in the clinic setting was essential for logistical reasons but was likely to have had a range of effects upon the data. On the one hand an informal interview room within the clinic environment promised security and safety where intimate disclosure was expected and anticipated. However this setting and the staff through whom the participants were recruited are synonymous with the dominant health ideologies and discourses that characterise this aspect of health and might be expected to encourage responses that reflect this position. I felt that it was important to reveal my clinical status to justify my presence in the unit, my request to discuss aspects related to a clinical diagnosis and my right to probe into the most intimate aspects of someone's life. My wish to create distance between the interview and its context, whilst acknowledging that this can only ever be partial, led to my decision to introduce myself as a researcher and a nurse who worked in the related but separate area of family planning and justify the study in these terms.

Whilst I was careful to distance myself to some extent from the GUM clinic setting by explaining my clinical role in a parallel and related setting, there was an implicit health professional-client relationship influencing the situation as well as the explicit

researcher-participant relationship. I did not consider it desirable or possible to achieve the conditions that Oakley (1981) subscribes to on a number of counts. Interviews were conducted with both males and females the majority of whom were teenagers and young adults. This created marked age differences in most interviews and gender differences in a proportion of them. The identity that I took into the interview was superficially subsumed within my professional role and I considered that sharing of personal experience was unlikely to be expected or welcomed by the participants and was therefore inappropriate. My claim to interest in the topic of enquiry was justified in terms of my experience from a professional rather than a personal perspective. Whilst I acknowledge that this provided me with a degree of personal protection, I would propose that it also provided protection for the respondents by sanctioning their responses as it was my professional role as a functionary that justified me probing into their private lives (Kuhn, 1962).

A potential consequence of my stated professional identity was the magnified impact of any opinions and views that I might proffer on the expectations of 'correct' responses. I was anxious to minimise this as far as possible and create a situation in which honest and open responses were encouraged. On the basis of this, and a personal viewpoint that it would have been inappropriate for me to have done so given the nature of the topic, I resolved not to offer opinions and to provide as neutral a response as possible if one was solicited. I anticipated that the interview would be bounded much in the way that a professional consultation is. By similar reasoning I expected that the interviews might generate questions of the type that I would typically encounter in a clinical encounter. I resolved therefore to answer any questions that were asked as accurately as I could whilst being aware of recourse to on site staff if necessary.

In the main I was not called upon to offer information of a specific or more general nature. In one or two cases the respondents did indicate some confusion about the details of their infection and sought clarification. However this was largely in reference to small details and the transient nature of their enquiry together with their readiness to pass rapidly over a specific sticking point led me to the conclusion that my input was of minimal effect. To an extent this may have been due to the timing of the interview which took place at the end of their clinic visit immediately subsequent to a variable number of health consultations. In essence it was probable that the respondents had already had the opportunity to elicit the information and explanations that they required.

#### **4.8.2 Creating a safe environment**

Whilst the position that I elected to adopt is likely to have contributed to a distribution of power weighted in favour of the researcher, I considered that it was justified in terms of the topic of enquiry. It was the content that might be expected to create the greatest vulnerability and therefore structural aspects of the situation that may have created a power differential were justified in terms of the security that they provided. As Brannen (1988) identifies the one-sided nature of the interviews concerning sensitive and often distressing matters arises primarily from the nature of the investigation and the situation of respondents. One of the problems with disclosure of personal information is the non-pluralistic nature of such information (Lee, 1993). As individuals only know of their own behaviour, they have no frame of reference within which to judge whether their behaviour is normal and may therefore tend towards constructing an account that satisfies the requirements of social acceptability, which attempts to conform to an unknown and unknowable social norm (Meerabeau, 1999). In order to do so they look to the researcher whose role as confidante creates her privileged position as a reservoir of knowledge. In this situation, the respondent scrutinises the interviewer's responses to her disclosures. Verbal and non verbal communications are judged and interpreted as indications of acceptance or rejection in an attempt to judge whether their behaviour is 'normal.'

What appears to be of greatest importance in an interview of this type is therefore not a co-participant approach, rather I would advocate for the creation of a setting which is sufficiently secure and comfortable that respondents feel able to choose to disclose intimate and personal information. Such a discussion can commonly produce an emotional response including tears which can be a further source of embarrassment. Such a situation is likely to produce an instinct on the part of the interviewer to intervene, either by offering comfort or terminating the interview. Whilst I would concur with the opinion of others who suggest that distress is not necessarily pathological or a cause for intervention (Oster, 2003, Finch, 1984), I would propose that such an interview setting contributes to a reduction in the amount of associated embarrassment in that it approximates to a situation where demonstration of distress is more normative.

In the main I consider that a conducive setting was achieved. The interviews were characterised by the respondents' marked willingness to discuss personal aspects of their sex life. Their lack of reticence in describing practices that did not conform to the health rhetoric suggests a high degree of honesty which was not unduly influenced by

my professional status or the interview setting. The single stand-alone interview contributed to the creation of a bounded episode, a space created by the structure of the situation with its guarantees of confidentiality that is outside of the 'real world.' Within this setting disclosure becomes possible and may even approximate to the opening of the floodgates (Gerson and Horowitz, 2002, Brannen, 1988). Although some have identified this as a potential problem in so far as it may lead to people revealing highly personal aspects of their lives that they may on reflection have chosen not to disclose and which may provoke considerations of the limits of informed consent (Mason, 2002, Seibold et al., 1994), I did not experience these concerns.

#### **4.8.3 Controlling the length of the interview**

Two examples serve to illustrate ways in which the respondents felt able to control the situation. The first of these was the extent to which they influenced the length of the interview to the point of actually curtailing it. The interviews in this study were immediately preceded by a clinical consultation and all that it involved. Initially they were pre-planned and pre-booked allowing the respondents to make prior provision for the time that the interview took. After modification of the process which will be explained in section 4.11.4, the interviews were conducted opportunistically. Clinic visits were often lengthy and by the end of the interview several of the respondents had spent an entire morning or afternoon in the clinic. I was therefore always mindful of time. I asked at the outset of interviews if we had specific time constraints and made it clear that we could terminate the interview at a set time if required. For the majority of the respondents it did not appear to be a problem and they gave their time freely without any evident constraints. For a small number who had specific commitments that necessitated finishing at a set time, I ensured that they had sight of a clock such that they could regulate and control the length of the interview accordingly.

#### **4.8.4 The effect of observers**

The second point that illustrates the respondents' sense of control over the process was the decision by two of them to be interviewed in the presence of a third party. In guidelines for sexual health research proposals, Ringheim (1995) makes the case for a greater level of confidentiality in sexual health research, in particular stating that "the nature of questions regarding sexual behaviour demands absolute privacy" (Ringheim, 1995 p. 1691). This was the expectation for this study and provision was made for interviewing in a private interview room within the two study sites in order to fulfil these conditions. It was therefore something of a surprise when two of the women respondents requested that a third person be present in the interview, in one case a

sister and in the other a partner. My acquiescence with the request stemmed largely from a sense that the participant should be able to dictate the conditions as far as possible within the constraints within which we were operating. However this somewhat unexpected experience raised several considerations both in relation to the consequent dynamics and content of the interviews as well as the extent to which sensitivity is defined by both researcher and participant.

At the outset I experienced a slight sense of concern about the impact of a third party, what I would feel able to ask and what the respondent would feel able to disclose in the presence of another. These concerns subsided after a very short time. In common with the experience of Brannen (1988), I found that the presence of another did not appear to impact upon the depth of discussion or the willingness of the interviewee to disclose personal information. Concern has been expressed in this regard about the possibility that information will be divulged and confidences shared that may be later regretted, in effect that once an interview is underway it is as if the floodgates were opened (Brannen, 1988) with revelations beyond the expectation of the researcher and possibly of the respondent (Seibold et al., 1994). Whilst this is a possibility, to suggest that a respondent would inadvertently, as a result of the interview situation, divulge confidences to which a sibling or partner was not already privy appears to unduly privilege the content of the interview. Whilst the contents of the interview are unquestionably sensitive, that sensitivity need not preclude those with whom many of these confidences have already been shared. By enabling the interviewee to determine who else is present in their interview, we allow them to control the setting by determining the limits of boundedness, who is included and who is excluded from hearing their account.

As another player in the interview setting, the presence of a third party will inevitably influence the interaction. It may influence decisions as to what is said and what is not said as well as how it is said. On the one hand if it increases the degree of comfortableness, it may increase the level of disclosure, alternatively knowing that another person is also hearing what you say may have an inhibitory effect. It will influence whether and how the role of the observer herself is represented in the account as well as the way in which the interviewee wishes to be viewed by the observer. These effects can only be a matter of speculation and it is a matter of remark that in both cases the supportive role of the observer was recounted by the participant. However to presume that their presence in the account was a product of their presence in the interview is to discount the alternative reading of this situation,

namely that their presence in the interview was a product of their support in the illness experience.

On reflection the presence of the observers was positive. In the first instance the sister was silent throughout and appeared to provide moral support by her presence. In the second instance, the 'observer' was the partner who had also been through the treatment process. Although he sat silent through the formalised interview itself, after the tape was turned off, a spontaneous three way conversation ensued and provided a second part to the interview that was captured by turning on the tape recorder again with mutual consent. This provided a somewhat unique opportunity to hear two sides of a story told together in a situation that it would have been difficult to produce intentionally.

#### **4.9 Gender specific considerations**

##### **4.9.1 The justification for including women and men**

I took the decision to include the experiences of men as well as women in this study. This was done for pragmatic reasons in response to the disproportionate focus of attention upon women in relation to this infection and the wider health research agenda. The majority of health efforts in relation to chlamydial infection have focused primarily or exclusively on women and organisational structures have retained a position where this infection is viewed and represented as being primarily of female concern. This is reflective of a tradition that persists in representing women as the source of STI's and their health and social surveillance as the means by which to control the spread of these infections.

Two core considerations in this study were the extent to which the historical legacy influenced the infection experience for women and the extent to which current organisational structures that focus predominantly upon women shaped and defined that experience. However this illness experience is not confined to women or indeed even predominantly associated with women and this one sided approach in current practice has been criticised for failing to address the needs of men (Hart et al., 2002). It is important therefore to hear the male voice, to consider the extent to which experiences are common or gender specific. Although the current representations of these infections appear to largely define the female experience, an omission of the male experience would have predisposed to interpretations that grounded the female

experiences within a gendered construction alone without any recognition of the wider aspects.

Our ways of knowing, what we see and how we see it, what we experience and how we experience it, are affected by our particular location in the world. Different social categories are located differently; men and women inhabit different social worlds and realities both subjectively and literally whilst living in the same location (Millman and Moss Kanter, 1987). Therefore any consideration and exploration of the subjectivity of an illness experience that affects both males and females necessitates listening to both groups. To have done otherwise would have invited the charge that Oakley makes of producing unwarranted conclusions about one sex by omission of the other (Oakley, 2000).

#### **4.9.2 The unequal focus of attention on women**

The structure of health services is such that there is an unequal focus of attention on women who are subjected to over surveillance, testing and treatment whilst men are effectively marginalised and ignored. This is particularly apparent in sexual and reproductive health. The situation appears to be replicated in related research which tends to foreground women's experience whilst leaving men's as an unarticulated backdrop (Annandale and Hunt, 1990). In infertility studies this has been justified by the specific purpose of the study (Whiteford and Gonzalez, 1995) or as a consequence of difficulties in accessing male study participants (Wills, 1996, Lloyd, 1996). Some sexual health studies concerned with behaviours and STI's have surveyed both males and females (Ramos et al., 1995, Brookes et al., 1993, Clarke et al., 1996). Others reflect a male perspective although these largely but not exclusively focus their attention on homosexual activity (Pryce, 2000, Flowers et al., 1999, Hart et al., 1992). Overall however, there does seem to be a disproportionate focus on women particularly in qualitative studies to the extent that men's attitudes and behaviours may even be reflected through the words of women (Fleisher et al., 1994, McKie, 1996) even though comparison of first and third party accounts of sexual behaviours demonstrates discrepancy between the two (Stoner et al., 2003) and there are evident difficulties associated with attempts to represent the opinion of one person through another.

Qualitative studies that have explored the personal experience of having an STI have similarly focused almost exclusively on women (Hammarlund and Nystrom, 2004, Duncan et al., 2001, Scoular et al., 2001) even though structured and semi-structured

studies that have taken a cross gender approach have identified gender specific differences (Brookes et al., 1993, Darroch et al., 2003, Maw et al., 1998).

#### **4.9.3 Cross gender interviewing**

The unstructured interview has been widely associated with research that specifically listens to the voice of women. Can we assume that it is an appropriate method to use with men and that the accounts that are produced approximate to a man's lived reality in the way that female accounts are considered to approximate to a woman's lived reality? Communication literature does suggest differences in communication styles between men and women. The way in which the message is conveyed appears to be more crucial for women than for men. Women might therefore be more likely to understand and communicate messages within information that contextualises them rather than as isolated utterances (Rubin and Rubin, 1995). This would suggest therefore that the conversational style of interviewing is particularly suitable to use with women and less appropriate to use as an approach with men. However such an assumption presupposes within-gender homogeneity and between-gender dichotomy, in itself a nonsense (White and Johnson, 1998) predicated as it is upon generalisations. However it may point to the need for flexibility of approach and identity potential considerations in cross gender interviewing. Brannen (1988) proposes from her experience that men are less practised in the art of being a respondent and this may be one of the reasons for the recruitment difficulties that have been identified in infertility studies (Lloyd, 1996). However neither this lack of willingness, nor Brannen's observation that men demonstrated greater trepidation, was born out by my experience.

There was an initial discrepancy in the proportion of males and females recruited to the study. However this was a result of the recruitment process and was largely resolved when the process was modified. The details of this are discussed later in this chapter. Whilst one of the males in particular did appear to find the experience difficult and terminated the interview abruptly, this was an isolated incident. The majority experience was of participants who were both relaxed and forthcoming. There was considerable variability in the length of interviews and depth of discussions, however this was similar to the degree of variability experienced in the female interviews.

Whilst social or cultural gaps between the researcher and the researched do not preclude the undertaking of such studies, they do necessitate consideration of the associated implications (Rubin and Rubin, 1995). The cross gender effect of myself as

a female interviewer conducting interviews with male respondents was a key structural difference. What are the influences upon this situation in terms of the power relationship and the content of the interview given the topic of enquiry? Reynolds (2002) proposes that the impact of structural differences is likely to reflect the structurally dominant positions. In an interview situation this will translate into power and dominance of one social group over another that is subordinate to them irrespective of whether they are the researcher or research participant (Reynolds, 2002). This would suggest that male respondents would exert greater power in the interviews than female respondents, possibly as a response to the vulnerability that arises from unaccustomed distribution of power (Walkerdine et al., 2002). I do not consider this to have been a significant aspect in this study, possibly as a consequence of other factors, particularly my acknowledged professional status.

#### **4.9.4 Embarrassment and disclosure**

The intimate nature of the discussion that was a key aspect of these interviews might be expected to produce some embarrassment and possible reluctance to disclose personal behaviours and attitudes, particularly in a cross gender situation. This effect is often not acknowledged in the literature to the extent that the sex of those contributing or collecting data may not even be identified (Holgate and Longman, 1998, Fleisher et al., 1994, Fortenberry, 1997). There is some evidence that gender does appear to influence data collection in sex surveys although the degree to which it does so may be small (Lee, 1993). The effect is most significant among women respondents who are much more likely than men to express preference for same gender interviewer and more likely to decline to answer questions with an opposite gender than with a same gender interviewer (Catania et al., 1996). For males, interviewer rapport may be more important than gender (Lee, 1993).

This effect might be expected to be more significant in relation to unstructured interviews which require articulation of ideas and explanation of behaviours rather than responses to pre-determined questions. It was on this basis that Skidmore & Hayter (2000) justified same gender interviews in their study of risk and sexual behaviour in young people. However in comparable studies where choice of interviewer has been possible in order to ensure same gender interviewing, few respondents elected for this option. In interviews with males about prostate cancer, Chapple and Ziebland report that only one of the forty men interviewed elected to be interviewed by a man (Chapple and Ziebland, 2002). Similarly in a study that examined sexual satisfaction and quality of life in those experiencing urological or gynaecological difficulties, only one of the

twelve female participants elected for a female interviewer in preference to the main interviewer who was male (Daker-White and Donovan, 2002). This suggests that there is no clear preference for same gender interviews among either males or females although there is some evidence that it may affect the data when mixed gender interviewers are used (Daker-White and Donovan, 2002).

As a lone female researcher I could not offer the option of a male interviewer to the male respondents and it is not possible therefore to know what their preference would have been. Equally it is impossible to determine whether the quality of data would have been different. Overall however I did not experience greater difficulties in interviewing the males than the females and their collective responses were similar to those of the females incorporating those who were relaxed and forthcoming as well as those who were reticent and demonstrated signs of embarrassment. In part I feel this was due to my own confidence in broaching sensitive topics with males and females alike which resulted primarily from my clinical experience and practice.

#### **4.10 The interpretation of ethics in a sensitive setting**

As the study was initially designed to take place in the GUM clinic the research protocol was constructed to take account of the specific and highly sensitive considerations inherent in accessing a population who were using this service. Where appropriate the processes and procedures were transferred to the second site (the FPC) protocol, although some aspects were amended in order to better fit with the structure and organisation of that service. These are identified and discussed later in the chapter. Each of the two sites produced their own challenges particularly in terms of the recruitment process and there was a need to make some modification as the study progressed. Consequently I will discuss the broader ethical considerations primarily in relation to the GUM clinic making reference to the modifications that came about with regard to family planning where appropriate. I will then address the recruitment processes in both sites and the specific considerations and difficulties associated with each of them.

##### **4.10.1 Ethical approval**

At the time of conducting this study, ethical approval at an organisational level required application to the local research ethics committee. The approval for this study was applied for as a two stage process. Originally ethical approval was sought and granted for the initial data collection in the GUM clinic. Subsequently when the decision was taken to also collect data in the FP clinic, I modified the research protocol and

produced site specific information sheets. At this point I returned to the ethics committee to request extension of the study which was granted.

#### **4.10.2 Inclusion/exclusion criteria**

Potential recruits to the GUM study were any patients who had been diagnosed and treated for genital chlamydial infection in conjunction with this clinic attendance. The type of referral and place of diagnosis were not limiting factors. Similarly it was not a requirement that the chlamydial diagnosis was the initial or the sole diagnosis. There were two exclusion criteria namely those who had been diagnosed at time of referral for termination of pregnancy (TOP) and those aged below 16 years.

For those diagnosed in relation to a termination of pregnancy, the decision was taken for logistical and psychological reasons. The time between referral for TOP and the procedure being carried out is often short and prompt treatment is required to reduce the risk of ascending infection from pre-existing chlamydial infection as a consequence of the procedure. The gynaecology department and genitourinary medicine department had developed a separate protocol to ensure the rapid treatment and management of these patients. This fast track route effectively eliminated these patients from the initial system of recruitment because they had not been referred to the GUM clinic at the same point in the process as those referred from other services. From a psychological perspective, concerns for the well-being of these women who had recently undergone a highly emotive experience contributed to the decision to exclude them from the study.

It was necessary to determine a lower age limit for inclusion in the study. There is no theoretical lower age limit of service users in either the GUM clinic or the FPC. In the area of sexual health, parent child dialogue is often restricted, highly charged, and fraught with anxieties. Many young people are fearful of parental responses to the consequences of their sexual activities and anticipate anger, condemnation and possible social sanctions. A significant proportion of those attending both services are below 16 years old and they commonly attend without the knowledge of their parents. It is accepted practice to treat these young people without parental knowledge or consent provided that they are themselves competent to consent. In order to do so they are required to fulfil the Fraser guidelines, having sufficient understanding and intelligence to fully understand what is proposed (DH, 2001d). In the GUM clinic assessment of competency in under 16's is formally undertaken and documented by

the doctor taking the initial medical history whilst in the FP clinic it is both assessed and documented in a less structured format.

There was therefore an established mechanism for identifying those under the age of 16 whom it may have been appropriate to invite to participate in this study. However, the legal ability of under 16's to consent to research is not clear and does not necessarily equate with their legal ability to consent to medical treatment although some sexual health research has included those under 16 if they fulfil the Fraser guidelines (Baird et al., 2002). Professional guidance indicates that research on those under 16 should not proceed without parental consent although the guidance documents refer to therapeutic research with no consideration of social research (Piercy and Hargate, 2004). Although there was theoretical facility to include those under the age of 16 who did attend with parents, such an approach was not in keeping with the spirit of the study or the service philosophy to treat all service users as autonomous decision makers. A decision was therefore taken reluctantly to exclude those under 16 years old from this study, on the basis of the lack of clarity in this area and on recommendation of senior staff members in the GUM clinic who anticipated difficulties in obtaining approval from the local ethics committee if this group were included. Notwithstanding this, I feel on reflection that although their inclusion may have produced difficulties, the exclusion of this group from the outset created a potential loss of valuable data and denied them the opportunity to have their voice heard.

#### **4.10.3 Access to the study population**

Primary considerations in relation to accessing potential participants and the recruitment process were the unique organisational characteristics of the primary study site, the GUM clinic. This service has been likened to a sanctuary, a safe zone for the disclosure of innermost sexual secrets, which promises relief from disease and distress (Pryce, In press). The safety that the clinic promises comes from effectively isolating and distancing attendance from the outside world. It provides a haven which is guarded and protected by the staff who safeguard privacy by carefully regulating the outward flow of information and controlling contact with outsiders. The function of these mechanisms is to ensure the highest level of confidentiality which is considered essential to the effective running of the clinic and the maintenance of patient confidence in the service. Patients are allocated a unique identifier and separate records are maintained, which are stored in the unit. Records are handled and generally only seen by those staff working in the clinic. Patients are referred to either

by that number or by their first name only in the open areas of the clinic. Access to them is carefully controlled, for example if there are visitors to the clinic (staff from other disciplines) the clinic staff always seek consent from the patient before the visitor is invited into their presence to observe a consultation or procedure.

The effect of these mechanisms is to restrict and control access to those who are attending the clinic. Consequently they influenced the decisions made at all stages of the process and determined the approach taken in accessing the study population. As there was no facility for the researcher to directly approach the clinic attenders and invite them to participate, a collaborative approach that involved the clinic staff was developed. These mechanisms were also core considerations in the establishment of consent procedures that neither compromised the ethical requirements of the research nor the confidentiality requirements of the study site. When it became necessary on occasion to alter or modify the approach taken, particularly in relation to recruitment processes, this was done without compromising the established mechanisms. A central consideration in deciding how these changes were to be made was to ensure that the sensitivity of approach was consistent with the sensitivity of the topic.

Three aspects of the research method required specific consideration in relation to confidentiality. These were the requirement to gain written consent, whether participants should be offered involvement in the study subsequent to the interview and the recruitment process itself. The first two required single procedural decisions and therefore presented no specific difficulties when those decisions had been made. As the means of access to the participants, the third was more complex and presented considerably greater challenges.

#### **4.10.4 Consent within a confidential service**

Signed consent forms are required by medical ethics committees as proof of valid and consensual participation. However the production of signed consent forms creates particular problems in relation to attendance at a GUM service as they represent proof of attendance at the clinic. Given that there may be no other written evidence of such an attendance other than the patient records which are stored in the clinic itself, this seemed somewhat problematic. It represented a potential threat to the confidentiality that the clinic structures had been established to maintain. It raised questions as to the purpose of such forms; who may have access to them and under what circumstances? Written consent was obtained for this study in order to satisfy the requirements of an ethics committee, however the forms were stored in the patient records with the

knowledge of the participant to ensure that they did not and were not seen to present a breach of confidentiality. This was explained in the study information sheets and verbally at the time of gaining consent. None of the participants objected to signing the consent form. As this approach worked successfully in the GUM clinic the same approach was adopted in the FP clinic.

#### **4.10.5 Participant feedback**

Participants may be involved in the research process to a greater or lesser extent. Repeat interviews or ongoing contact beyond the interview can be valuable in a number of respects. Returning transcripts to respondents provides opportunity for clarification and modification of the content as well as the means by which to contribute further content. In a more extended relationship it may extend to involvement in the analysis process, either in the production of the analysis or by providing opportunity for feedback on the understanding and the acceptance of the analysis (Bloor, 1997). The attraction of this approach is that involvement beyond the interview can help to redistribute the balance of control within the research process (Oakley, 2000). It is common in feminist research where involvement in all stages of the process may be represented as the ideal (Gregory and McKie, 1996) such that the participants may even be considered as co-researchers (Crotty, 1996). It may also contribute to the validity and credibility of the data and its interpretation if the research participants agree with the interpretation of the data (Bloor, 1997, Gregory and McKie, 1996, Altheide and Johnson, 1998). However opportunities for involvement are variable and influenced by logistical as well as philosophical considerations.

This study was conducted in a sensitive area where the emphasis is upon confidentiality. A decision was taken to simply conduct one-off interviews with no subsequent contact acknowledging the resultant lack of opportunity for clarification and feedback. For participants to have read the transcripts and comment on them would have required development of a system whereby either information was posted to a home address or a follow-up meeting at the GUM clinic was arranged. Neither of these was considered acceptable. The organisational structures of the clinic are designed to enable separation of this aspect of one's life and whilst this may not have been a concern for everyone, it seemed to be important that a study conducted in the clinic mirrored the philosophy of the clinic and was seen to do so.

## **4.11 The recruitment process**

### **4.11.1 Recruitment in the first study site**

Recruitment of participants was by way of a third party. This is an approach that has been used by others researching in this sensitive area (Holgate and Longman, 1998, Duncan et al., 2001, Hammarlund and Nystrom, 2004, Duncan, 1997). Initially involvement in recruitment was limited to the health advisor but in the latter part of the study it was extended to include other members of clinic staff, both nursing and medical. It was not feasible for the researcher to have direct access to potential study recruits. The clinic structures described above precluded such an approach. Patients attend the GUM clinic for a number of different reasons and only one small sub section of the clinic population was eligible to participate in my study. As a visitor to the department I did not have direct access to the patients or to their notes. Therefore I had no way of knowing who would be eligible to participate.

From an ethical perspective it was not appropriate for me to approach patients directly. For me to know who was eligible would have required staff to divulge diagnostic details to me without the knowledge or consent of the individual. It would then have required me to approach that person in a public setting, the waiting area, either discussing the study in a public place or taking that person into a private area in order to do so. This study focussed on those with a specific medical diagnosis. To discuss the study in a public setting would constitute a gross breach of confidentiality as it would necessitate diagnosis specific discussion whilst taking them into a private room specifically for the purpose of recruitment caused me concerns regarding possible coercion. Whilst coercion is an ever present possibility during the recruitment process, I was anxious to minimise its effect as far as possible.

At the beginning of the study, recruitment was via the Health Advisor. The majority of those who are diagnosed with chlamydial infection are interviewed by the Health Advisor in order to discuss aspects of the infection and partner notification. Establishment of a confidential professional relationship is one of the fundamental skills of the Health Advisor whose role is centred round obtaining highly sensitive information related to people's sexual activities. Within this context, an explanation of the study and an invitation to participate sits comfortably and informed consent becomes a reality. For those who agreed to participate, an interview was scheduled to coincide with the routine four week follow up appointment. From an ethical perspective this time lapse also provided opportunity for them to consider their decision.

From a logistical point of view, this was also conceived as a reasonable approach because the attendance of those eligible for recruitment was expected to be sporadic and unpredictable. Appointments are often made without diagnostic details and those with chlamydial infection represent only one small proportion of those attending the clinic at any one time. Consequently the recruitment process was initially designed to reflect these attendance patterns.

#### **4.11.2 Recruitment difficulties**

The recruitment method presented a number of difficulties. Recruitment proved to be extremely slow and problematic. It required frequent rearrangement of interview appointments and in several cases participants failed to attend for interview. Although this may have reflected a decision not to participate in the study, it seems much more likely that the failed interview was the result of a decision not to attend for the follow appointment. The estimated non attendance rate for follow up appointment at this study site was 25% indicating that whilst follow up was important to the majority, a sizeable minority elected not to return. The reasons for this will be multiple and are not a matter of consideration at this point other than in relation to their impact upon a research interview that had been timed to coincide with a clinic appointment.

A further contributory factor was the dependency of the process upon the Health Advisor consultation. Whilst this is part of the management process for those with chlamydial infection, it is itself dependent upon the availability of the Health Advisor. Staffing considerations of sickness and absence as well as workload pressures necessarily impact upon this consultation. During the data collection phase, sickness was a significant issue in the department and its effect on the research was such that a number of potential participants were missed.

#### **4.11.3 Gender profile**

From the outset, this study was designed to explore the perspective of both males and females for reasons that have been previously discussed. However this recruitment method was less well suited to the recruitment of males. In the GUM clinic at the time there were significant differences in the initial clinical management of males and females in relation to chlamydial infection. Those men who attended the clinic with symptoms suggestive of chlamydia were treated presumptively but given a provisional diagnosis of non-specific urethritis (NSU). If the laboratory results indicated chlamydial infection, they were given this diagnosis at their return visit at which point they may have been retested. There were compatibility problems between this clinical approach

and the initial recruitment method that relied upon recruitment at diagnostic visit and interview at follow up visit such that it effectively eliminated most males from recruitment. This was evident in the recruitment pattern where all but one of the first nineteen individuals who were recruited by this method from the GUM clinic were female.

#### **4.11.4 Changes to the recruitment process**

After considerable discussion with the clinic staff and particularly the Health Advisor, the decision was taken to modify the recruitment method. I undertook to spend one day per week in the clinic and potential participants who attended on that day were invited to participate. They were given the option of either being interviewed at that time or at a later time. If they elected for the latter and a return clinic visit was planned, the facility was available to co-ordinate the two.

This method of approach proved to be considerably more successful than the previous approach. It had a significant effect upon the recruitment process and resulted in a considerably faster rate of interviewing. My attendance in the clinic one day per week effectively limited recruitment to 20% of the clinic population. However this was offset by the benefits of being based in the clinic on that day. My physical presence in the department had a number of benefits. Recruitment continued to be through the clinic staff, however my presence had two positive effects. Firstly it raised the profile of the study in the department such that the staff came to view my presence and the conduct of research interviews as part of the clinic routine on that day of the week. This seemed to validate the study for the staff themselves and for their involvement in it in so far as the researcher was physically present in the clinic at the time. They could therefore offer interested patients the opportunity to meet and discuss the study with me in person before deciding whether they wished to be involved. Secondly, linking the recruitment process to a set time rather than a set person also resulted in other staff being involved in the process and consequently it was not dependent upon the Health Advisor being present in the department and operating in her specific role. Subsequent to the changes, most of the active recruitment was managed by the clinic nurses who reviewed the appointment lists for potential recruits and then ensured that either they or a member of medical staff discussed the study with potential recruits.

This change of approach proved to be very effective and also provided some insight into the willingness of patients to be involved in the study. Although statistics were not collected, the majority of potential participants, identified from the list at the beginning

of the session, did agree to participate. This is in contrast to the experience of Duncan (1997) who carried out a study in the GUM clinic and conducted interviews on aspects of sexual health behaviour. She used a similar recruitment process but reported a low recruitment rate of 48%. The high uptake rate in this study may reflect to some extent the relevance of this topic to the individuals concerned.

This approach also largely eliminated the problems experienced in recruiting males to the study as the approach was no longer dependent upon a clinic visit subsequent to recruitment. The effect of this was a more even balance in the recruitment of males and females. Of the twenty five respondents recruited using the second approach, nine were male. In total, ten male and forty females were involved in the study as one male was recruited by the first approach in GUM and no males were recruited from the second study site, the FP clinic. Whilst this is clearly not a balanced gender sample, it is sufficient to refute claims of tokenism by ensuring that the male voice was represented sufficiently to be meaningful. It also highlighted the influence of subtle differences in patient management procedures on recruitment and the importance of understanding the magnitude of their effect in order to safeguard against stereotyped conclusions about men and women's willingness to be interviewed.

The success of the modified approach was gratifying and to some extent challenged my pre-conceptions. I anticipated that many people would be reluctant to participate in a lengthy interview without prior planning and that there would be an overall reluctance to discuss such an intimate and sensitive topic in a research situation. My experience indicates that I was often wrong on both counts. All but one of the participants elected to be interviewed on the spot with only one person electing to postpone it until his return visit. The majority were returning for a follow up appointment subsequent to treatment although in a few cases they were recruited at the treatment visit. Given that clinic visits were often very lengthy and exceeded one hour, the willingness of the respondents to increase their stay even further represented a considerable personal commitment.

#### **4.11.5 The effect of time constraints**

Outside influences including time constraints can never be eliminated from an interview situation. They are a reflection of reality and therefore justify acknowledgment (Reinharz, 1992). Whether they were a greater consideration in the unplanned interviews is a matter of conjecture. Whilst time constraints were something of an issue in a few of those interviews, this was not the majority experience. The length of

the interviews was extremely variable ranging from ten minutes to over one hour. Two people elected to finish the interview prematurely on the basis of outside commitments. In the vast majority of cases however, there was no expressed need to conclude the interview prematurely and I had no sense either verbally or non verbally that the interviewees were attempting to foreshorten the process. On several instances the interviews extended beyond the end of the formal clinic session and in a further two instances the interview restarted spontaneously after it had been formally concluded.

Whilst some researchers have experienced difficulty in recruiting to a qualitative study that explores the sensitive topic of sexual health (Getty and Stern, 1994), others do not report such problems (Scoular et al., 2001, Hammarlund and Nystrom, 2004, Skidmore and Hayter, 2000). My experience suggests that the sensitivity of the topic did not form a significant deterrent to involvement and within the interviews there was little sense that people were unwilling to speak openly about sensitive issues. Many of them revealed detailed intimate information and there was little indication of extreme discomfort in their non verbal communication. A marked exception to this was one male who was clearly very uncomfortable in the interview and brought it to an abrupt conclusion by jumping up and absenting himself. These responses to time constraints and discomfort are in themselves encouraging, as they are indicative of a willingness and ability of the interviewees to exercise overt control over the interview and the power balance operating within that situation.

#### **4.11.6 Recruitment in the second study site**

The recruitment process in the FP clinic was designed to mirror that in the GUM clinic. As a service which is run almost exclusively by sessional staff, recruitment in FP produced its own problems of recruitment despite the fact that this part of the study had been confined to the main FP clinic as a means by which to minimise anticipated recruitment difficulties as described previously. Potential recruits were identified either opportunistically or on receipt of positive laboratory results at which point an information sheet and consent form were placed in the notes of potential recruits by the nurse responsible for processing laboratory results. The purpose of this was to trigger recruitment by staff at the patient's next visit to the clinic. This method whereby only one person was involved in identifying potential recruits appeared to be less cumbersome than other approaches. However, although a considerable amount of time and effort was invested in communicating and working with the clinic staff, and particularly with the nurse who agreed to flag up potential recruits as described, recruitment through the FPC was problematic. The inclusion of study sheets into

eligible sets of notes was sporadic and even when they were included, a recruitment discussion appeared to rarely take place when the patient attended the clinic. Notwithstanding this, six women were recruited through these means by a small number of enthusiastic nursing and medical staff including the researcher in the course of her clinical work. It is not possible to comment overall on the extent to which participants declined to be interviewed. My personal experience suggests that the rate was low as no-one who I invited to be interviewed declined although I acknowledge the possible influence of my personal involvement at this stage of the process.

#### **4.12 The gatekeepers**

A key consideration in this study was the role of gatekeepers, particularly in terms of their effect on recruitment. Gatekeepers are those in authority who have the ability to grant or withhold permission to conduct research and have some control over the conduct of a study (Neumann, 2000, Sapsford and Jupp, 1996). Gatekeepers function as guardians of the potential study population. As such they have the power to both restrict and facilitate the researcher's access to that population. Their role and significance is variable depending upon the type of study and may be more or less formalised. When a population is potentially vulnerable or requires particular protection the role of the gatekeeper becomes especially important. In the GUM clinic, their involvement ensured that the study did not compromise the standard of confidentiality or the patient's perception of that standard.

Gatekeepers have the potential to exercise considerable influence upon the research process, particularly if they are the means by which the researcher has access to the recruits. Even though inclusion and exclusion criteria provide a framework that determines who can participate, the decision to invite them to do so lies with the gatekeeper and will be influenced by a number of factors. Their motivation and overall commitment to the study as well as the immediate impact of outside influences such as time constraints and conflicting priorities all have an effect. Their influence however extends beyond simply determining who may and who may not participate. The way in which they present the study will influence the way in which it is perceived and therefore influence recruitment.

Their involvement in the process from the outset was therefore essential. I was a visitor to their clinic who was reliant upon the goodwill and co-operation of the staff for recruitment of participants. It was essential that they considered the study to be worthwhile, but equally, in an area where confidentiality is such a cornerstone of the

work, that they considered me to be both credible and trustworthy. Although I used the same approach in both sites, the overall attitude of staff to the study and their ongoing commitment to it was markedly different between the two sites. There was much more commitment in the GUM clinic than the FP clinic, in all probability as a result of a number of reasons. The GUM clinic is a more stable clinic environment operating on a daily basis in a single site with a stable workforce. By contrast the FP clinic, although a single site, has different staff running the clinics that operate during each week and most members of staff who work in the clinic do so on a weekly rather than a daily basis. There is therefore a larger total number of staff involved in the FP service and less day to day continuity in staffing. Although the recruitment strategy was designed to operate through one of the substantive staff members, she was inconsistent in her identification and flagging of potential recruits. This factor together with the staffing patterns meant that recruitment in the FP clinic was slow and problematic. Arguably however the greatest contributory effect was the regular physical presence of the researcher in the clinic which was logistically achievable in the GUM clinic but not to the same extent in the FP clinic.

Over and above these organisational and cultural factors that influence recruitment, the personal interests of the gatekeepers may result in some people being invited to participate whilst others are not and thereby remain invisible to the process. In a social setting concerns about what is said, and how well it reflects upon oneself and the group or community that is the focus of study, may have considerable impact upon the amount of control exercised by the gatekeepers (Song, 1998, Miller, 1998, Reynolds, 2002). As such they will exercise considerable influence over the data collected although their expectation of what another person may contribute to the data is at best supposition. This may also operate within the more structured approach of recruitment within the clinic setting.

Although I had no sense of this occurring in my study, staff may conceivably exclude those patients who they feel will not present a 'good account' of the clinic or select those who they feel will do so. A more common experience for me was the identification and more purposeful selection of those clients who were atypical, who would present a 'more interesting' account either because of some aspect of their clinical condition or clinic attendance pattern, or because the opportunity to partake in a detailed one to one interview was considered beneficial for a patient struggling to come to terms with her diagnosis. As one element of the overall approach to interviewing, this was helpful. It contributed to the diversity of the study population and therefore to

the exploration of the dimensions of the emerging categories. In effect it represented a form of theoretical sampling conducted by proxy.

#### **4.13 Data collection**

All interviews were conducted within a private room in the clinic and fully recorded. None of the respondents expressed reservations about the recording process having been assured that their voices would disappear in the process of transcribing and that names would be substituted with pseudonyms. The positioning of the tape recorder on the table between us served as a visual reminder of its presence, however it was quickly disregarded and appeared to have little effect upon what was said.

I undertook all transcribing myself and transcribed all the interviews in their entirety. Although time consuming and limited by my novice transcribing skills, I consider the effort worthwhile for ethical and methodological reasons. It enabled me to give and honour a promise to the respondents that the tapes would only be heard by myself, thereby reinforcing the sense of confidentiality. Interviewing and transcribing were conducted concurrently with the data that emerged from the earlier interviews. This informed the content of the later interviews in so far as it gave me the opportunity to explore issues that emerged as significant in those earlier interviews. For example, the symbolic significance of retesting after treatment which became apparent in the earlier interviews prompted me to specifically explore this issue in later interviews and led to a consideration of what happened when treatment occurred in a setting that did not routinely offer test of cure. This in turn contributed to the decision to try and access those who had bypassed the GUM facility and the subsequent inclusion of the second study site.

In terms of data analysis the increased theoretical sensitivity that came from listening again to the words and translating them into written text was considerable. It enabled me to mentally revisit the interview and supplement the impression notes that I had recorded immediately after the interview. It highlighted those aspects that reappeared as concerns from one interview to another, the dominant and forceful voices of concern that were recognisable from the outset. This enabled me to recognise and explore these concepts when they arose in subsequent interviews. However it also sensitised me to those elements that had previously gone unnoticed, the apparently smaller and less powerfully articulated elements that had been swamped in first impressions. In accordance with the view of Strauss & Corbin (1990), the intimate interaction with the

data that transcribing produced provided insight and understanding about the phenomena contained within it.

#### **4.14 Data analysis**

A key feature of grounded theory is the way in which the stages of the process are not temporally delineated. Rather than undertaking and completing one stage prior to commencement of the next, in grounded theory literature searching, data collection and data analysis occur concurrently. Parallel activity in the different processes enables interconnectedness such that each is informed by and developed in response to one another. Data analysis commences from the outset by the process of constant comparisons in order to confront the similarities, differences and degrees of consistency of meaning within the emergent categories (Strauss, 1987). This produces an initial coding that reflects what is said or what is going on and leads to comparison and clustering of codes such as to produce a category (Chenitz and Swanson, 1986). The purpose of comparative analysis is multiple. It enables the accuracy of concepts to be verified by comparison between groups and the testing of empirical generalisations as well as the means by which to verify and generate theory (Glaser and Strauss, 1967). The result is an approach that is both open minded and responsive, which requires the researcher to respond to what is emerging in the data and to ground the analysis in the data rather than trying to make it fit into an a priori framework (Parr, 1998). A consequence of this approach is that it is somewhat difficult to formalise the analytic processes and tease them out sufficiently to coherently articulate the stages of the analytic process. However, validity depends upon transparency of the decision making trail in all stages of the process including the coding and categorisation process.

The slow recruitment rate meant inevitably that data collection was initially very slow and sporadic. Although frustrating, this did provide some advantage in so far as it enabled me to keep pace with the transcribing and to begin the analysis such that one interview could inform the subsequent ones in identifying areas that appeared to merit further exploration. It also meant that there was sufficient time to conduct a detailed open coding, examining the text line by line and allocating labels that described what appeared to be going on although it did result in the creation of numerous labels, a process identified as a common problem in the early stages of a project (Strauss and Corbin, 1990). Although this was problematic in so far as there were too many to manage, this depth of labelling ensured that I examined the transcripts in detail rather than simply categorising the most dominant themes.

A preliminary analysis of the first few interviews concentrated on the dominant aspects that were recurring through the interviews. It is inevitable that we see the data through a set of lenses that comprise our own assumptions, experience and immersion in the literature. It is this that colours our interpretation of events, what we choose to label and how we choose to label it (Strauss and Corbin, 1990). On reflection, my personal clinical and educational background that has been predominantly biomedical, positivist and reductionist heavily influenced my initial coding systems. Two broad categories emerged at this stage. The first was the interpretive aspects of the accounts, of symptoms, procedures, tests, information and advice and in particular the decision making processes around condom usage. The second category concerned responses to the presence of the infection, in particular the emotional responses and the sense of bodily pollution and the effect of these upon behaviours.

My early interpretation of the data and particularly the meaning that I constructed around the first category was largely a product of my clinical background that embraced the dominant health promotional discourses around condom use. My instinct in the early stages was to adopt a rationalistic perspective, however this proved highly problematic in the interpretation of accounts where explanations of behaviours and decision making were characterised by contradictions and anomalies, where the rationalistic behaviour patterns promoted through the dominant health discourse appeared to have little significance in the out workings of people's lives. Whilst these early themes do on reflection seem overly simplistic, lacking in depth and dimension, they were valuable in identifying the initial theoretical paths to follow. Initially these led to sociological explorations of aspects of health behaviours such as condom usage but moved increasingly to embrace literature that explored the wider sociological perspectives.

My gradual immersion in a wide range of sociological literature increased my theoretical sensitivity to the social and cultural processes that were dominant influences. The repeated reference to dirt terms had identified this as a highly relevant concept from the outset and it had emerged as one of the first two categories, however I initially understood this as an adjunct to the central issue of stigma, as a label that is routinely applied to STI's and a term that commonly appeared in the transcripts. This directed my reading initially into Goffman's seminal text on this topic and subsequently to literature that further explored this concept in health specific contexts. Whilst this was valuable it became apparent that the central concept was not of stigma but of dirt

and bodily pollution and its spoiling effect upon identity. Appreciating the centrality of this concept led me into an exploration of the dirt literature, in particular that of Mary Douglas. This together with the historical literature pertaining to STI's, and in particular that of Spongberg, provided insights into the social symbolism of the body and led me gradually into the body literature, initially that of Turner and Frank and more latterly the feminist literature, in particular Grosz and Shildrik.

The civilising process that has created a social imperative for a body that is both contained and controllable became apparent in the light of the tensions that exist around the contaminating nature of body products, and the threats and dangers inherent in body margins and leaky boundaries. This shift of perspective from the processual and procedural aspects of the infection to the embodied experience and its out workings in an interpretative and interactional sense proved to be crucial in the analytic process. The vulnerable and precarious body moved centre stage and I moved from an analysis that was largely descriptive and thematically based to a greater degree of conceptualisation that explored the sociological tensions and constructions acting upon and enacted through the individual body.

Although data analysis had been ongoing throughout the process, the theoretical sensitisation that occurred at this stage created an alternative set of lenses through which to view the data. Consequently much of it was reanalysed and recoded. Many of the earlier descriptive labels were replaced by conceptual labels. This led to a spontaneous decrease in the number of codes and a regrouping of the codes under several headings that became the core categories. Under these headings the alignment of codes provided substance for the categories, creating their properties and dimensional range. It is these categories that have formed the chapter headings of the findings section.

## **Chapter 5 – Theoretical considerations part one**

### **Section one: The problem of the body**

#### **5.1 Introduction**

The body, previously largely absent or marginalised in sociological theory, has in recent times moved centre stage. The plurality of theories that have collectively contributed to this current position bear witness simultaneously to the centrality of the concept of the body in 21<sup>st</sup> century social science and the degree of contestation about its meaning and representation. In an empirical sense the body is an entity. It has a physical presence and a corporeal reality and can be considered the 'rock bottom unit of social explanation' (Frank, 1991 p. 36). However it is much more than this. It is the self by which we present ourselves to the world and through which our self is interpreted by the world. It is therefore a medium through which we interact with others, an interpersonal means of communication as the carrier of identity. Identity is not individualistic but rests on social recognition, on the collectively shared memories of individuals and the body in this respect is also a social phenomenon (Turner, 1992). It is also a discursive construction, the product of sociological and biomedical constructions, whose form and feeling are rhetorical features shaped in the telling (Radley, 1997), marked by environmental process and power (Shildrik, 1997).

#### **5.2 The constructed body**

The way that we see the body is a construction of the times within which we live, a product of the knowledge that shapes our understanding of it, our attitude to it and our inter-relationship with it. Social management of the body is an outworking of the theories of the times. These provide the means by which the body and its boundaries are defined, and the basis upon which body management and control is founded. As a product of social processes, the body itself and its interrelationship with other bodies has been constructed and re-constructed over the course of time. Historical representations of the body from the 16<sup>th</sup> century reveal the changing concepts of a clean body (Vigarello, 1985) and the production of civilised bodies, individualised, separate, controlled, and restrained (Elias, 1994). The social management of the body throughout the 18<sup>th</sup> and 19<sup>th</sup> century was exemplified by the tangled and complex relationship between the body as a producer of smells and a surface upon which to imprint smells, in the olfactory interface between a body and its environment (Corbin, 1986). Similarly, the development of medical knowledge wrote and rewrote the way in which the sick and diseased body was conceptualised and its consequent management. This was evident in the move from bedside medicine to hospitalisation of

those who were sick which intensified medical scrutiny of the individual body (Foucault, 1973). Latterly it was identifiable in the extension of the surveillance of populations of bodies in the community, and in the development of processes and techniques which probed and searched for disease in those in whom it was not immediately apparent (Armstrong, 1983).

### **5.3 The embodied self**

From a phenomenological perspective the central concept of the body is as a 'lived body' and it is the embodiment, the lived experience, that is the focus of investigation, presenting an individualistic account from the perspective of the subject (Turner, 1996). Merleau-Ponty proposed that the concept of the body is central to our mode of being. He argued for the need to replace accounts of consciousness and the body with an account of embodied human being in the world on the basis that our understanding of the world is grounded in our corporeality (Moran, 2000). In this respect he provided a direct challenge to mind/body dualism through the focal point of his philosophical reflection, the concept of the body-subject (Kwant, 1963, Williams and Bendelow, 1998).

The body is not in space, rather it inhabits space. It locates us in external space and it is our bodily situation, our 'corporeal schema' that provides us with a practical and implicit notion of the relation between our bodies and other things. We do not experience our body as an object among other things in space. If we move our body we do not do it as we move other objects, we move our body because we have direct access to it. The body is more than an object or a means, it is our expression in the world (Merleau-Ponty, 2002). Merleau-Ponty's analysis of actions is not limited to the undertaking of physical tasks, but is intended to reflect the body as encompassing a far wider remit and a considerably more fundamental role. In this sense the body is both a sensory and expressive medium which recaptures the operation of the mind and symbolises corporeal existence (Merleau-Ponty, 2002). In its actions it reflects the natural aspects of the world which it inhabits. Simultaneously however as an active body, the movements, gestures and language produced by the body are projected onto that world.

### **5.4 Attitudes to the body**

To consider the body purely as a construction of discourse is to deny the experience of having a body, of being a body and the way that embodiment defines the experience and perception of being human. Bodies cannot be simply understood as objects of

social process, of disciplinary forces; they are part of and participate in that social process. Although they are addressed by social process, they do not lose their materiality (Connell, 2002) and social process is realised in so far as it produces effects upon components or functions of that material body. Bodies emerge from bodies, not from discourses and their corporeality is a dimension of their constitution (Frank, 1991). As agents of social practice, bodies are themselves involved in the construction of that world (Connell, 2002). An understanding of the relationship between one's self and one's body arises from systems of belief that shape personal attitudes to the body, body behaviours and the processes of self management. As a means by which to consider the world as constructed and experienced by humans, Jenkins proposes three distinct orders; the individual order, the interaction order and the institutional order. Whilst all three occur simultaneously and occupy the same space both intersubjectively and physically, such a structuring enables one to consider separately and collectively the phenomena that occur as individual experiences, as interactions between people and as organisational ways of doing things (Jenkins, 2004).

A body may be regarded as simultaneously discursive and animated, both socially constructed and objective (Turner, 1992). A dialectical approach to the body, that simultaneously recognises the location of bodies in nature and the effect of social discourse that acts upon the body, operates at the point of interface between the phenomenological and the constructed body. Such a position enables one to consider the body as a corporeal entity capable of individual actions and experiences whilst acknowledging that those actions, experiences, and opportunities are both influenced and limited by the social discourses which effectively restrict the amount of control that any individual has over their actions (Lupton, 1995).

### **5.5 Control of the body**

Over the course of time, attitudes towards the body, its management, and its presentation to the world have been shaped by social changes and scientific theories. In tracing the embodiment of social process, Elias (1994) demonstrated the way in which society became increasingly concerned with the determination and management of outward bodily propriety. The publication of treatises from the mid 16<sup>th</sup> century onwards which included Erasmus' text 'De civilitate morum puerilium' provided detailed instructions on social conduct. These covered all aspects of social life, including eating, drinking, sleeping, deportment and bodily apparel. Their detailing of what constituted good and bad manners included instructions that advised one not to gnaw a bone and then return it to the communal eating dish, not to blow one's nose on the

tablecloth and not to pick one's nose whilst eating. These reflected social reality at that time, when the communality of living meant that people lived in a different relationship with one another than we do now, when affects were conditioned to forms of conduct which by today's standards are embarrassing (Elias, 1994). Over time, changes in social structure produced an increasingly strict code of conduct which required a greater degree of consideration for others, an increasing social imperative not to offend. As a result of this, bodies became more controlled and managed and bodily functions became more private disappearing both from sight and from speech. As potential sources of offence to others and embarrassment to self (Elias, 1994) their polite management was fundamental to the civilising process (Turner, 2003). The effect of this was a progressive socialisation, rationalisation and individualisation of the body. Socialisation transformed the body into a location for codes of behaviour, whilst rationalisation enhanced the desirability of body control and diminished the acceptability of emotional impulses. As a result the body came progressively to be considered in a differentiated way rather than as a whole and its parts came to be considered amenable to control. Individualisation occurred as bodies became more aware of self and others, with the result that the flesh of humans became a matter of increasing concern, a source of embarrassment which required to be managed within the social norms of behaviour (Shilling, 1993).

### **5.5.1 Body control**

"In terms of modernist ontology, epistemology and ethics, the ideal parameters of thought and action in the social world point to an inviolable self/body that is secure, distinct, closed and autonomous. In setting up a model of such invulnerability it is inevitable that for all of us there is a struggle to maintain the necessary boundaries" (Shildrik, 2002 p. 51).

Frank (1991) positions control and predictability as the normal state of the body in everyday life that we tend to take for granted, an inherent body property. In doing so he identifies control as the first of his four problems of embodiment that are located at the point of intersection of institution, discourse and corporeality. He proposes that a state of health is associated with a high degree of bodily control and predictability of function. As a product of societal expectations and values, high levels of contingency that may be acceptable at some times of life, for example in infancy, are not socially acceptable at other times and therefore necessitate body action. Self conscious monitoring techniques and close attention to the management of body functions are required in order to either regain control or conceal the loss of control, a requirement

that is fundamental to a sense of identity and social status (Lawton, 1998, Chapple and Ziebland, 2002).

As a body problem, the concept of control applies to a wide range of bodily states. Body actions, intentional and unintentional, pre-meditated and spontaneous, emotional and physical, are all susceptible to predictability or contingency. Arising from corporeality, controllability is a feature of embodiment. Control in these terms requires the vigilant supervision and protection of body boundaries. It requires the maintenance of a clear distinction between insider and outside and careful control of the passage between the two. Contingency indicates leaky boundaries with consequent facility for uncontrolled movement either in or out and thereby carries connotations of danger.

The dominant discourses dictate certain conceptions of the body (Shildrik, 1995) and privilege certain bodily positions. Body control presents a rigid and delimited perspective of the body, where movement and flow occur as a controlled, predictable and managed process and the body is contained and confined within tight and rigid boundaries. However, male and female representations of the body in health and disease suggest that control is a particularly male construction. As such it both privileges the male position whilst denying that of the woman, whose corporeality has been inscribed as a mode of seepage, leaking and uncontrollable, threatening to overflow boundaries and lacking in self-containment (Grosz, 1994, Shildrik, 2002). This representation is clearly derived from the reproductive capabilities of the female body and gives rise to what Grosz (1994) describes as

“a broadly based coding of the female body as a body which leaks, which bleeds, which is at the mercy of hormonal and reproductive functions” (p.204).

However it extends far beyond this to encompass wider conceptions of health. Male accounts of healthiness reflect a sense of body ownership and control with a tendency to concentrate on function, capacity and bodily mechanics (Cameron and Bernandes, 1998, Saltonstall, 1993, Watson, 2000). Female accounts by contrast are more likely to incorporate emotions and feelings, ideas of energy, vitality, coping ability and to describe the body as having a momentum of its own, reflecting body subjectivity rather than control (Saltonstall, 1993, Cameron and Bernandes, 1998, Blaxter, 2001). In relation to emotions, control is problematic because they seep and flow, they overspill boundaries and they are resistant to control. As such they represent danger and are conceptualised as polluting in their challenging of body boundaries, inspiring fear and discomfort. Women are linked with uncontrollable embodiment, with softness and

fluidity of emotion, whilst the control of emotions, portrayed as rational and associated with dryness and hardness, is clearly equated with maleness (Lupton, 1998).

### **5.5.2 Constructing a clean body**

Whilst the social desirability of a clean body has remained a feature of social decorum over past centuries, it is evident from the historical accounts of what was required to achieve such a state that the concept of cleanliness has changed over time. In the 16th century cleanliness was associated with decorum but was not associated with water and washing. Rather the reverse, within a construction that considered the body porous and vulnerable to infiltration, water and particularly bathing was considered extremely dangerous. Cleanliness was achieved by dry rubbing and the role of water was confined to removing dirt from the visible areas, the hands and face. To be clean in this sense meant attending to that limited part of the body that was visible to others. It was largely portrayed through the whiteness of the linen that adorned the body rather than through the body itself and therefore had little to do with anything other than social appearance (Vigarello, 1985).

### **5.5.3 Miasma and hygiene**

The 18<sup>th</sup> century was marked by conditions of urbanisation. This resulted in health problems associated with urban living such as water supplies and sewage disposal together with the epidemics of contagious diseases such as cholera. The sanitary reforms that emerged as a response to these problems drew on miasmatic theories of disease causation. Miasma from the Greek 'to pollute' derived from theories that primarily located danger in the smells that permeated the environment. The earth was considered as a source and repository of the products of fermentation and putrefactions. The noxious vapours that were given off from such processes produced foul air which represented a threat to health and well being. Vapours were considered the primary cause of disease, to the extent that Edwin Chadwick stated that 'all smell is disease,' and they thereby became the focus of anxiety-laden discourse (Corbin, 1986). Within this discourse ventilation and circulation of air became increasingly significant and dirt as a source of contamination acquired a status that it had previously not been afforded (Bashford, 1998). As a direct response to this, dirtiness which had not been listed as a cause of disease by commentators in the 18<sup>th</sup> century (Vigarello, 1985), became essentially synonymous with disease in the 19<sup>th</sup> century (Bashford, 1998).

The sanitarian discourse increasingly conceptualised the body as a domestic space and applied the same principles of order, cleanliness and hygiene to the body as it did to the home. Similarly, efforts to maintain a clean body were not limited to its physical state, but incorporated moral welfare as cleanliness and dirtiness encompassed both physical and moral well being within the interconnected activities of sanitary and moral reform. The lack of distinction between them meant that the dirtiness of either could influence the other and the maintenance of health required a constant struggle against impurities that had a tendency to defile in a moral or physical sense (Bashford, 1998).

The concept of dirt encompasses and has become intertwined with ideas of hygiene due in part to its oppositional relationship to cleanliness. The determination of the microbe as the cause of disease facilitated the transference of those hygienic principles that had previously arisen whilst providing a scientific focus for them. This has resulted in a situation where current ideas of dirt are dominated by the concept of pathogenicity such that it is difficult to consider it in other terms. However dirt is a much broader concept and is the product of loss of identity, system and order. The concept of dirt is grounded in social and cultural values that incorporates but extends far beyond considerations of germs and hygiene. At a most fundamental level it is simply 'matter out of place' (Douglas, 1966).

### **5.6 The concept of dirt**

As Douglas pointed out in her book 'Purity and Danger',

"Dirt is essentially disorder. There is no such thing as absolute dirt: it exists in the eye of the beholder. If we shun dirt it is not because of craven fear, still less dread of holy terror. Nor do our ideas about disease account for the range of our behaviour in cleaning or avoiding dirt. Dirt offends against order. Eliminating it is not a negative movement, but a positive effort to organise the environment." (Douglas, 1966 p. 2)

Dirt exists as a result of the process of systematic ordering and classification through which we make sense of the world. It is this process which creates the structure and order that informs individualised behaviour, our relationships with one another and thereby forms the basis of social stability. Any system of categorisation produces anomalies, those that do not fit and which therefore require to be dealt with. Dirt serves as a compendium category for those events that blur, contradict or otherwise confuse the accepted categorisations. However dirt is a source of danger to the system because it has the means to defile. As disorder it represents a continual threat to the establishment. The response to this, the means by which order and stability is maintained, is through the imposition and application of pollution rules.

The body serves as a symbol of society, and the powers and dangers that reflect social structures are reproduced upon and within the human body (Douglas, 1966). The effect of the dirt category and the imposition of pollution rules operate directly upon the body itself at an individualistic level, governing and determining attitudes towards it in terms of its presentation and management. It is an abject category. Its existence is testament to the continual threat of loss of order, and its effect is deep and profound, producing emotions of revulsion and recoiling, those 'twisted braids of affects and thoughts' (Kristeva, 1982 p. 1). It also has wide ranging effects at a societal level, with the categorisation of some social behaviours and activities and specific groups of people as being dirty and polluted. These two inevitably overlap. The impact or even the threat of being classified either by self or others as being 'dirty' produces effects at an individual level invoking feelings of contamination, whilst the social impact upon those who are assigned to such categories will be realised primarily at an interactional level where the result represents a direct challenge to the sense of self.

### **5.6.1 The dirty body**

In any bounded system, the margins and boundaries are inherently precarious and therefore represent areas of danger (Douglas, 1966). The thresholds, the points of exit and entry, carry particular symbolic significance which is related to their liminality. As places of transition between separation and reintegration, they are neither inside nor outside and are therefore inherently dangerous (van Gennep, 1960). Body margins and orifices, the points of entry and exit are areas of particular vulnerability of the body, both as potential entry points, the routes through which the body can become defiled, but also as sites from which dirt is produced. Efforts must be directed towards not only ensuring that orifices are guarded, but also in directing and controlling that which flows from the body. Uncontrollable and unpredictable flow is therefore intrinsically problematic and abject. Its fluidity presents a challenge to stability by tending to dissolve the boundaries between inside and outside, creating a state of liminality and horror and fear, necessitating continued vigilance (Lupton, 1998).

The effect of this is the conceptualisation of a clean and proper body as one that is secure, distinct, closed and autonomous. In his anatomy of dirt, Enzensburger (1972) drew on multiple theoretical perspectives to explore the associations of the body and self with the concept of dirt. In doing so, he identified the separateness of the body as being the central concern in the avoidance of dirt. Isolation of the body is jealously guarded and much effort is directed towards maintaining its separation. Anything that

approaches the body or is allowed to escape from it therefore represents a threat to that cleanness (Enzensberger, 1972). The construction of such a body is not only of material practice but also of psychic unity. However that security is constantly unsettled by the abject, those elements which do not respect boundaries and rules and which cause feelings of vulnerability, disgust and discomfort. Maintenance of security is therefore contingent upon the struggles that ensue in the maintenance of body boundaries (Shildrik, 2002).

The concepts of body and dirt are closely interconnected and inseparable, but in many ways appear paradoxical and full of contradictions. Dirt derives from the body and the pollution rules that are invoked to uphold cleanness are exercised upon the body. Purity is a bodily state (Khare, 1977), however the body might be considered a primary producer of dirt. Indeed, Kubie (1937) describes the body as a dirt factory. Bodily products are closely associated with dirt, however they only come to be considered as such when they have been excreted from the body. It is their contact with the surface of the body that then renders the body itself dirty. Most pollution rules apply to the products or functions of the bodily processes in effect prohibiting physical contact with them (Douglas, 1975).

The effect of dirt produces feelings of discomfort, an emotional and physical response which may be described in physical terms, but reflects an integrated mind and body response (Freund, 1990). The scale of the response is influenced by a number of factors. In the first instance, dirt is a matter of degree where the smallest stain or blemish is commonly most offensive to our sensibilities, whether it is on a garment or a reputation (Enzensberger, 1972). The diminutive nature of such a blemish produces a level of discomfort that is of a disproportionate magnitude. The smaller it is, the more marginal the violation of order, the more emphatically it emphasises the precarious nature of cleanness, as something that can be spoiled so readily and by such a small and seemingly trivial event or object.

### **5.6.2 The hierarchy of dirt**

Whilst all body products might be expected to be dirty in so far as they represent seepage and flow from the body and therefore signify uncontainability, some are very much dirtier than others. In her original classification, Douglas exempted tears from the dirt category on two counts. Firstly their symbolic significance as cleansing and purifying agents, clear and fast flowing, and secondly their lack of association with the functions of digestion and procreation which limits their scope for symbolising social

relations and social processes (Douglas, 1966). Kubie (1937) appeared to challenge this position in describing all body products as dirt, but went on to propose that there was a difference in the extent to which different body products evoke responses of discomfort. Adopting a psychoanalytic approach, he drew primarily on clinical studies to identify what he called a universal set of assumptions associated with dirt. Thus he equated dirtiness with softness, sliminess, wetness and hairiness in comparison with hardness, dryness and the absence of hair, with old age rather than youth, with pigmentation, and with holes and cavities as opposed to prominent or out jutting parts of the body. On this basis he proposed a tacit hierarchy of dirt and a gendered differential of dirtiness. For Kubie the degree of dirtiness of bodies, bodily parts and bodily products could be predicted in relation to the intensity of response that they elicited, and parts of the body could be classified as more or less dirty as a result of their proximity to body apertures. Thus the genital area was constructed as dirty because of the orifices located there and the female as dirtier than the male because 'she has one dirty aperture too many' (Kubie, 1937 p. 398).

Experimental testing of his hypothesis which used a variety of approaches and subject groupings identified discrepancies between the individual findings, but overall claimed support for Kubie's hypothesis. Whilst all body products produced negative responses, the extent of that negativity was variable with products such as tears considered less dirty than other products such as menstrual blood and faeces (Ross et al., 1986, Hirt et al., 1969, Lawler, 1991, Kurtz et al., 1968). A more comprehensive exploration of this concept was undertaken by Clark and Davis (1989) which measured the scale of reaction elicited in response to hypothetical situations involving identified body products of others. They too found differential responses, with vomit and faeces in particular producing severely negative responses. In explaining this they drew on anthropological rather than psychoanalytic explanations to propose that it is the imminent decompositional state of bodily emissions associated with excretory or sexual functions that determines their degree of dirtiness rather than their character and form (Clark and Davis, 1989).

### **5.6.3 The relative dirtiness of males and females**

The statement of Kubie that woman is dirtier than man, presented as a matter of fact and requiring no justification other than a reference to a quantitative assessment of orifices, reflects widespread cultural representations of a gendered differential in considerations of pollution and contamination. This appears to derive from a stance that positions women's bodies as intrinsically dirtier than those of men. It also

suggests that women's bodies are more problematic as producers of dirt. This is a twofold movement in which women's bodies are marked as inferior in comparison to those of men and in which their biological functions are conflated with social characteristics. This creates the edifice upon which gender inequality is founded (McNay, 1992). Over the course of history, women have been constructed as internally polluted through the discursive and non-conscious strategies of power of a patriarchal society. These constructions derived from and served to reinforce ideas that women were socially, morally and intellectually inferior to men (Shildrik, 1997). In the 17<sup>th</sup> century when the term 'clean' was extended to incorporate attitudes and behaviours, it was the cleanliness of women as a distinguishing feature, a measure of seemliness and moral character that became a matter of judgement and comment (Vigarello, 1985). Equally it was women who for centuries were considered immanent and permanent carriers of gonorrhoea and thereby the means by which men became infected (Brandt, 1987). In the late 18<sup>th</sup> and the 19<sup>th</sup> century, binary constructions of women were dominant in which they were portrayed as either morally and physically impure prostitutes (Bashford, 1998) considered in the same way as cesspools and sewers (Spongberg, 1997), or as morally and physically pure domestic women (Bashford, 1998). The purity of such women was however always fragile and precarious, with the capacity to 'fall' a function of the quantity and to a lesser degree the quality of the men with whom she was associated (Grosz, 1994). Chaste female bodies were the site on which sanitary codes of order, purity and cleanliness were written, but there was a sense in which this purity was always under threat, both from the outside in the form of filth and also from the inside through impure thought (Douglas, 1966).

As producers of dirt, women's bodies have been constructed as more problematic than those of men. This appears to be the basis on which Kristeva (1982) excludes seminal fluid from her category of abjection. This assertion of seminal fluid as non polluting is much contested by Grosz who proposes that it simply arises from the lack of any mainstream phenomenological accounts of men's body fluids (Grosz, 1994). This observation is supported by the experimental findings of Clark & Davis (1989) who demonstrated in their data that semen was considered a highly polluting fluid, evoking a more negative response than either saliva or blood. In this respect this work provides a direct challenge to Kristeva's assumption which appears unfounded and sexist.

The root of much of the assumption about the dirtiness of women's bodies is located in menstruation and menstrual flow. This is consistently reported by ethnographers as

viewed dangerous and/or polluting among a wide range of different populations. In symbolic terms menstrual flow epitomises 'matter out of place' qualifying as such because it is not only a bodily discharge, but because it is blood that does not conform to the 'normal' blood loss patterns of random and accidental discharge (Buckley and Gottlieb, 1988). The portrayal of menstruation within biomedical science grounds it firmly within the context of pathological processes, where terms such as degeneration, sloughing and deterioration punctuate scientific descriptions of this process. In these terms, metaphors which draw on images of productivity and loss of control portray menstruation as the visible and uncontrollable evidence of production gone awry. It serves as a visible demonstration of the failure to conceive, of uterine products that were created for a purpose but have been discarded and therefore represent waste (Martin, 1987).

The contaminating nature of menstruation remains a dominant social concept. The terminology of menstruation that continues to describe sanitary management and sanitary protection perpetuates an association with disease and hygiene (Bashford, 1998), whilst euphemistic visual and verbal references that characterise the advertising of such products with blue ink and references to freedom and carefree existences bear witness to a continuance of the surrounding anxieties (Lupton, 2003).

These representations, which are so well accepted that they are taken as truisms, are overly simplistic. As Buckley and Gottlieb identify

"It is men who have by and large defined menstruation as polluting, and the typical ethnography rarely tells us what the women of the culture think of their menstrual periods and those of other women."  
(Buckley and Gottlieb, 1988 p. 31).

When women are listened to, the plurality of menstrual views become evident within which the concept of dirt is very much less significant. Whilst Martin found that the failed reproductive model was common among middle class women in North America who had embraced the biomedical discourse, she discovered that this viewpoint was totally absent from the accounts of working class women (Martin, 1987). Among women in a South Wales mining village, Skultans (1988) identified two distinct attitudes towards menstruation; those who wished to avoid menstrual loss, seeing it an unwanted occurrence and a deterrent to well being, and conversely those who viewed it as beneficial and rejuvenating, a vital contribution to their physical and emotional well-being (Skultans, 1988). The personal context within which it occurs will also determine the way that menstruation is viewed; its appearance carrying very different

significance for someone who is trying to conceive as compared to someone who is not (Martin, 1987).

#### **5.6.4 The dirtiness of talking about dirt**

There is a singular absence of the subjective perspective in explanations that have attempted to explain the concept of dirt and the relative dirtiness of different substances. These accounts do not attempt to examine why individuals feel and respond as they do. This is due in part to the fundamental problem of dirtiness which is the difficulty that people have in talking about it. As language is the medium through which we classify, and the prime administrator of order, to speak of dirt is itself dirty. As the management of bodily functions moved them increasingly from sight, to speak of them became a source of embarrassment, a product of the civilising process (Elias, 1994). The language of dirt has itself become a source of embarrassment and has therefore become replete with indirect speech, euphemisms and allusions (Enzensberger, 1972). This effect creates fundamental difficulties in understanding personalised responses to dirt, a problem that Clark & Davis encountered. They used a self completion questionnaire in their study after they discovered it was unfeasible to collect data through interview because of the difficulty that people had in talking of dirt. Their experience of conducting such work was illuminating in this respect. Their description of purification rites carried out by some of the respondents who wrote biblical texts over offending phrases in the research tool, or symbolically wiped their hands after completion of the questionnaire, demonstrates how the process of contemplating dirt could constitute a defiling experience (Clark and Davis, 1989).

One might consider that those who deal with dirt regularly would have no problem in talking about it, however this does not appear to be the case. Lawton drew attention to the way in which body disintegration and loss of body boundedness is a core feature of hospice care, with the result that the dying process is characterised by dirt. However, issues of dirt, decay, disintegration and smell are rarely if ever acknowledged in professional or public writings about hospice care (Lawton, 1998). Lawler explored nurses' differential responses to body products as part of their caring work, a perspective that limited her consideration to a narrow range of excretory products and therefore by definition those that would be considered very dirty. As she interviewed the nurses, her explanation is frustrating in so far as it does not explore the construction of dirt to any extent; however she identified sputum and faeces as particularly problematic. The problem of faeces was located to offensive odours particularly in conjunction with the threat of uncontainability and the consequent

challenges that it presented to physical and social management. Her explanation of sputum was less clear cut but more revealing in terms of the personal responses that it produced in the nurses. The inability of some of the nurses to discuss sputum even though they were accustomed to dealing with it on a regular basis (Lawler, 1991) underlines the persistent difficulty of this topic.

The problem of speaking about dirt also extends to speaking of 'dirty areas' not only in everyday speech but in medical and nursing practices where body management and body care is the primary activity. Difficulties in discussing body parts, in particular the genital areas, produces embarrassment and confusion for both nurse and patient alike, a situation compounded by a lack of shared language and shared understanding (Lawler, 1991). This problem is also evident in more specialist settings for example in gynaecological and midwifery practice where some discussion of these matters is essential. In all these settings, choices have to be made between types of language, anatomical and biological terms on the one hand and crude terms or euphemisms on the other (Lawler, 1991). The result is a reliance on indirect terms, on allusions and euphemisms in which 'it' and 'down below' become common parlance for genitalia (Lawler, 1991, Bergstrom et al., 1992) and 'doing a pelvic' and 'checking you up there' are used to announce a vaginal examination (Henslin and Biggs, 1971, Bergstrom et al., 1992).

#### **5.6.5 Dirt and the problem of smell**

Grosz (1994) primarily attributes the powerful effect of body fluids to their lack of solidity, to their tendency to flow, seep and infiltrate such that they demand control. If the visibility of body products is problematic in this respect, how much more so is the problem of smell which is both powerful and pervasive? Smells are primarily concerned with aesthetics in humans and consequently classified as either unpleasant or pleasant (Kubie, 1937). Dirt that smells bad is most powerful because it gets furthest inside a person (Enzensberger, 1972). This situation signifies the problem with smells which relate to difficulties of containment together with their historical association as an indicator of disease.

The social changes of the 18<sup>th</sup> century resulted in the increasing development and use of latrines and bathrooms and consequently led to the increased segregation and private management of bodily processes. This in turn resulted in a decreased threshold of tolerance to odours as a consequence of their olfactory disappearance from the environment. With the rise of the concept of the individual, there was a

greater definition of the odours of the 'I' and a greater degree of repugnance to the odours of others such that they became a source of intense self consciousness and embarrassment (Corbin, 1986). An increased sensitisation to bodies as olfactory producers necessitated a greater degree of personal surveillance. The masking techniques of perfuming which had been utilised for centuries increasingly defined sensibilities of class and status as well as fulfilling a role of bodily purification in the 17<sup>th</sup> century (Vigarello, 1985).

The association between the odours of putrefaction and the precarious nature of organic life which was realised in the miasma theory of disease crystallised anxieties surrounding smells and produced increasing social efforts to control and manage them. As such, they played a central role in the construction of a managed and contained body as well as in the development and management of social hygiene practices (Corbin, 1986). Washing the body which became an imperative within the hygiene discourse of the 19<sup>th</sup> century had initially found favour as the means by which to rid the body of its own smells, as a way of attacking the smell of dirt (Vigarello, 1985). This imperative for olfactory sanitisation remains clearly apparent today in the overwhelming array of body products on the commercial market. These powerfully portray the social necessity of smell containment but simultaneously reinforce the fragility of our contained state. As a particularly challenging representation of dirt, it is perhaps not surprising that current literature that considers the problem of olfactory management in relation to health care appears to be almost entirely absent other than the work of Lawton. As a powerful indication of the unboundedness of the body, smells produce powerful emotional responses of embarrassment, distress, revulsion and disgust. In social terms they produce marginalisation, creating a boundary around the individual and separating them from others (Lawton, 1998).

#### **5.6.6 Social dirt**

Douglas & Calvez (1990) identify the way in which pollution rules operate to produce broad categories of insiders and outsiders as a means of maintaining social stability. Within any community, types of cultural grouping can be identified, each producing its own type of bias in knowledge. The majority group is the central community in which the interpretation and ordering of experiences serves to reinforce existing classifications thereby encouraging conformity and conservatism. The purpose of such classifications is to protect those in the community, to defend its boundaries and to maintain the internal lines of order by reinforcement of the social norms.

In order to do so it is necessary to have a residual category within which those elements that cannot be assimilated in the social order can be deposited. These are those who have done something wrong, developed a wrong condition or crossed a line that should not have been crossed (Douglas, 1966). In terms of social groups these are the isolates, who represent those marginalised by society by virtue of their life style (Douglas and Calvez, 1990). However on an individual level, the role of pollution beliefs is to maintain conformity by bringing pressure to bear on deviant individuals (Douglas, 1975) although such a position presupposes that conformity to predetermined norms is possible.

The effect that categorisation as a 'dirty or polluted person' produces, the subjective experience of being contaminated, has received little consideration other than in terms of the effect of the actual or anticipated social sanctioning that results. In effect it has therefore been collapsed into considerations of stigmatisation and their impact. Stigma as a separate but related phenomenon will be considered in the next section; however it is important to identify contamination as a separate but largely unacknowledged entity.

One example of contamination as a significant emotional and embodied response, in the absence of considerations of stigmatisation, comes from the work of Dyson (2004) which identified responses to bodily disorder in relation to ethnicity beliefs. His work centred round antenatal screening for the haemoglobinopathies, sickle cell anaemia and thalassaemia, conditions which people commonly associate with specific racial groups and particularly with being black. When individuals who self identified as white-English were screened and discovered that they carried sickle-cell trait or beta-thalassaemia trait the effect of diagnosis was profound. It produced powerful feelings of contamination, pollution and tainting, a response to internalised disorder at the most fundamental level of genetic composition. This work identified not only the impact of embodied pollution, but also the necessity for some form of purification which is clearly problematic with a source that lies in one's genetic make-up. In this circumstance, efforts to restore bodily order lay in explanatory forms of realignment. These typically rested upon constructing 'socially acceptable' genetic roots which drew on explanations of ethnic mixing in the distant past for example linking genetic lineage to the Roman occupation of Britain or to the British occupation of India during the time of imperialism (Dyson, 2004).

## **5.7 Conclusion**

The effect of dirt upon the body operates at a number of levels. As a socially determined categorisation system it serves as a means of exerting pressure on individuals to conform to pollution rules. To avoid being categorised as dirty in physical or moral terms by oneself or others necessarily requires a high degree of personal surveillance and management in a corporeal and interactional sense. Pollution rules produce an effect that arises from the fact that they exist. Therefore whilst they may not be enforced, their power and the threat to self lie in the reality of their existence and enforceability. Much of this is realised in sociological terms through the concept of stigma.

## **Section two: The concept of Stigma**

### **5.8 Introduction**

The term stigma originates from the Greek word *στίγμα* meaning mark. Its meaning derives from the Greek practice of marking the skin of a person by cutting or burning, as a means by which to provide a visible indication of the underlying moral status of the individual. It signalled their pollution and defilement in order that they could be identified and avoided (Goffman, 1990). Its original significance therefore lay in its visibility, as an easy and obvious way of identifying one person as being different in some way from those around him. To mark someone in this way was a means by which to exercise social control, to enforce those structures and standards of behaviour that ensured social stability. Subsequently within Christianity the term took on a wider meaning being applied both to the stigmata which were signs of heavenly grace and to the bodily signs of physical disorder (Goffman, 1990). As a term that is in common usage it has largely lost these specific meanings and the original significance of its visibility has largely been lost as the term has come to be applied to those characteristics or behaviours that the mark was intended to signify. In essence stigma has come to refer to an attribute that is deeply discrediting, a state of otherness that is taken to imply inferiority or deviance from the socially constructed and tacitly agreed standards of normality (Seale, 2002, Page, 1984, Katz, 1981, Goffman, 1990).

### **5.9 Social structures and pollution rules**

In order to make sense of the world we employ a process of systematic ordering and classification. These categorisations are shared within cultures and enable us to produce shared meaning within communities. They create structure and order that informs individualised behaviour and our relationships with one another. It is through these structures that social stability is created (Douglas, 1966). Any given attribute that is stigmatised is not of itself inherently pathological, immoral or deviant. It does not have value in itself because of its intrinsic qualities; rather it acquires such a judgement when it breaches the code of social acceptability. Any form of deviance is located within a particular historical period and cultural context (Alonzo and Reynolds, 1995). The historic basis of labelling ensures that specific concepts of stigma are passed from one generation to the next and therefore have a degree of persistence. However as social meanings change over time, the stigma that they produce are also not fixed, they are in part subject to negotiation and change as the social boundaries are drawn and redrawn over time (Seale, 2002). Therefore the stigma associated with some attributes may diminish over time whilst others may become more prominent.

### **5.10 The spoiled identity**

The significance of the assignation of a stigma label lies in the fact that such an application has occurred. The stigmatisation process is therefore one of relationships rather than one of characteristics. Its relevance lies within the social context of relationships because it is at the point of social interaction that its meaning acquires relevance. Stigmatisation has the effect of invoking fear and hostility in the non stigmatised (Katz, 1981), responses that result in social sanctioning. It serves to reinforce the norms and values of the group and strengthen the cohesiveness of the group by enabling individuals to express disapproval of certain types of behaviour. It therefore serves as a form of social control, a means of maintaining conformity by bringing pressure to bear on deviant individuals who have strayed beyond the acceptable limits of a behavioural norm. In this respect the term is used as the explanation for the attitudes and behaviours of one person to another.

As a sociological concept stigma exists in the interactional process between people where the behaviour of one is based upon and justified in terms of the condition or attributes of the other. When these behaviours become established as social responses to those conditions, it provokes expectation and anticipation in those with the condition that they will be the object of such behaviours. In order to avoid or diminish the effect those with the condition modify their own behaviour. The burden of effect of stigmatisation therefore falls on the vulnerable individual whose social identity has been spoiled, who is subject to potential or actual social sanctioning and who is required to manage the social and personal consequences of these processes (Goffman, 1990). Internalisation of the concept of stigma is however not inevitable, rather it is situational and in some social circumstances that may be considered stigmatising, it is relatively rare (Page, 1984). However if it is internalised, if one considers one's own attributes as defiling and discreditable, stigmatisation produces psychological effects. It generates negative emotions, in particular shame and also guilt, particularly if it is associated with feelings or accusations of culpability (Oddens et al., 1999, Whiteford and Gonzalez, 1995, Imeson and McMurray, 1996).

### **5.11 Negative emotions**

Shame and guilt are elements of social anxiety associated with actual or imagined social interactions. They are social emotions that emanate from unintentional and undesired social transgressions (Edelman, 1985). They are generated as a result of the evaluation and judgement of one person either by himself or by someone else on the basis of what he has done or a characteristic that he possesses. They underpin

the rules and standards of society providing motivation for adherence and in this respect serve important functions in behaviour regulation (Tangney, 1995, Barrett, 1995).

Shame refers to a feeling of self-blame or self-disgust (Edelman, 1985). It is not produced as a result of any specific situation; rather it is produced as a result of an individual's interpretation of that situation. It may be related to the public or the private nature of a situation and may result from moral action, for example as a consequence of not having acted in a way one considered appropriate in a given situation (Lewis, 1995). It can therefore be considered a self-evaluative emotion that constitutes a global attack on self. It involves an appreciation that one is bad and that others consider that one is bad and as a result generates painful feelings (Barrett, 1995). It develops as a result of socialisation therefore the extent to which any particular situation elicits shame is variable. The generation of shame is also dependent upon the significance that one attaches to adherence to a particular social standard (Barrett, 1995) which in itself is subject to personal evaluation which changes over time and with increasing experience (Strauss, 1959).

Guilt by contrast is a largely interpersonal emotion produced as a result of transgressions and is most pronounced within close relationships. It occurs as a response to having done wrong and produces reparative behaviours whereby effort is directed towards repairing the damage produced by the wrong doing. Guilt produces appreciation that one's actions have produced something bad and that someone else has been affected as a consequence (Barrett, 1995).

#### **5.12 Discrediting and discreditable stigma**

Goffman (1990) distinguished between those stigmas that are readily apparent and highly visible and those that are not. He categorised these as discrediting and discreditable. Something that is discrediting is readily known about and the task of the individual is to manage social interactions in the light of this additional factor. A discreditable stigma is more complex and provides a larger number of options in terms of social management. Its primary characteristic is of a differentness that is not readily apparent and therefore in circumstances where it is not known about, there exists an ever present possibility of it being revealed. The issue here therefore becomes one primarily of information management and control. To share such information with others carries the risk of evoking negative responses, anything from mild disapproval to shaming, snubbing, ridicule and ostracization. Decisions therefore present themselves

on an ongoing basis as to whether or not to tell others, and if so who to tell and how, and when. These decisions to disclose or withhold information from others rest upon an anticipation of the response of others, however the inherent danger lies in the fact that one cannot know what that response is until after the disclosure has been made.

### **5.13 Felt and enacted stigma**

A common response to this situation is secrecy and concealment. It is the fear of disclosure and an expectation of negative responses, of social sanctioning, rather than any actual experience that becomes the central issue. This effect is particularly associated with medical conditions such as epilepsy which are not immediately apparent but which are defined first and foremost as stigmatising even in the absence of experiences of negative discrimination by others (Scambler and Hopkins, 1986). Scambler and Hopkins proposed a distinction between what they termed felt and enacted stigma. Enacted stigma refers to instances where discrimination has occurred. Felt stigma by contrast occurs in the absence of discrimination. It is founded upon a fear and anticipation of stigmatising processes rather than being produced as a consequence of them. Felt stigma therefore is predominantly a self perception of stigma founded on an interpretation of what it means to have a specific condition. It reflects an internalisation of the social and cultural values and attitudes that determine differentness (Jacoby, 1994). Thus although there may be no experience of having been the victim of enacted stigma, it is the anticipation and expectation of it happening and shame of disclosure, that produces an internalised feeling of being stigmatised and consequent distress, shame and secrecy.

Felt stigma results in the management of social situations to reduce the risk of detection. Social activities may be constrained and social interactions restricted. Tight information control leads to a conspiracy of silence, limiting those who know about the condition to a small and very select group of individuals, effectively imparting very powerful messages that it is not an appropriate topic of discussion. This perception is reinforced over the passage of time and by the efforts of others who serve as stigma coaches. The purpose of such strategies is to reduce the occurrence of enacted stigma although it is by no means certain that it would result from disclosure of diagnosis (Scambler and Hopkins, 1986).

### **5.14 Diminishing felt stigma**

If secrecy and lack of talk appear to perpetuate the existence of stigma, the solution required to counteract it would seem to be less secrecy. However information spread,

carried through a social network by the process of talk and gossip carries with it the risk of discreditation. Whilst discrimination on the basis of stigma may not be the reality of experience for many, it is the fear and expectation of it occurring that produces continuance of the feelings of stigma. In this respect therefore felt stigma would appear to be unassailable. However the stigma effect is founded in the social responses of the individual, in intimate contacts, in social groupings and on an institutional level. It is therefore dynamic, shaped by the passage of time, reinforced and strengthened or diluted. If there is non realisation of enacted stigma as a result of disclosure, it does appear over time to diminish perceptions of felt stigma (Jacoby, 1994).

### **5.15 The historical roots of stigma and disease**

The concepts of health, disease and morality have long since been intertwined and produced associations between disease and stigma in a search to find meaning in sickness (Porter, 1998). This is apparent in any society where particular symptoms and illness categories are charged with cultural significance that marks them out as being of a stigmatising kind (Kleinmann, 1988). In Western culture, the advent of Christianity imposed moralised notions of disease which led to an increasing association between a disease and its victim (Sontag, 1991). These reflected the Christian view of the body as a temporary and often problematic container for the eternal soul, a view clearly portrayed through the writings of St Paul.

From the Middle Ages, disease, particularly in epidemic form, was considered to be caused by God as punishment for sin. It provided a means by which to sort the good from the bad because its occurrence inside the body could locate and punish hidden sins. This attribution of moral causation to illness diminished and modified over time, coming increasingly to be class dependent, located predominantly in the working classes (Patton, 1985). Increasingly therefore disease came to be seen as proof of bad habits, a physical manifestation of the presence of underlying moral sickness. As such, it provided a powerful means by which the church could enforce social codes. Those with disease could be easily identified and judgments made about their character on the basis of their physical state. This created a simple means of social sorting, whereby people could be assigned to categories of insiders and outsiders. Disease was located in those who were immoral and therefore social outsiders, and consequently inferior to others. Such a system provided a location for disease placing it firmly in otherness, outside the social boundaries that were carefully controlled by moral codes and sanctions.

### **5.16 Stigma and sexually transmitted diseases**

Nowhere was this more evident than in the attitudes towards and the explanations for sexually transmitted diseases. As outlined earlier the traditional venereal diseases of syphilis and gonorrhoea have been closely associated throughout history with stigmatising practices, with isolation, ostracism and condemnation. Over the course of time they became inseparable from stigmatised populations, in particular prostitutes such that the two had become indistinguishable in the public consciousness by the nineteenth century (Spongberg, 1997, Brandt, 1987, Norberg, 1996).

The place of these venereal diseases was taken by HIV when it made itself evident to medicine in 1980 and seropositivity arguably represents one of the most stigmatised health conditions in the 21<sup>st</sup> century. The social history of HIV and AIDS has been a catalogue of discrimination, marginalisation and vilification (Sontag, 1991, Patton, 1985, Allen, 2000) with those infected vulnerable to scapegoating as the object of accusations and displaced fear, anxiety and contagion (Gerdt, 2001). The stigmatisation of HIV is complex. It derived from a number of aspects that characterised the nature of the disease and also the communities within which it first emerged and with which it became synonymous. Its association with 'deviant' behaviours, with concepts of culpability were subsumed in determinations of morality and its transmissibility. These resulted in anxieties and fears associated with contagion and collectively contributed to a legacy of widespread and devastating stigmatisation which reverberated through society at all levels (Altman, 1986, Shilts, 1988, Patton, 1985, Green and Platt, 1997) and continues to do so.

Those STI's that do not have the history of the traditional venereal diseases, or the personal and social impact of HIV, clearly do not generate responses of a magnitude comparable to either of these. However their construction as a sexually transmitted disease does carry a high degree of moral agency both in terms of their association with sexual behaviours and with constructions of culpability. Viral STI's, and in particular genital herpes, attracted considerable public attention and social ostracism in the early 1980's on the pretext of contagion (Altman, 1986) although they effectively paled into insignificance in the public consciousness when HIV emerged onto the scene (Mindel and Carney, 1991). Although the stigma label is readily applied to all sexually transmitted infections the impact of that label is dependent upon the characteristics of the specific infection. If an infection is either treatable or episodic and manageable, this might be expected to diminish the intensity of the stigma label and the duration of its effect in both personal and social terms. With such infections, their

constitution as discreditable stigma may necessitate considerations of information management, who to tell and who not to tell. However their transiency effectively time limits the physical experience, the length of time for which transmissibility is a specific consideration. Whilst someone with HIV needs to consider themselves a potential source of danger to all sexual partners and needs therefore to consider ongoing disclosure, this does not apply to chlamydial infection once the original infection has been eliminated. The stigmatising effect of this infection is therefore likely to be transient.

The stigma effect of a discreditable rather than a discrediting condition is based upon experience of publicly voiced negative attitudes towards such conditions and a fear that such negative attitudes will be directed at oneself if the condition becomes publicly known. Talk and gossip are therefore important in terms of reinforcing feelings of stigmatisation. The element of known aboutness becomes very prominent in relation to invisible stigma that are perceived to carry a high degree of moral agency, such as HIV infection where disclosure potentially jeopardises moral identity (Stanley, 1999). In a community in which such an infection is prevalent, competing discourses co-exist. Whilst it is viewed as a topic unsuitable for discussion because it is considered both dirty and taboo, it is simultaneously a common cause of gossip. Speculation and debate as to who does and does not carry the infection is rife, with judgements following stereotypical lines of insider and outside categories, largely based on physical appearance (Smith et al., 1999). In a society in which a sexually transmitted infection is portrayed as being associated with outsiders who were morally culpable for the presumed infection, the persistence and widespread presentation of such attitudes have a powerful effect upon the continuance of stigma and feelings of stigmatisation.

The stigma relating to a curable condition resides in the knowledge that someone has or has had such an infection which, when it becomes known about, has the propensity to colour social reactions to that individual. Moral judgements are made on the basis of the presence of the infection and perpetuated through the media of talk and gossip. Conceivably therefore, in these circumstances, the stigma effect has the propensity to outlive the original infection, similar in this respect to other deviant behaviours where chronicity of the stigma rather than the behaviour is considered to influence social interaction (Albrecht et al., 1982).

### **5.16.1 Efforts to quantify the stigma effect of STI's**

A small number of studies have considered the stigmatising effect of sexually transmitted infections other than HIV. In the main, they have attempted to examine the possible effect of stigma upon actual or anticipated service access or simply reported descriptions of responses to having an STI (Liu et al., 2002, Dixon-Woods et al., 2001, Holgate and Longman, 1998, Duncan et al., 2001, Go et al., 2002). Much of the stigma effect that is presented in the data is reported in terms of the generation of negative emotions, the most common of which is shame. The majority of studies use the term stigma as a collective label to describe a cluster of negative emotions which are elicited as a response to the actual or anticipated infection (Liu et al., 2002, Dixon-Woods et al., 2001, Duncan et al., 2001, Go et al., 2002). Two other studies however did attempt to distinguish between shame and stigma (Fortenberry et al., 2002, Cunningham et al., 2002). Stigma in these terms was measured in terms of the expectations of other people's behaviours, for example, if you had an STD, people would think you were unclean. However, as both studies sought the opinions of those who did not have STD's, their findings can only be suppositions.

Those studies that considered the actual responses to infection focused largely, but not exclusively, on the generation of shame. The overriding and unquestioning assumption was that it occurred because these are discreditable and therefore stigmatising infections. In one study shame was used as the sole measure of stigma (Go et al., 2002) whilst another study measured stigma from assessments of both shame and guilt (Fortenberry, 1997). Two small qualitative studies identified shame as one aspect of stigma but also identified a separate aspect; a feeling of contamination associated with notions of contamination (Duncan et al., 2001, Holgate and Longman, 1998). This concept of contamination is central to any consideration of stigma in relation to STI's because it provides some indication as to why negative emotions may occur and why the label of discredibility may be applied in this context.

Within this literature it is striking that there is a marked absence of any documented accounts of enacted stigma having occurred, a failure to describe interactional circumstances within which social sanctioning of those with an STI has occurred. This appears to stem from a lack of any consideration of this central aspect of stigma in the research question of the studies available. Their focus has been a purely psychological one where stigma is considered to relate to the emotional response to those behaviours whether they are realised or anticipated. However, such emotions stem from an internalisation of the cultural values upon which those behaviours are

founded. In essence therefore what is commonly represented as stigma, in relation to curable and consequently episodic sexually transmitted infections such as Chlamydia, appears to be limited to a description of negative emotions. These have been evoked as a result of self evaluation that generates feelings either that one is bad or that one has done something bad or harmful to someone else.

The social context that leads to such an evaluation is the perpetuation of attitudes where STI's are associated with, and a marker of, those categories of people who were considered morally and socially condemned and excluded, those who were classified as outsiders. The perpetuation of such socially and culturally embedded views creates a climate within which someone who discloses diagnosis of an STI risks becoming the object of such a categorisation. This climate is the basis of the two elements of a felt stigma. Although someone may not actually be exposed to actions that constitute stigmatisation, the fear of them, which is founded upon negative attitudes and continuance of stereotyping and promoted through the communicative processes of rumour and gossip, is sufficient to generate anxieties about the response of others. Because these anxieties are founded upon expectation of responses, they do not necessarily materialise, either because of avoidance strategies such as information control or because there is discrepancy between the actual and the anticipated response. It is this component of felt stigma that appears so difficult to isolate, to the extent that it appears to be presented as subsumed within the more readily articulated and identified second component, the negative emotions. These emotions however are not generated as an inevitable response to an STI. The evaluative processes that accompany diagnosis will only result in such responses if there is acceptance and internalisation of the persistent stereotypes that accompany STI's.

### **5.17 Conclusion**

It seems reasonable to assume that the two facets of a felt stigma are closely associated with one another; indeed it is not clear to what extent the expectation of adverse comment in someone else is actually an expression of one's own discomfort with the concept, a means of expressing shame without presenting it as an internalised feeling. If this is the case, then the two elements become inseparable and should perhaps be considered as two ways of expressing the same thing. However stigmatisation is not an inevitable process, it requires incorporation of specific social perspectives into one's self-concept (Anspach, 1979). Equally these negative emotions may be generated as a response to conditions other than those that would fit

the category of stigmatisation. Thus although the association between the two is evident, it is not inevitable.

## **Chapter 6 – Theoretical considerations part 2**

### **Section one: The development of health surveillance services**

#### **6.1 Medical control of the body**

In 'Discipline and Punish,' Foucault (1977) traced developments in the historical relationship between the body and the State and the way in which, from the classical age at the end of the 17<sup>th</sup> century, the body came to be seen as the target and the object of power, as docile and amenable to manipulation, something that could be subjected, transformed, used and improved. As the institutional mechanisms of social control which were involved in the formation of a productive population came increasingly to focus their attention upon the body, there emerged sets of disciplinary practices. These were operated upon the body through those organisations and institutions within which power was located, and within which a corpus of knowledge and methods developed. The exercise of disciplinary power relied upon the establishment of hierarchical observations and normalising judgements through which, and against which, the individual body could be assessed and evaluated. Power in this sense is not a property to be transferred or a thing to be possessed. Rather it is functional, operating as a piece of machinery which rests on individuals and it is effected through a network of relations (Foucault, 1977). As the site upon which and through which it operates, power in this sense does not exist independently of the body. Rather it operates through discourse as a subtle and social force which reaches into every aspect of life and constructs the body as a product of that discourse (Pryce, 2000, Lupton, 1995). Its analysis therefore should not be considered as something to be wielded but rather as a way of looking at strategically complex situations (Goldstein, 2003).

Central to the exercise of disciplinary power is the examination. The examination objectifies the body by subjecting it to the techniques of an observing hierarchy. It provides a means by which to assess and evaluate the body, to judge and classify it against those normalising judgements which have been created as a product of knowledge and generated through disciplinary processes (Foucault, 1977). The power of normalisation, in this respect, comes from the absence of fixed points from which to make those judgements. It therefore serves as a means of organising people through the operation of corrective and regulatory mechanisms (Rabinow, 1991).

## **6.2 The medical gaze**

In relation to medicine, Foucault (1976) detailed the way in which the formation of institutions, established for the sole purpose of treating disease, served to remove the patient from their home environment and locate them within a setting that individuated them and subjected them to an ever increasing degree of medical scrutiny. The establishment of clinic medicine enabled the development of those clinical techniques and procedures that systematically constructed the body as a site of attention and scrutiny. The medical gaze became increasingly intense as the body of knowledge was constructed and as clinical techniques and procedures were developed that enabled the doctor to discern processes and structures previously hidden from view. The medical gaze was no longer confined to the surface of the patient. It transcended body boundaries to reveal the hidden depths and discover the places within which disease was hiding. Anatomical dissection revealed those layers and structures that had been previously hidden from view. Cells, tissues and organs were given a pattern, as relationships between organs and tissues were made apparent. The body came to be discerned as a physical entity by those clinical techniques that rendered it into an analysable and observable space (Armstrong, 1983, Radley, 1997).

In the clinic the patient came under increasing scrutiny. However the focus of attention fell increasingly upon the disease rather than the patient as a consequence of the increasing level of specialisation. The establishment of the clinics provided opportunity for the concentration of cases gathered together in one place that were deemed to have high instructive value. Rather than the patient being a case, the subject of the disease, he became instead an example of the manifestation of the disease, the object within which the disease was located.

“One is dealing with diseases that happen to be afflicting this or that patient, what is present is the disease itself, in the body that is appropriate to it, which is not that of the body itself but that of its truth.” (Foucault, 1976 p. 59).

The body became a surface upon which the disease was imprinted, a means by which to observe the outworking of the disease and was constructed as an object of the disease.

## **6.3 The rise of social medicine**

The development of social medicine at the end of the 19<sup>th</sup> century moved the focus of attention from the patient confined to the hospital and thereby it both extended and expanded the medical gaze. It extended the depth of penetration into the social spaces which the patient occupied, reaching into a multitude of social settings; homes, places of work and places of leisure. In doing so it also encompassed larger numbers

of people. As the range of the medical gaze moved into the community it ceased to be restricted by the confines of the hospital and therefore limited to those individuals situated therein. An expansion of its range of focus brought an increasing population of individuals within the scope of medical surveillance.

The extension of medical control was exemplified by the developments in the management of tuberculosis and the creation of the dispensary. Functioning as a centre through which the infection could be detected, monitored and treated, the dispensary enabled those with this disease to be managed in the community. The traditional function of directly observing the patient was accompanied by the surveillance of these individuals within their own environment. Techniques were devised for observing, monitoring and reporting on patients and their domestic surroundings. In this way increasing numbers of people and incrementally more aspects of their social life came under scrutiny as the medical gaze extended in order to prevent the further spread of infection through the community. Those who appeared normal were subjected to examination in order to detect early disease, whilst social behaviours and relationships came under increasing scrutiny (Armstrong, 1983). Increasing acceptance of the germ theory, which intensified popular concerns about the contagious properties of the body and particularly body products, validated the health education crusades which became increasingly directive in their efforts to control and regulate. In the case of tuberculosis, sputum became a particular source of concern. Efforts to control its infectious effect were intensive. Initially directed at public behaviours, control measures extended from anti spitting campaigns and the closure of public drinking facilities, to the prohibition of stamp licking. In the private domain of the home, dust and sputum represented the two loci of anxiety with activities such as cup sharing and dusting the house erroneously considered dangerous in the extreme (Tomes, 1997, Feldberg, 1995, Ott, 1996).

#### **6.4 Governmentality**

Governmentality is "simultaneously about individualizing and totalising" (Gordon, 1991 p. 36) and represents the way in which populations have come to be managed and directed, by indirect means operating through organisational systems. The purpose of government in this respect is the welfare of the population and the improvement of its conditions. The means by which the government attains these ends is by acting upon the population, either directly through large-scale campaigns, or indirectly through processes that achieve these ends by guiding human activities in particular directions, often without the full awareness of the population. Thus the

population is both the subject of government and the object through which it achieves its ends (Foucault, 1991).

The concept of governmentality is used to explain how populations are regulated through various techniques such as those directed towards improvement of the health and the longevity of the population. This is effected through a network of institutions and through procedures which employ complex techniques of power to order social relations. The individual body is the ultimate site of surveillance and control (Foucault, 1977) the discursive construction of which occurs as an effect of power and knowledge. This provides a focus for disciplinary and regulatory techniques practised upon the individual as person (Shildrik, 1997) and thereby provides the means by which to maintain social control (McNay, 1992).

Biopower is that form of power which Gordon describes as being

“exercised over persons specifically in so far as they are thought of as living beings; a politics concerned with subjects as members of a population, in which issues of individual sexual and reproductive conduct interconnect with issues of national policy and power” (Gordon, 1991 p. 5).

Biopower operates in two dimensions. In the first, anatomo-politics, it discursively constitutes the individual body, through the interpersonal relations between patient and doctor. The second is concerned with the exercise of disciplinary power exercised over and through populations. This is biopolitics that seeks to regulate and document the health status of populations, although the exercise of its control and the focus of its discipline rests upon the individual body (Lupton, 1995).

The increasing medicalisation of the body has produced a greater degree of control and regulatory surveillance of human behaviours and activities. In the name of the achievement and maintenance of a state of good health, the discourse of health has expanded to encompass increasingly detailed aspects of life as well as becoming increasingly directive as to what is permissible and what is prohibited. As part of the process within which responsibility for health has come to be constructed increasingly as a moral obligation, the deployment of disciplinary power has contributed to the creation of the active patient who self regulates and self examines in assuming personal responsibility for health and self (Pryce, 2001). An increasing emphasis upon self-administration of self surveillance requires one to police one's own body, to subject it to intense scrutiny, observing, monitoring and charting against standards of normalcy (Shildrik, 1997). Whole body self surveillance techniques are multiple and increasing.

Technological developments have brought those processes that were previously the domain of the medical arena into other settings. Through the increased use of self sampling and home testing kits, the boundaries of self surveillance have extended and continue to extend further into the physical and the social body.

### **6.5 The Genitourinary Medicine Clinic**

The establishment of Venereal Diseases Clinics created facilities for the discrete treatment of those in the community who were infected. However it simultaneously created a location within which the development of medical knowledge and the exercise of medical power could operate in an increasingly systematic and far reaching way. Those activities that comprised the 'duties' of the clinic in the 1920's have been subjected to a Foucauldian analysis by Pryce (2000) which clearly identifies the ways in which the clinic functioned and continues to function as a panopticon in processes that operate at a micro and macrolevel. For example, the recording of details about individuals creates an epidemiological map of the population, whilst at an individual level examination of the body combines the disciplinary knowledge and the normalising judgements which are realised through the doctor-patient relationship. Through the process of productive power this creates the active patient who becomes involved in self-monitoring and self-observing (Pryce, 2000, Pryce, 2001).

Within the clinic the role of the active patient is not confined to self monitoring, but extended to recruitment in the wider health surveillance activities of the clinic. Partner notification which was initially developed in 'The Tyneside Scheme' (Wigfield, 1972) expanded the reach of the medical gaze into the community, however its operation relied on the exercise of power through those attending the clinic as the means and the ends of the process. As objects of surveillance themselves, within the confines of the clinic, the patients have become increasingly involved in the surveillance of others, active not only in terms of their own health but also that of others. The processes of partner notification have increasingly relied upon active engagement of the patient in the process. In the beginning, it was the clinic staff who took on the task of notifying those sexual contacts whose names had been provided by patients in the clinic. This mechanism, which is referred to as service referral, remains an option; however current practice has come to rely much more heavily on patients informing their own sexual contacts, a process labelled as patient referral (Chippingdale, 2002). Whilst these processes remain a matter of debate for clinicians and epidemiologists who contest the relative merits of each, they are assessed and judged not in respect of the patient herself but in terms of effectiveness of the process (Matthews et al., 2003, Fitzgerald

and Bell, 1998), measured in quantitative terms within which individuals are coded and categorised as contacts rather than considered as individuals.

The current developments in GUM services and the expansion of services, which include a greater involvement of Primary Care providers, were discussed in chapter two. The technological advances in the detection of chlamydial infection and the increasing availability of non invasive sample collection methods were discussed in chapter three. Both of these factors have been identified as a means by which to tackle the increasing levels of sexually transmitted infection, to reduce the morbidity of individuals and preserve the reproductive capabilities of the population (DH, 2001a).

Closer examination of these health surveillance techniques and services demonstrates the way in which one set of operations replaces another as components of what Armstrong describes as 'the mechanisms of power' (Armstrong, 1983 p 2). The overall effect is an increase in the extent to which the disembodied gaze reaches into the social spaces. The movement of services into a community setting extends the degree of surveillance on those attending medical services for any other purpose. Opportunistic screening provides the justification for initiating screening in identified groups of the population every time they attend a sexual health clinic or visit their GP whether or not their concern is sexual health related (Perkins et al., 2003). In this context every visit, every contact with the health service, is translated into a potential opportunity for infection screening and the frequency of attendance for whatever purpose equates to the frequency of scrutiny.

The development of sampling techniques that enable self collection using urine samples and self administered vaginal swabbing have relocated the detection of infection outside the clinic boundaries. They have been heralded as a welcome advance, considerably less unacceptable to males and females alike (Pimenta et al., 2003). Genital examination in women represents a particularly disembodiment and disempowering experience (Martin, 1987) reflecting the control of disciplinary power at its most extreme through subjectification of the body to the authoritative vision of the practitioner (Sandelowski, 2000). Self collection of samples protects the body from this intense scrutiny and as such may be considered to diminish the degree of control over the individual. However it simultaneously facilitates the spread of the surveillance web further into the social network. As procedures become more acceptable, the levels of individuated resistance are reduced. The increased portability of tests further contributes to the increased deployment of medical procedures into community settings

as they become easier to administer and cease to be reliant upon specialist equipment or expertise for their collection.

### **6.6 The disproportionate focus of attention on women**

From a feminist perspective the work of Foucault has been criticised for its gender blindness, failing to acknowledge the different ways in which men and women relate to the institutions of modern life (McNay, 1992). He has also been criticised for being male-centred and gender indifferent, in so far as his discursive concentration on the disciplinary practices that operate on the female body fails to acknowledge the effects of a patriarchal system in relation to the differential power relations between men and women (Shildrik, 1997, Ramazanoglu and Holland, 1993).

In relation to health activities, the emphasis on women's health has produced a situation where 'gender and health' has become synonymous with 'women's health' (Courtenay, 2000) although an increasing amount of work that acknowledges the male perspective has provided some challenge to this position in relation to both health and illness (Watson, 2000, Cameron and Bernandes, 1998, Chapple and Ziebland, 2002, Saltonstall, 1993). Notwithstanding this, the vast majority of health activities are concentrated upon the female body, particularly in relation to their reproductive capabilities. In relation to contraception, women are expected to assume primary responsibility and often solely absorb the physical and social impact of doing so. Contraceptive options rely predominantly upon chemical and mechanical manipulation of the female body and represent the majority experience for women. However research studies indicate that women have ongoing concerns regarding the adverse health effects of contraceptives and they further report women's apparent difficulties in obtaining adequate information upon which to base their decision making (Edwards et al., 2000, Oddens et al., 1994).

The difference in the way that pharmaceutical industries assess the physical risks associated with contraceptives for men and women is striking with systems of assessment that downplay the impact of side-effects in women and magnify the impact in men. Appraisals of female contraceptives evaluate the associated side-effects against other factors, primarily the risk of unwanted pregnancy and the risks and benefits of other methods. By contrast, an appraisal of male methods primarily uses an individual risk model in which the side effects are calculated against the health status of untreated men (van Kammen and Oudshoorn, 2002). In social terms the supply and promotion of the condom, which represents the single male controlled option, is largely

mediated and managed through women who constitute the primary attenders of sexual health services. Whilst this provides women with some degree of control over the process, it places the burden of responsibility upon them. It also perpetuates a system within which men are left out of the picture (Courtenay, 2000) and where their accessibility is predominantly managed through women.

This gender imbalance is evident throughout reproductive health care. More recent developments reinforce an established pattern within which sexual and social meanings are imposed on women's bodies rather than men's, and men are enabled to marginalise themselves because to be defined is to be controlled (Courtenay, 2000). In relation to assisted conception, developments in reproductive technologies have arrived at a situation where in-vitro fertilisation (IVF) represents a first-choice option, increasingly considered a routine procedure. This stance appears to validate highly invasive procedures being meted upon the female body even though the structural dysfunction may be located within the male (Shildrik, 1997, Strickler, 1992).

### **6.7 The cervical screening programme**

The cervical screening programme constitutes a most striking example of a mechanism of power, institutionalised and operating at a number of levels to ensure that women comply with the requirements of the programme. A pre-determined population and frequency of examination provides the framework for an administrative machinery that operates through the regulatory component of the call recall system where women are personally invited to attend for screening. This is supported by a network of accessory mechanisms including targets and incentive payments for general practitioners which result in differential levels of coercion upon women accessing those services. These structures contribute to a situation where over 80% of the eligible female population undergo testing (DH, 2001f) and thereby to the constitution of its status as normalcy. Consequently the majority of women consider that undergoing a smear is a requirement of womanhood, to the extent that they not only feel a moral obligation to attend themselves, but also to ensure that others do so (McKie, 1995, Howson, 1999, Bush, 2000). This both creates and reinforces a surveillance of women's sexual lives within which the cervix is the sole site of surveillance (McKie, 1995) from which the male is totally absent. This occurs despite empirical evidence that indicates the cause of cervical abnormalities to be a sexually transmitted organism, namely Human Papilloma Virus (HPV) (Londesborough et al., 1996).

Cervical screening grew out of routine aspects of female embodiment in its original conception. Antenatal, postnatal, and contraceptive consultations were used as opportunities to take smears. In this way, the mechanism of the cytology programme was built upon the pre-existing mechanisms of reproductive care until it acquired its own structure with the establishment of the call recall programme in 1989. To use one framework of surveillance as the structure upon which to construct another produces significant conceptual difficulties as the two become so tightly intertwined in terms of meaning and purpose. This is evident in the case of the cervical screening programme. The challenge to effectively separate it from other reproductive processes such that it operates as a stand alone mechanism of its own has been going on since 1989 (NHSCSP, 1997).

### **6.8 The chlamydia screening programme**

However this 'piggybacking' approach is attractive to health care providers because it effectively provides a means by which to target those already actively recruited into surveillance activities. It is perhaps not surprising therefore to see it being used in a comparable way in relation to chlamydial infection since screening became a realistic possibility. This was the basis of the rationale outlined in the CMO Expert Advisory Report (DH, 1998) and subsequently developed, initially in the Sexual Health Strategy (DH, 2001a), and subsequently in the mechanisms of management that are evolving in the screening roll out programme (LaMontagne et al., 2004). However if cervical screening represents a service that "creates and reinforces negative views of women and female sexuality" (McKie, 1995 p. 132), how much more so does the concentration of chlamydial screening upon women ?

The moral imperative for the exercise of governmentality through techniques of health surveillance falls disproportionately upon women as guardians of the family's health and moral welfare (Lupton, 1995). This expectation is clearly portrayed through health accounts which construct the concern and responsibility for people's health as being generally and properly the concern of women (Johnson, 1991, Cameron and Bernandes, 1998). However in relation to chlamydial screening, the targeting of women simply because they are considered an accessible population takes this function to a level not previously afforded it in such an overt and systematic way and contributes to a representation of this infection that focuses exclusively upon women. Subsequent to the release of the Government White Paper 'Choosing Health' the following statement appeared in a broadsheet newspaper.

"The acceleration of plans for a national screening programme for Chlamydia means that this should be in place by 2007. One in 10 sexually active young women under 25 may be infected with this disease, which if untreated can lead to ectopic pregnancy and infertility." (The Guardian, 2004 p. 4)

The basis of a health approach that targets a distinct population of women, those under 25 years, has been justified in epidemiological terms and rationalised as a means by which to protect these women and their future fertility. However professional and lay perspectives which repeatedly fail to even acknowledge from whence these women obtained their infection are highly reminiscent of the approach adopted in the mid 19<sup>th</sup> century towards another distinct and identified population of females.

## **Section two: Sex and risk**

### **6.9 Theories of risk**

The term risk which was once neutral, used to describe losses and gains, has since modern times become associated with negative consequences and has increasingly been employed in the field of health as an expression of the untoward consequences of an action or behaviour (Fox, 1999). In this context it has been widely adopted as the means by which to inform behavioural decisions. In many instances these relate to medical therapies and treatments but increasingly, identification and reduction of risk has been appropriated in directive efforts to steer people away from or towards specific behaviours because of their association with identified health consequences. These estimations of risk derive from a technico-scientific perspective that considers risk as a largely taken-for-granted phenomenon, where the identification of risk and the determination of causal relationships which form the risk assessment are undertaken by rational calculation of ends and means in order to inform proposals about limiting their effects (Lupton, 1999, Fox, 1999). They assume objectivity and require that subjective values are kept at bay to ensure that they do not interfere with the analysis (Douglas and Wildavsky, 1983). However, as the underlying concept of achievable objectivity is itself questionable, this approach to risk assessment is highly problematic.

Risk assessments applied to human actions are based upon the intellectualist view of human thinking which assumes that people work out the effects of their actions and then choose the course of action according to their self-interest (Broadbent, 1985). However the notion of risk upon which this is based is conceived as autonomous of the concept of danger. It arises, not from a precise danger embodied in an individual or a group, rather from the effect of a combination of abstract factors which render more or less probable a set of undesirable outcomes (Castel, 1991). It is therefore a depersonalised concept. The recognition of identified risks associated with a specific behaviour does not automatically translate into personal risk. Probabilities are derived from numerical data which are drawn from an identified study population. They are then extrapolated, applied to a wider population and presented as a statistical probability in terms of that population. That statistical calculation of risk therefore only makes sense in relation to a population of people. It has little personal relevance to a single person whose future remains indeterminate. Consequently its social representation does not translate into a personal representation of its subjective relevance (Breakwell, 1996).

A rationalistic approach fails to problematise risk and risk assessment in relation to human behaviours. Firstly it assumes that choosing is the essence of rational behaviour and secondly, it provides no indication of how self interest is conceived (Douglas, 1994). Alternative approaches have developed in order to explain the concept of risk from a sociological perspective, the way that it is understood and utilised in relation to a number of social circumstances. Lupton (1999) identifies three major approaches; the 'cultural/symbolic, the 'risk society' and the 'governmentality' perspectives.

### **6.9.1 Risk society**

Beck, and other major proponents of the risk-society theory, adopted a macro-structural perspective to address considerations of the socio-scientific and socio-political issues associated with the technological developments in the modern era. Central to the explanations of the way that these have been represented and understood is the individualisation process that has occurred as a consequence of the modern era, a product of the disaggregation of the family and other social structures that have resulted in the progressive loss of social structures and tradition as a means of structuring the life-course. This social process produces the conceptualisation of individualised risk, where the individual is effectively floating free from security and tradition, being required to make choices (Scott, 2000). The effect of this is that individuals are considered to have a high degree of control over the risks to which they expose themselves and by extension, that exposure to risk is associated with culpability. The avoidance or management of risk is constructed in these terms as a responsible act (Lupton, 1999).

### **6.9.2 Sociocultural theory**

Adopting a sociocultural approach, Douglas challenged the prevailing view that perceptions of risk and its acceptable levels are collective constructs. Within any society there are innumerable risks and considerable disagreement between groups of individuals both as to what constitutes a greater cause of concern than any other and what magnitude of risk is acceptable. Similarly, any one activity may be beset by a number of identifiable risks and there will inevitably be disagreement as which are most worrisome. She developed her 'group-grid' model to consider the concept of risk from an analysis of cultural responses to risk in societies and communities initially in relation to environmental and technological risks (Douglas and Wildavsky, 1983) and subsequently applied her theoretical construction to the cultural responses to HIV infection (Douglas, 1994). In this model, group indicates degrees of incorporation and

relates to group ethos whilst grid, indicating degrees of autonomy, relates to the constraints and expectations that shape the social relations. Thus high group, high grid reflects a community that is hierarchical in nature, that accepts the authority of established professions and puts its trust in organisations. Their overall tendency is conformation to group norms and responses to risk. Other grid-group combinations reflect other responses that challenge this perspective (Douglas, 1994). The effect of this approach is to move the focus beyond the individual to consider the sociocultural context within which she is located and through which her assessments and judgements about risk are made (Lupton, 1999).

### **6.9.3 Governmentality.**

As a means by which to control and govern the population, extensive networks of expert knowledge have developed over time, in conjunction with the emergence of organisations and institutions within which and through which such knowledges have been constructed, reproduced and disseminated. Within this context, risk is understood as a collection of strategies through which disciplinary power operates, a means by which to monitor and direct human behaviours (Lupton, 1999). The rise of epidemiological surveillance of populations which occurred during the twentieth century, in conjunction with the expansion of medicine from the hospital into the community, resulted in the focus of attention resting increasingly upon seemingly healthy populations. This resulted in a blurring of the boundaries between health and illness and the problematisation of normality (Armstrong, 1995). Categories of normality were constructed from the collective data of populations and used as a standard against which to compare the health status and health behaviours of an individual. This provided the means by which to distinguish between those who were 'normal' and those who were 'at risk' in order to concentrate a greater degree of surveillance and observation upon the latter group (Lupton, 1999).

Although models of disease causation are commonly a product of the complex interplay between biological, social and environmental factors, social factors which are deemed modifiable are the focus of attention in health promotional efforts. The labelling of specific activities and behaviours as 'risky' because of their association with a specific disease or illness sanctions exhortations to reduce or modify that specific aspect of life. These are realised through health promotional efforts designed to steer the population away from specific activities and towards others. The effectiveness of such efforts is measured in terms of the degree to which they are considered to have produced change in behaviour. In the construction of these risk discourses, within a

climate that emphasises personal responsibility for health, certain activities that are considered beneficial to health become socially desirable whilst others that are decried as deleterious are outlawed and associated with implications of irresponsibility and blame.

### **6.10 Risk and sex**

The public representation of sexual practices was extensively reconstructed in the light of the emerging reality of HIV. Although sex had always been acknowledged to cause unwanted consequences, these had been largely confined to identifiable situations and populations, predominantly to the procreative consequences of sex outside the socially defined bounds of respectability. HIV changed all this and resulted in the construction of sex within a risk discourse whereby all sexual intercourse came to be defined as an inherently dangerous thing and safe or safer sex became the imperative.

The social construction of HIV risk can be traced from its focus of attention on specific groups of individuals, with the delineation and resultant social vilification of those in 'at risk' groups, towards a focus on specific behaviours (Delor and Hubert, 2000). As the focus of attention extended from specific 'at risk' populations such as homosexuals to the heterosexual population, the accompanying health messages became increasingly directive. They moved from making suggestions about who one had sex with, to making specific recommendations about personal behavioural patterns and the adoption of specific practices, primarily the use of condoms (Brown, 2000).

Although human behaviour has historically utilised a repertoire of activities designed to avoid sexually transmissible diseases (Donovan, 2000a, Donovan, 2000b), condom usage, identified at a global level as a primary intervention strategy against STD's (WHO, 1985), is almost universally considered the main weapon in the fight against HIV and AIDS. It is the key message in government funded media campaigns and has been adopted wholesale in innumerable health educational and promotional efforts. Widespread distribution schemes, the promotion of 'double dutch,' and skills teaching through the practice of condom demonstrations represent a small number of the health efforts which have resulted in a population who understand safe sex in terms of condom use (Thompson and Holland, 1994). The literature base related to condom use reflects the extent to which it is also understood in these terms by health professionals. A single search on Medline for a three-year period between 1998 and 2001 using the key words condom use and HIV yielded in excess of six thousand articles.

Implicit in the portrayal of condoms in this way is the basic premise that the virus is indiscriminate and non-preferential in terms of whom it affects. There is an acceptance that everyone is at potential risk of becoming infected, every sexual partner is a possible source of infection and therefore that all sexual activity is risky unless certain behavioural codes are followed (Brown, 2000). An intellectualist stance would suggest that knowing and understanding this would result in the adoption of consistent standards of health protecting behaviour. However epidemiological data that charts steadily rising STI rates (chapter 2.13), recognised re-infection rates (Fortenberry et al., 1999, Orr et al., 2001) and studies that report a significant proportion of the population who do not change behaviour or increase condom usage subsequent to an STI (Payn et al., 1997) clearly demonstrate that this is a naïve and unsubstantiated assumption.

This one dimensional perspective also denies the possibility that different cultures produce their own biases in knowledge and give rise to different theories about the body. This is most graphically illustrated by Douglas who drew on fieldwork to identify four attitudes to the risk of infection which co-existed within a single population. Firstly, that the body is porous, open to every dangerous invasion and basically unprotectable. A second conviction is that the body is very strong and able to cope with infection, a belief so strongly held that special precautions and changes to behaviour are not considered necessary. A third position purports that the body has two skins; a physical skin that covers it and a community skin that envelops it. Safety comes from maintaining the integrity of the outer layer because the body of itself has insufficient resources. Only the fourth attitude, that considers the body as a machine with a protective envelope that requires to be maintained and supplemented is fully consistent with the accepted viewpoint of prophylactic activities (Douglas, 1994).

### **6.11 The problem with condom usage**

Condoms provide a protective covering and thereby prevent the transmission of micro-organisms from one person to another. Representations that offer this mechanistic solution as the sole or primary solution to prevention of infection fail to problematise not only the diversity of beliefs but also the complexity of human sexual behaviour and the location of condoms within that behaviour. They ignore the role of desire and pleasure in sexual relationships (Lupton, 1995, Flood, 2003) which are dominant in explanations of non-usage. Accounts of non-usage reflect dislike of condoms which are considered to be both publicly and privately embarrassing. Condom sex is viewed as other sex by men and women, as de-sensitised and requiring a degree of adjustment and action

which interrupts the flow of sexual encounters and decreases sexual pleasure (Browne and Minchiello, 1994, Hillard et al., 1993, Gold et al., 1992, Flood, 2003).

Public health efforts that promote consistent condom usage as a necessary and desirable activity also rest upon the assumption that all individuals are risk averse. However, aspects of a sexual encounter that constitute risk to an individual may not always be seen as something to be avoided (Lupton, 1995). For example, Flowers et al. conducted a study with homosexual men who engaged in sexual activity in a public place. In this setting, within which they constructed risk as relating more to personal safety and possibility of criminal conviction than to sexually transmitted infections, they engaged in such activity precisely because of the thrill and excitement that it afforded (Flowers et al., 1999).

#### **6.11.1 The privileging of infection risk**

Condom usage privileges the risk of infection transmission above all other possible sources of risk in sexual practice. However, the concept of risk is fluid and dynamic, with a range of competing interests that change and fluctuate over time and risk in this context may well mean something very different from the possibility of infection transmission. Broaching the subject of condom use itself can be considered risky. In this respect, the verbal component of sexual behaviour may be more threatening and dangerous than the physical component, carrying with it the possibility of rejection, the necessity of self-disclosure, or the implication of mistrust within a relationship (Browne and Minchiello, 1994, Pliskin, 1997, Wyn, 1994) all the more so because it is necessarily a repetitive activity.

#### **6.11.2 Gender specific considerations**

There are well defined inconsistencies in the targeting of health messages, the targeting of services and the expectation of adoption of preventative measures with the onus being placed firmly upon women (Bell et al., 1999). However, condoms carry a number of symbolic meanings which are a product of the gendered nature of responsibility and 'appropriate' behaviour within sexual relationships. As such they are a potential source of social tension, when a woman's demand for the safety that condom usage represents, constitutes a subversive challenge to male sexual power and the privileging of men's sexual pleasure. Young women's social reputations are fragile and under continual threat by the way that their sexual behaviours are interpreted by others. Condom negotiation or even possession of condoms may

represent a potential threat to that reputation because 'when you carry condoms all the boys think that you want it' (Holland et al., 1996, Hillier et al., 1998).

Targeting of health interventions primarily at women assumes that women are more risk averse than men and that they will therefore adopt protective practices. However, this assumption is not supported by the literature. In adolescent girls, having an internal locus of control for STD acquisition does not correlate with condom usage (Rosenthal et al., 1999). In those who have high levels of self-efficacy (the belief that one has the ability to exert personal control), there is a positive association with sexual risk taking in both casual and regular relationships (Seal et al., 1997). These findings were unexpected. They contradicted the assumption of the authors that if women felt able to exert control, they would necessarily do so in terms of safer sex. In a wider context, they challenge the construction of women as guardians of moral and physical welfare of self and other.

For women, the risk of HIV often pales into insignificance in comparison with pregnancy risk (Gold et al., 1992). Teenagers' concerns are focused primarily upon prevention of pregnancy and condoms are largely considered within the context of contraception (Holland et al., 1996, Garside et al., 2001). Women who rely on condoms for contraceptive purposes are ten times more likely to report consistent use than those who use condoms only for disease prevention (Fleisher et al., 1994) and the use of hormonal contraception results in a marked decrease in condom usage (Cushman et al., 1998).

### **6.11.3 Condoms and relationships**

The context within which sex occurs has a clear impact upon any consideration of infection and associated condom use. Studies consistently report higher levels of condom use with non-regular or casual partners than with regular partners (Lansky et al., 1998, Evans et al., 1997, Forst and Morgan, 1998, Herlitz and Steel, 2000, Anderson et al., 1999). Within relationships there are two aspects that will reduce the likelihood of condom usage. The first of these is the degree of personal commitment to, and emotional investment in that relationship. In a relationship, the perception of self-risk decreases inversely with the level of relationship satisfaction (Hutchinson, 1998). Additionally the likelihood of condom usage is inversely associated with the degree of emotional investment in the relationship. As women are more likely to place greater emotional significance on sex within relationships, it appears that within this context they are less likely to view their partner as a source of infection (Bell et al.,

1999). The second contributory factor is the way in which assessment of infection risk is based on inference from perceptible characteristics. The way a partner looks, speaks or behaves leads someone to think they are not infected (Gold et al., 1992) and subsequent actions are sanitised because they feel that they knew or could trust their partner (Skidmore and Hayter, 2000).

These findings have led some to conclude that condoms have a limited role in a relationship that is marked by familiarity (Bajos and Marquet, 2000). However, whilst they may reflect limited usage of condoms within relationships, this does not equate to a limited role, rather it reflects a role other than that portrayed by the dominant health messages of ever present threat and the need for continual self surveillance. These findings indicate that people commonly base their decisions upon and subsequently justify their actions in terms of alternative and subjectively determined information. The kind of rationalisation which figures in accounts of sex within relationships is also apparent in the negotiation of commercial sex, a situation that arguably constitutes the least emotionally invested and the most evidently high risk. In a study of street prostitutes and their clients, McKeganey and Barnard (1996) report how clients made their choice of which prostitute to approach for commercial sex using the same criteria of cleanliness, of general appearance, clothes and general hygiene.

Within relationships condoms commonly have symbolic significance. Their non-use in this context represents familiarity and trust and may be construed as evidence of commitment in terms of anticipated future monogamy (Flood, 2003, Skidmore and Hayter, 2000). This is clearly portrayed by two circumstances where non-use is an active choice in direct contradiction to the accepted rhetoric. The first of these is the decision not to use condoms in non-discordant HIV couples where the presence of infection and the possibility of onward transmission is acknowledged and accepted (Rhodes and Cusick, 2002). The second is the selective usage patterns among prostitutes. One of the ways in which prostitutes effectively manage to separate their working life from their social life is by a series of rituals, the applying of make-up and the wearing of specific clothes. Within this context the use or non-use of condoms enables her to ritualistically separate sex undertaken as a financial transaction from that which occurs within a relationship (McKeganey and Bernard, 1996).

The availability of testing for STI's and HIV provides a way in which to determine whether or not an infection has been acquired. Whilst it clearly cannot be considered a protective mechanism, it might be expected to be indicative of an increased perception

of risk, albeit after rather than before the event. However, the literature challenges this assumption. In examining the explanations for initiating and undergoing HIV testing among apparently low-risk individuals, Lupton et al (1995a) identified a number of different reasons for which testing was undertaken. Although reasons given were variable, they rarely resulted from a careful assessment of behaviour and perception of risk. Similar findings were reported by a second study that examined the records of a sample of GUM attenders. This study compared the level of risk identified by the patient with that estimated by the health advisor who had conducted the pre test discussion and found considerable discrepancy between the two assessments (Chippindale et al., 1998). What is particularly striking in the reporting of these two studies is the contrast between the conclusions drawn by the authors. In the first of these, adopting a largely sociocultural perspective, Lupton concluded that HIV testing has become a cultural icon that is largely associated with relationships, used either to symbolise responsibility and commitment at the outset of a relationship, or as a means by which to reaffirm bodily integrity at the end of a relationship (Lupton et al., 1995a). In the second study, a biomedical perspective led to the conclusion that patients are 'resistant to regarding their behaviour as risky, while at the same time wanting HIV testing' (Chippindale et al., 1998).

### **6.12 Conclusion**

These accounts collectively represent discursive challenges to the public health orthodoxy of risk. They indicate the complexity of competing interests and considerations, the fluidity of practices that constitute the reality of sexual activity in contrast to the unidimensional and fixed categorisation of risk behaviours conveyed in health messages. Rationalistic risk assessments are rarely the means by which one determines sexual partners and the likelihood of considering oneself at risk of infection within a relationship, however new, appears to be low. Although undoubtedly there are those that do consider themselves and their practices in this way and those that do ascribe to the practices recommended by the public health messages, they represent one position among the diverse set of beliefs and practices that comprise the disparate collection of views and practices of a heterogeneous population. Representations of risk are multilingual. The concomitant communication and comprehension difficulties between those who ascribe to and uphold the tenets of health risk discourse and those to whom they represent and promote them are evident in the literature relating to requests for HIV testing. As an effect of governmentality, this activity is commonly construed as socially responsible. However, social responsibility requires that one does not only do the 'right' thing but also that one does it for the 'right' reasons. One is

expected to request testing for those reasons prescribed within the health risk discourse. Failure to do so attracts corrective and reiterative efforts within which condom usage plays a central role.

## **Chapter 7: The significance of symptoms**

### **7.1 Introduction**

The point of diagnosis forms a pivotal point in the account of an illness episode marking the point of transition from health to ill health with the assignment of a biomedical label. Locker (1981) coins the phrase 'illness career' to identify those meanings and actions that constitute illness and suggests that responses to illness can be viewed as a management sequence. This begins when a problematic experience is encountered and is the outcome of the response to phenomena; their interpretation in medical and lay terms and those social actions that are taken to cope with the events. As accounts begin at or near the point of diagnosis, aspects of life previous to this point are justified for inclusion in the narrative account in terms of their place and significance in relation to it. Some of these may function as cues; symptomological, behavioural and communicative elements that give rise to the suspicion that something may be wrong, that both point to and are explained in the definition of the disorder. Individual cues may be sufficient in themselves to indicate the presence of disorder, or they may contribute to a composite collection of cues that collectively indicate that something is wrong. Alterations in bodily function that had previously passed unremarked assume a greater degree of significance in the process of re-alignment, re-evaluation and retrospective reconstruction enabling the past to be realigned with the present. Symptoms therefore have particular significance in an illness account. They are commonly the means by which an illness becomes manifest. Subsequent to diagnosis and establishment of the cause of the illness, the body changes that constitute symptoms are likely to be re-interpreted in the light of the illness event and to provide the means by which to make sense of that event.

Recognition of altered body function causes the body that was previously in the background of consciousness to come to the foreground. The focus of attention upon the body causes it to become the object of attention moving it out of a state of taken-for-grantedness (Radley, 1997). The interpretation of body changes is predicated upon a concept of the physical self. The identification and assessment of one's own body experiences is an ongoing process that forms a focus for self-reflection. The extent to which that reflection results in labelling of body changes as symptoms is determined by a number of factors. Central to this is the level of underlying knowledge of 'normal' bodily function and the possible significance of changes. Body changes are also interpreted within a specific cultural context which influences the degree of social significance that is attributed to specific changes. If personal and social circumstances

favour the affirmation of normality and a display of good health, then signs of dysfunction may be suppressed or contained, an effect that is apparent even in relation to severe illness, such as chest pain associated with coronary artery disease (Radley, 1997).

If personal experience does not equate with preconceived ideas as to what specific symptoms are indicative of a particular disease, this too may influence the degree of significance attached to them. For example Johnson (1991) describes considerable efforts among those experiencing myocardial infarction to normalise the onset of symptoms, a refusal to consider their symptoms as extraordinary, which was offset by a background of preconceived ideas around the typicality of symptomatic presentation. When symptoms overlay a cyclical bodily process such as menstrual flow, their recognition and acknowledgement may be more problematic as it occurs against a changing background that is commonly disregarded until the time when suspicion of dysfunction brings both normal and abnormal under increased scrutiny. In conditions which affect cyclical body activity, identification of dysfunction is commonly characterised by a 'wait and see' period which involves monitoring and evaluating symptoms against the experience of self and others (Chasse, 1991).

Previous personal experience is also influential. Interpretation of dysfunction occurs within the context of a health biography within which the physical body is itself embraced. A health biography in this sense incorporates not only physical events that have occurred previously, but also those personalised memories and meanings that accompanied such events, the pain, discomfort and anxiety as well as the experiences and treatments that accompanied them. Continuously modified and expanded throughout the lifespan, experience forms a rich source of definitions, a baseline against which to evaluate new and familiar symptoms (Oleson et al., 1990).

## **7.2 The significance of symptoms in chlamydial infection**

The role of symptoms in chlamydial infection is inherently problematic because a large proportion of infection is asymptomatic. When there are symptoms, there may be considerable variability in the way in which they are experienced and described by the individual. Although there are a cluster of recognised body changes that are considered to be symptomatic of chlamydial infection, an individual may experience some or all of these changes. Equally the severity of effect is variable, ranging from mild changes that may be readily dismissed, to those that have considerable bodily impact. This is not unusual; many illnesses vary considerably in their presentation, and

individual bodily symptoms may be suggestive of a number of conditions. The absence of signs or reported symptoms does not indicate that a person is not ill, as symptoms may be unrecognised, denied or unreported (Dingwall, 1976).

The vague and diverse nature of symptoms when they do occur, together with the high probability of them being absent for some or the whole course of infection, contributes to the illness experience. Consequently, symptoms occupy a central position in the interpretation and understanding of illness episodes associated with this infection. The variability in the bodily presentation and interpretation of symptoms provides the framework against which the social, physical and psychological ramifications of this infection are understood. As identifiable landmarks in the course of the illness event, they occupy a pivotal position in the construction of an understanding of the implications of the infection from a retrospective and a prospective perspective. In social terms, the timing of their appearance within a relationship, and the extent to which they are identifiable in one or both partners, impacts upon the construction of transmission routes and therefore has the potential to create moral high ground that may be claimed by one or both partners.

In physical terms, symptoms are evidence of a loss of body control, an indication that body boundaries have been breached and as such represent bodily danger. Psychological implications stem from fear of the causes of those body changes and a subsequent awareness of infection status. In social terms, the visibility of symptoms provides potential for the infection to become visible to others and as such represents social danger. However this visibility also provides a means by which to rid oneself of the infection. Symptoms represent an indication of bodily dysfunction. On a personal level, the types of symptoms, their severity and the timing of their appearance are incorporated into a construction of the effect that the infection has had on the body. In this respect they provide a structure against which to make estimations and assumptions regarding the long term effects that the infection has produced.

The central role that the symptoms of chlamydial infection occupy in Public Health efforts to raise public awareness of this infection, in terms of their absence or presence, further reinforces their significance. All public information, leaflets, posters, radio advertisements, lays particular emphasis on the threat posed by an infection that is commonly characterised by a lack of symptoms. Simultaneously however, the more detailed forms of information, for example information leaflets, do supply a list of

possible symptoms that one may experience, to the extent that they become collectively synonymous with the infection in its symptomatic form.

### **7.3 Identifying cues**

The extent to which symptoms were identified by the participants in this study was highly variable although the lack of any appreciable amount of opportunistic screening, other than in specified circumstances such as patient request or prior to instrumentation of the uterus, produced a situation where the majority of them had experienced some body changes. However, one of the key difficulties that many of the respondents experienced was in establishing that something was wrong, of acknowledging that alteration of bodily function was sufficient to justify categorisation as a cue. This is not uncommon. Locker (1981) identifies how the strategy of 'wait and see' is employed if cues that are identified provide insufficient evidence for location of meaning. In relation to this study, the primary problem was in identifying a cue against the background upon which it was superimposed.

#### **7.3.1 Recognising abnormality**

The fundamental problem with identifying abnormality is recognition and attribution. Difficulties in recognition may be more problematic if the background upon which they are superimposed is variable. There is considerable acceptance of variability in bodily function and the cues that present may be interpreted in contexts other than abnormality, for example as a consequence of alterations in activity, they are absorbed within the construct of normalisation (Locker, 1981). There is considerable capacity to incorporate body signs into an explanation of variability and normality. In terms of bodily discharges such as vaginal secretions and menses, the underlying variability is readily apparent; however the concept of variability and normality may also be extended to encompass transient physical experiences such as pain on intercourse which can be explained in terms of variation in activity and partner. This was evident in the data.

*"I can't remember what they were, I think one of them was abdominal pain during sex, I got that and just assumed that it was, I don't know, I just assumed that it was something that came with sex" (Margaret)*

#### **7.3.2 The individuality of body changes**

The highly individualised and subjective nature of these body changes and experiences is not confined to sexual health. It is fundamental to any bodily experience. However

the private and sensitive nature of these experiences further individualises them because of reticence in discussing sexual issues. A result of the consequent lack of dialogue is that it may be difficult to distinguish normality from abnormality. The sharing of one's body on a physical level that is part of sexual intercourse does not inevitably extend to a sharing of the responses of one's body to that experience. In the context of an activity that is charged with expectation, bodily experiences are likely to remain private. As such, an explanation of normal variability is more probable although subsequent information may result in reassessment as illustrated by Sue.

*"I don't think so. It was painful during sex more. It wasn't painful, it wasn't that I couldn't have sex and it wasn't that it was absolutely excruciating, it was more afterwards. It was a stinging sensation and things and my boyfriend didn't say anything at the time but he had noticed a bit of discharge but he didn't think anything of it, he just thought that it was normal because it was just sort of every now and then. He thought nothing of it, and he said that it was painful for him as well during sex but neither of us said anything, just kept it to yourself, and because I can't imagine turning round to him and saying that hurt that did that time, I can't imagine saying that so..."*

### **7.3.3 Vaginal discharge**

Vaginal discharge is a key component of female cyclical bodily function. As a physiological response to the secretion of reproductive hormones, it heralds the imminent onset of menarche in the adolescent and largely ceases with the arrival of the menopause. As such it is intrinsically associated with female functioning, an integral part of the reproductive capability of woman. As a physiological response to hormonal influences it is not fixed. Subject to influences, it alters in response to hormonal levels that ebb and flow during the cycle. Alternatively it may achieve a degree of imposed stability when contraceptive hormones negate bodily cyclical activity.

Despite commonality of experience between women, vaginal discharge is largely absent from both lay and professional discourses. Its marginalised status derives from two interrelated counts. As a product of the body that has emerged from the body and been sullied by contact with the body, vaginal discharge is dirt (Kubie, 1937). The second problem of vaginal discharge lies in its uncontrollability. It is evidence of a lack of bodily control, of uncontrollable body leakage that leaves a reminder of its unpredictability as a mark on clothing. It therefore necessitates bodily management. In its uncontrollability, it represents a risk to which the symbolic order is permanently exposed (Kristeva, 1982) and it is therefore not a suitable topic of discussion.

## **7.4 Determining abnormality in an uncertain normality**

### **7.4.1 Attempts to determine normality of discharge.**

Vaginal discharge is an essentially individual and personal bodily experience. In bodily terms it serves as a visible reminder of normal female function, however in social terms it is invisible, largely absent from discourse other than in relation to abnormal function. In a society where increasing bodily control and self-constraint (Elias, 1994) and the polite management of human excretions has been fundamental to the civilising process over the course of centuries (Turner, 2003) there is no capacity for the acknowledgement and inclusion of vaginal discharge in social discourse. As such, it remains largely undetermined in its parameters. The reference points as to what constitutes normality are largely individualised because there is no norm against which to compare one's own experience. It may therefore be intrinsically difficult to determine what is normal and what is abnormal because of the lack of capacity and permission to discuss it in the social arena. The problem of determining abnormality against this background of change was encapsulated by Sue.

*"I think people just see it as being, this must be normal, my body's changing and if you're a teenager especially, you think my body's changing, it does something different every day because it does when you're a teenager. It's like your mood, it goes like that..... Yes because it's like a normal change. It's like going into a teenager and having a period. That sounds like something so abnormal, starting to bleed and things. It seems so abnormal so how do you know when you get an odd coloured discharge or something like that, that it's uncommon because if something like that is common and it's normal, how do you know what isn't?" (Sue)*

The nature of discharge is that it evokes a particular type of descriptor, reminiscent of liquidity and flow, adherence and adhesion. It defies simple description and lacks a vocabulary because it is not a 'suitable' topic of discussion. Knowledge of the body is conveyed through language which produces and maintains a collective and shared understanding. Elaboration of the concepts of the body is founded upon the use of an extensive and detailed vocabulary (Dingwall, 1976). For a topic that is outside the realms of social acceptability however, such an elaboration is problematic because there is little or no collective shared understanding of terms and therefore no formal vocabulary that serves as effective descriptors to describe either normal or abnormal discharge. This was evident among those respondents who described discharge. They

struggled to articulate meaning adopting vague and non specific terms such as 'gooey' and 'gungy' and 'weird.' This difficulty of both discussing discharges and of using effective descriptive terminology is illustrated by the words of Tess.

*"It's funny stuff, is it thick, is it thin, what colour is it, does it smell? You don't want to talk about your discharge with other people do you? That is the hardest thing [knowing what is normal]. Like I say, it all comes down to discussing discharges which I suppose is as big a stigma as talking about diseases. Maybe it's the thought of people knowing that you've got a discharge which is perhaps the biggest stigma of all - ohh, you've got funny bits coming out, ooo errr, it's like when you've got a kid with a runny nose - somebody with a runny eye -oooo errr."*

Discussion of vaginal discharges is almost exclusively confined to the sanctioned arena of medicalisation. When alteration is identified, it generates the creation of explanations that attempt to make sense of change, the construction of causal mechanisms (Locker, 1981). In relation to vaginal discharge, the two alternative constructions are of normality or abnormality. If abnormality is suspected there are two possible courses of action; either to do something or to do nothing.

The decision to do nothing is largely based upon an expectation that spontaneous resolution may occur, that the identified alteration is an extension of the boundaries of normality rather than an indication that something is wrong. This is an indication of the 'wait and see' approach that Chasse (1991) and Locker (1981) identify, although the social unacceptability of discussing either the discharge itself or the infection status that it may indicate, restricts opportunity for evaluation against the experience of others. To this end therefore, the most likely approach appears to have been one of waiting for resolution and subsequent initiation of action in the event of non-resolution.

*"Without being tested with swabs and that official things, you don't know that you've got it, probably you've just got a little bit of discharge, you don't think what could this be, you just think, maybe it'll go away, give it a week." (Tess)*

and

*"First it was about a year and a half ago and I didn't think nothing of it, I just thought it was normal like, then it got that this last month or two it's got worse you see so I thought I'd better get it checked out." (Gail)*

To do something is either to self treat on the basis of assumed cause or to initiate medical consultation on the expectation of assessment and investigation. Although construction of explanations for alteration may occur, the lack of public discourse increases the necessity to consult a licensed problem solver (Locker, 1981) although the sensitivity of the topic may delay or preclude consultation. It is within a medicalised context that the right to rule on the normal-abnormal divide is located, the medical gaze privileging knowledge of normal and abnormal and the capacity to search for causes of abnormality that may or may not confirm the previously constructed causal mechanisms. This 'expert' ruling may be considered sufficiently reassuring that the patient feels confident with the judgement even in the absence of investigations.

*"I've always had well, for quite a few years I've always had quite a heavy discharge and at one point I went to the doctors, I think about 2 or 3 years ago and said, and told her and she said oh it's perfectly normal." (Jill)*

However the lack of an established understanding of normality may create continued uncertainty about what is subjectively considered as excessive discharge even when infection has been identified, treated and confirmed as eliminated.

*"No, at the time I thought it was because there was just a lot, it wasn't, it was still whity colour and there was just a lot of it and I've mentioned it to them and they say that I'm alright with that , but I just had another swab took, but I've still got it now, the discharge, so I'm a bit, I know that the tablets can clear it up, but all the same I'm a bit worried about that..... I'm still worried that I think I could still have it." (Jacky)*

#### **7.4.2 Smelly discharge**

Whilst an alteration to the quantity and consistency of discharge may be dismissed and ignored or self managed in the short term, a more significant occurrence is a perception of alteration in its odour. This is likely to be more demanding of attention both because it represents a stronger indicator of abnormality and because it presses itself more urgently on the senses. This increases self consciousness and therefore demands management. If discharges per se are taboo, how much more so are odorous discharges? An abnormal odour is treated with distrust and aversion, signalling either consciously or subconsciously the threat of contamination and is taken to imply dirt (Kubie, 1937). More than anything else, abhorrent smells threaten the social order because they produce a direct threat to the hygienic and fragrant promises that buttress its stability (Corbin, 1986). Whilst there is an ever present threat of

uncontrollability as a result of their seepage and leakage, bodily discharges are largely controllable in terms of their physical appearance. The physical evidence of their existence can be managed and hidden from public view, either by controlling excretion or by using devices to absorb and collect. Odours defy these strategies of control and containment. Their miasmatic qualities defy confinement and impose themselves upon the senses. They are uncontrollable in both emanation and in the responses that they evoke. As such they invoke a profound sense of self consciousness which may well be disproportionate to their olfactory presence. The effect of this is to establish an association between the smell and abnormality, and then to trigger a variety of bodily responses intended to minimise their impact upon self and others, an effect that clearly links the concepts of smell and uncleanness.

*“Erm, I don’t know, the smell more than anything, like if you have a bath and you feel like you haven’t had a bath, it’s not very nice” (Tracy)*

and

*“I just thought it can’t be right really, that smell because I was showering every day and I thought it’s not normal to be smelly like that” (Kate)*

#### **7.4.3 Alteration to menses/ blood flow**

Several of the respondents described alteration to menstrual patterns which formed the basis of concern. Although comparable to vaginal discharge in terms of its uncontrollability, the visibility of blood necessitates more elaborate management strategies. Menstrual bleeding is characterised by intermittency, being confined to a specific part of the cycle with a relatively fixed duration, and is defined in terms of temporality and magnitude. The boundaries of normality and expectation are more defined and delimited in relation to menstruation because bleeding is expected to follow a regularised and relatively predictable pattern with expectations of stopping and starting during the course of the menstrual cycle. Consequently when it occurs outside those expected parameters, either by occurring at other times or for an extended length of time, it may be recognised as abnormal and thereby constitute a cue to action. This was the situation for several of the respondents who determined either that they had experienced an unfamiliar and therefore abnormal extension to the length of their menstrual period, or that the volume of blood flow was uncharacteristically severe.

*“It started off as a normal period but it never really went and then it sort of looked as though it was going and then it just got heavier and then really heavy. (Shirley)*

Although several of the respondents reported that a perception of abnormality in bleeding patterns had resulted in them seeking a medical consultation fairly urgently, they had not inevitably associated the problem with dysfunction and therefore there was variability in the extent to which they considered the abnormal bleeding a symptom of infection either prior or subsequent to diagnosis. However the distinction between normality and abnormality became more problematic when other factors impinged upon it and superimposed other patterns of normality. The effect of this was to produce a blurring of the boundaries from normal to abnormal.

The most common circumstance that produced such merging was the use of hormonal contraception. In these circumstances the definition of normality is rewritten with reference to the contraception. Different contraceptive methods have different effects upon the cycle. In general these produce greater predictability and may therefore increase the rapidity with which deviance is recognised. Thus the combined contraceptive pill produces a bleeding pattern that is both highly regularised and predictable. Similarly the injectable contraceptive Depo Medroxyprogesterone acetate which is available in the generic form of Depo Provera is most commonly associated with absence of bleeding. These methods therefore re-write what constitutes normality in this situation, to the extent that the stability and consistency associated with lack of bleeding was defined as normal by one of the respondents even though it was artificially imposed.

However, whilst the regularisation that accompanies these methods may produce a starker contrast against which abnormality is more readily detectable, this is commonly not the case. Hormonal contraception produces increased facility for the absorption of phenomena within alternative explanations of normality, the concept of normalisation (Locker, 1981). It is within this construction that the determination of cues becomes more problematic.

It is not inevitable that Depo Provera produces amenorrhoea and when it does occur, it is commonly preceded by a period of irregular and erratic bleeding. Similarly the highly predictable bleeding pattern associated with the combined contraceptive pill is not inevitable in all people and with all preparations. For those such as Angela who had experienced altered bleeding as a result of the pill there was a resultant difficulty in establishing possible causes other than the pill.

*"I don't know because the bleeding had happened before but that was to do with the pill, because I've had about 6 different pills and they've given me really bad side effects." (Angela)*

When predictable bleeding does occur with the combined pill, it is as a result of artificially imposed body hormonal levels. It is therefore dependent upon a routine of pill taking such that alteration to that routine provides facility for rationalisation of the alteration in bleeding pattern. In this context, the extent to which irregular bleeding constitutes a cue, indicative of abnormality, rather than a consequence of missed pills is intrinsically problematic.

The effect of hormonal contraception therefore is to alter the boundaries of normality and provide facility for normalisation of those body changes that may otherwise cause concern. By the imposition of a predictable bleeding pattern they may serve to tighten the boundaries of normality. However the inherent and acknowledged variability in producing this effect provides facility for accommodation of alternative explanations of abnormality such that differentiation of normal/abnormal becomes difficult.

### **7.5 The danger of symptoms**

On a bodily level, symptoms simultaneously represent both danger and a means by which to remove oneself from danger. Their danger exists at two levels. Firstly, from a psychosocial perspective, danger resides in the extent to which symptoms represent a loss of bodily control and produce an imperative for bodily control strategies. Their magnitude of effect will largely determine the extent to which they force themselves upon the consciousness and therefore influence the probability and the speed of response that results. The likelihood that they may become visible to others will further contribute to the extent and the rapidity with which they are acted upon. Although bodily control strategies may be adopted, the nature and the unpredictability of the symptoms may be such that they threaten self presentation and increase self consciousness. Thus a change in the smell of a vaginal discharge will be more likely to trigger action than a change in quantity and consistency. Not only is it more likely to be perceived as abnormal, but it is also likely to cause a greater level of self consciousness and necessitate more elaborate body control strategies. For other symptoms, it may be the greater requirement for personal management and the visibility of that management that is problematic. In the case of urinary frequency, the

trigger to action is not necessarily the loss of bodily control that frequency indicates; rather it is the visibility of the action that is taken to accommodate the change.

*“Again it wasn’t so much the burning as the frequency that I was going that was annoying and sometimes embarrassing, with people at work who had set their watches by me going to the loo again – you know, every hour, so that was probably the thing that made me go.” (Tess)*

The second danger lies in the nature of the symptom itself and the extent to which it heralds the possibility of body damage. Thus body changes that are not considered a threat may be tolerated for longer than those that are more commonly associated with disease.

As discussed previously, in a number of cases, the cues to action were non specific and sometimes transient in nature, at times highly obvious but at other times less apparent. This resulted in them being readily disregarded, at least for a period of time. The difficulty here lies in determining the extent to which a cue constitutes a symptom and whether it justifies medical consultation. The decision to seek a medical appointment for what may be perceived as a vague presentation is likely to be affected by a general level of reticence in seeking assistance for a problem that is potentially embarrassing and sensitive, and by experience of a health service that can be difficult to access. As a consequence several respondents utilised other opportunistic events, including those related and unrelated to sexual health matters, to discuss their cues and consult ‘the expert’ either for reassurance or confirmation of their concerns.

*“I do go there for my pills every 6 months and I do ask them usually if they will do a test to see if I am alright and last time I went I were getting a lot of symptoms so I asked them if they’d do me one then they did one.” (Helen)*

and

*“I just started having a burning sensation when I went to the toilet and I’d had a chest infection and I was run down, I wasn’t well at all, I’d just lost my job so I was run down as well and so I went to the doctors with the chest infection and I happened to mention that I’d got a burning sensation, could it be a water infection, as well, because I was so run down.” (Dave)*

## **7.6 Symptoms as a means of regaining control**

From a biomedical perspective, the significance of symptoms lies in their association with abnormality, as indicators of bodily dysfunction. However in relation to an infection that may be present in the body but produce no evidence of its presence, symptoms as visible indicators also provide the means by which the infection can be identified and eliminated. As such, they represent the means by which bodily control can be re-established and regained and they therefore have particular value as the means by which to remove oneself from danger. In an infection that is characterised by a lack of symptoms, the fear of undetected presence is a frightening reality. The appearance of symptoms provides the means by which detection and therefore treatment and elimination can be achieved. It may therefore be viewed as a positive event which serves to modify the degree of shock that is experienced upon diagnosis. Consequently the appearance of symptoms was viewed positively by several of the respondents, as they provided a means by which the infection had made its presence known. Michelle described herself as "*glad*" to have experienced pain because otherwise "*I probably wouldn't have known*" whilst Sarah considered herself as "*lucky that I did have the symptoms.*"

### **7.6.1 Normal infections produce symptoms**

The concept of an asymptomatic infection was difficult for many of the respondents to grasp. Although they were aware that such a situation was possible and indeed probable in many instances, the fundamental question of how it could be there but give no apparent indication of its presence was conceptually problematic. Our lay understanding of infections is most closely associated with those that are most common, for example colds and chest infections. It is the occurrence of symptoms, the sore throat, the runny nose, that serves as a trigger to action and treatment is sought in order to rid oneself of the symptoms. Indeed, in relation to these examples, infection and symptoms are considered synonymous to the extent that discontinuation of treatment commonly accompanies resolution of symptoms with consequent identified therapeutic implications in relation to antibiotic resistance (Twomey, 2000). This viewpoint was well illustrated by Peter who understood the theory but had difficulty with the concept.

*"I would expect if someone had an infection, like a normal infection, I would expect, like a chest infection, they would have the symptoms of it and they would know, but then, with Chlamydia, there's no symptoms and so you just wouldn't know."*

### 7.6.2 The possibility of dormancy

When physical signs are equated with physical presence, there may be a fundamental difficulty in accepting that an infection may be present in the absence of symptoms. Efforts to resolve this conceptual difficulty are further complicated by the possibility of a variable and in some instances extremely lengthy time-span between the assumed time of infection and the appearance of symptoms. Although the point at which infection occurred can only be a matter of speculation, its relevance from a physical and social perspective caused the majority of respondents to speculate on this matter. In social terms, the construction of an understanding that accommodates duration and source of infection has considerable relevance for information management decisions. These will be discussed in chapter ten. From a physical perspective, the relevance of determining the history of an infection lay in the explanations that were constructed to provide a satisfactory answer to the way in which it may have been physically present but effectively invisible, an answer to the question 'where has it gone?' Explanations largely hinged upon the concept of a two stage process, in which a lack of symptoms was associated with the infection having disappeared or having assumed a state of dormancy and inactivity. The appearance of symptoms heralded the reappearance or the activation of the infection.

*"The bleeding started, there was about three months, but where is it because he [her ex partner] told her 2 or 3 days after that he'd got it and there was three months and nothing was happening and we thought, oh, we've missed it, and all of a sudden wooo, it's there." (Luke)*

Such active terms may convey concern in relation to an infection that is known to have the potential for causing structural damage, particularly when they are contrasted with passive terms such as dormancy. However an active and therefore visible infection provides opportunity for discovery and may therefore also be viewed positively as discussed previously. The merit of visibility is not absolutely confined to medical treatment. It is also located within a lay understanding of infection which is founded upon the necessity of ridding the body of the germs which have invaded it and now need to be ejected or flushed out (Helman, 1995, Rogers, 1991). In this context, the revelation of infection by the presentation of symptoms may be understood as a necessary part of that process, a landmark on the road to healing.

*“...I think sometimes you don’t get symptoms with it, I don’t think anyway, but obviously mine did, mine came out of my system sort of thing.” (Kate)*

Even though they were aware of the facts, a few of the respondents found it impossible to accept the possibility that they may have had the infection for a considerable length of time and shown no indication of it. This necessitated the construction of an alternative explanation. The degree of difficulty stemmed from the issue of duration and a fundamental difficulty in accepting that a lengthy asymptomatic period of infection is possible. This was the basis on which Liz determined how long she was likely to have had the infection.

*“But all I can say is, I don’t think it could be for years and years otherwise I think I would have had symptoms before then. I know it can probably be 2 years or so before you get symptoms, but I don’t think it would be years and years old because I would have got symptoms way before then and found out.”*

### **7.6.3 The possibility of a lengthy infection**

Adjusting the length of infectivity to accommodate one’s understanding of an acceptable duration of asymptomatic infection may be unproblematic if there are no significant relationship implications. However in a long term and assumed monogamous relationship this may not be possible. Two respondents were in this position. Yvonne reported having been in her relationship for seven years producing two children during that time, whilst Dave had been with his partner for eleven years. For Yvonne, infection was detected subsequent to severe symptoms, probably indicative of pelvic inflammatory disease. She appeared able to accept the idea that the infection *“can lie dormant for quite a few years”* an explanation that was reinforced by the supply of supplementary evidence, the indication that both her children may have been infected during delivery.

*“When the doctor told me, both my children had had conjunctivitis when they were born and she told me it was caused from me having Chlamydia, but she said they won’t have picked up on it the doctors, they don’t automatically do swabs and things for that, so obviously I’ve had it for quite a while.” (Yvonne)*

For Dave there was no supplementary evidence. When symptomatic presentation resulted in diagnosis, he searched for an explanation. In relationship terms, he had two

options. The first option was to assume that the infection had been in the relationship from the outset and therefore that he and/or his partner had been infected for eleven years. The second option was to consider that one of them may have introduced the infection into the relationship at some later point as a consequence of a concurrent relationship. His rejection of both explanations necessitated the search for an alternative explanation. Drawing upon alternative information sources in order to construct a solution that was acceptable to him, the result was a possible explanation founded upon theories of contagion.

*"But, saying that, where it's come from, I haven't got a clue. So I did a bit of research on the internet and I found out what it was, where you get it from, lots of different reasons and some can't be explained. They don't entirely know exactly where it comes from, they don't know if some strains can be airborne with, what was it, an international research centre in America, you know if someone coughs or spits, if it's, you don't know if it's going to be airborne or not, so it was from that that I wondered what, you know, you start to question where it's come from...I can't see us having it for 10 or 11 years, one of us would have shown signs somewhere in 11 years I would have thought so it's we must have picked it up somewhere else, we can't have had it that long. I'm trying to narrow it down, I don't know whether, I don't know if you can pick it up from water. I'm sure I must have picked it up from water, I must have done if I was the one. I'm not saying that I was the one that picked it up, but if it was me that picked it up, I must have picked it up from water. Where my partner's picked it up from if she's picked it up during 11 years then I don't know."*

Sexually transmitted diseases have long been associated with theories of contagion. At the beginning of the 20<sup>th</sup> century many physicians subscribed to the view that the most innocent behaviour could lead to infection. Public drinking fountains, eating utensils, door handles, towels, and bed linen were all considered possible points of transmission with consequent impact on public hygiene activity and advice. These beliefs were subsequently reflected in the anxieties that were generated by the emergence of the HIV virus at the end of the 20<sup>th</sup> century (Brandt, 1987, Altman, 1986). Such beliefs may be considered to reduce the associated stigma. Separating the infection from the exclusivity of sexual transmission detaches it from moral judgements about behaviour and culpability. However it simultaneously represents danger to all from the uncontrollable and miasmatic effect. If it is socially transmitted, no one is safe. Social contact and social activity represent an ever present threat as a potential source

of contagion (Brandt, 1987). The social implications of such an explanation are apparent in Dave's inevitable conclusions.

*"But you can't get too complacent, because then it makes me think well, you can't if you don't show symptoms, then like any of my close friends could have it and they not know, so better not get too close if you know what I mean to people like, because they might not know that they've got it."*

### **7.7 Determining the severity of infection**

In an infection which is associated with potentially serious sequelae, the inevitable questions that accompany diagnosis concern the probability of resultant damage and the extent to which it may have occurred. This was clearly apparent in the data. Almost all the respondents expressed concerns about this issue and for some it appeared to be a cause of considerable anxiety. Although there are a number of recognised complications of chlamydial infection which affect several body systems, with a single exception, only one complication figured in the accounts; that of tubal infertility that is considered to occur as a consequence of fallopian tube damage.

#### **7.7.1 The question of fertility**

In the female accounts, these concerns centred almost exclusively round female fertility. In the male accounts, the possible impact of infection upon fertility was mentioned by several of the men although none of them dwelt on the topic or discussed it in anything other than in a very fleeting way. The majority of their comments related to female infertility, primarily in relation to literature or verbal accounts that identified this as a possibility as Robert explained.

*"I'd read up that it could cause infertility, but mainly in women"*

Two of the men made reference to the possibility of male infertility. Andrew described himself as being 'a bit worried' while Tom expressed relief that he had experienced symptoms in terms of the possible consequences that may have resulted from undetected infection. However in none of the male accounts, whether they alluded to male or female infertility, did the discussion extend beyond a passing comment. This suggests that infertility was not a topic that produced significant concern and anxiety among the male respondents. This was in marked contrast to the female accounts. The impact of infection upon their subsequent ability to conceive and become pregnant was a matter of considerable concern for a number of the women. It commonly formed

a significant part of the discussion, for those who did or did not have children and for those who had considered that they did not want children as well as those who appeared to be considering pregnancy in the foreseeable future.

Interesting exceptions to the female perspective were the accounts of Margaret and Sue, both of whom were in the third trimester of pregnancy at the time of interview. They did not dwell upon the possibility of infertility and did not appear to have any anxieties in this respect. Instead their thoughts and concerns centred on the possible effects of infection upon the health of their baby both now and at the time of delivery. Their concern was to ensure that the infection was eliminated in order to prevent transmission of infection to the baby at the time of delivery. This is perhaps not surprising. They had no reason to question the possible impact of the infection upon their fertility because their pregnancy represented current proof of their assured fertility. Their current status was one of a fertile woman and any consideration of the consequences of infection was in terms of this.

It is perhaps not surprising that female infertility was the one sequelae mentioned repeatedly in the data. The dominant social and cultural expectation in Western culture is of women as mothers. Women have traditionally been viewed as reproducers, regardless of their intention or ability to fulfil that function (Shildrik, 1997) and it is in these terms that their existence has been justified (Morrell, 1994). Their bodies have been socially constructed in terms of reproductive capability and function, viewed as production units in the commodified production of children (Martin, 1987). In a society where infertility represents a flawed social identity (Whiteford and Gonzalez, 1995), an infection that has the propensity to damage reproductive capability represents a threat to their identity as a woman and mother.

This is also the position that is reflected in the health promotional literature that identifies infertility as the primary or the sole consequence of infection in posters and information cards where messages are designed to be concise and memorable. This is clearly portrayed in the example presented previously (section 3.9.4). This postcard, which clearly targets women by the picture, has a caption that reads "Chlamydia is a sexually transmitted infection that often doesn't have noticeable symptoms and can make you infertile."

This tendency to make health messages accessible by simplifying complex arguments has been criticised in terms of the way that it obscures the inherent uncertainties of the

situation (Duncan et al., 2001). In relation to this example, the choice of such a slogan incites a sense of fear and anxiety in relation to the fragility of this most central aspect of female identity. Whilst the value of alerting individuals to this information is not contested, it is the way in which it is represented as the sole consequence that is disputed. Mass media information, such as the postcard previously referred to, were evidently produced for and intended to be widely distributed to young people. Through the use of the animation and text they portray one message only and exclude others. The female character and the lack of a male equivalent effectively identify this as a gender specific infection with gender specific complications. The focus is solely on fertility with a consequent lack of reference to other possible female complications such as chronic pelvic pain that have implications for long term health. An exclusive focus on female infertility reflects the predominant social norms but also serves to reinforce women's primary function as reproducers. Since the nineteenth century, public health strategies have represented woman as guardian of the family's health and emphasised her responsibility in regulating and monitoring all aspects of health for all other family members, a role which she in turn has internalised to a considerable degree (Lupton, 1995). A focus on the precariousness of her fertility in relation to this infection also serves to expand the temporality of her guardianship by focussing on the moral obligation of women to safeguard fecundity. It is perhaps not surprising that there was such disproportionate difference in the extent to which this was viewed as a significant issue by the men and the women in this data.

### **7.7.2 The pathophysiology of Chlamydia**

There is data available to describe the statistical relationship between chlamydial infection, pelvic inflammatory disease (PID) and tubal infertility. However its interpretation is fraught with difficulties for a number of methodological reasons. Many of the studies are small scale and there are inherent difficulties in establishing cause-effect relationships when the primary infection is commonly asymptomatic. There are also difficulties in determining the occurrence of PID which is a clinical diagnosis associated with a low diagnostic sensitivity and a significant proportion of silent infection (Simms and Stephenson, 2000). Notwithstanding these reservations, PID is calculated to occur subsequent to chlamydial infection in 10-40% of cases of infection (Stamm et al., 1984) with a range of genetic, immunological and bacterial virulence factors implicated in the causal pathway (Cohen and Brunham, 1999). Screening for and treating chlamydial infection has been shown to reduce the incidence of PID although the associated duration of infection was unknown in the study that reports this (Scholes et al., 1996). The time interval involved in the development of PID is largely

unknown; however some evidence indicates that it may be very short in some cases. Studies with mice demonstrated that PID can develop within 5 days of primary infection, whilst a failure to receive treatment within 3 days of the onset of lower abdominal pain may result in a threefold increase in the risk of PID and infertility (Hillis et al., 1993). Equally, estimations of infertility are difficult to establish as they only become an issue in those who elect to attempt to conceive. However the results of a large study involving 2501 women indicated that those with a history of PID were 14 times more likely to have tubal infertility than women with no evidence or history of PID (Westrom, 1994).

### **7.7.3 Concerns about infertility**

Several of the respondents assumed that the relationship between infection and infertility was inevitable, and on discovering that they had chlamydial infection, assumed therefore that they were infertile. As Julie described, the impact of infection produced a rapid transition from a feeling of invulnerability to one of assuming inevitable consequences, from *"it's not going to happen to me"* to *"it really worried me, not being able to have children."*

This is not an unreasonable assumption, given that the link between the two has been portrayed so forcibly in the public information surrounding this infection. The realisation that this infection can be and indeed is something that happens to you transports the person from the safety of being uninfected to the danger of being infected. As a result, they move from being detached from the health information messages to identifying with them. In the process the term 'can cause infertility' is interpreted as 'does cause infertility.'

It was therefore a matter of some relief to discover that the linkage was not assured, although the fundamental question 'has it caused damage to me' remained unanswered. This raised two issues for the individual. Firstly there was an imperative to consider the cause and effect relationship between infection and infertility and determine the extent of personal risk. The second and related requirement was to manage the uncertainty that resulted from this situation.

The link between infection and infertility has been established in pathological and epidemiological terms as outlined previously. However a considerable number of unknowns remain and it is therefore an area fraught with uncertainty. In the literature, the linkage between infection and infertility is made but in a non quantifiable way. The

central concept portrayed in the literature is that of risk as a probability, the likelihood of adverse effects as a consequence of a specific event (Lupton, 1999), in this instance infection. As with all risk appraisals, any calculation can only be made on an aggregate basis and transformation of this information to the level of the individual is difficult (Lauritzen and Sachs, 2001). There are fundamental difficulties in attempting to translate the findings of scientific data drawn from study populations to their consequences on an individualistic basis. Risk is the property of the epidemiological population from which it is derived rather than the property of any individual within that population. However this does not preclude the inevitable question that any individual will ask, and the issue of greatest personal relevance to them, namely the extent to which the data relates to them. In other words, what is the likelihood that they will be infertile as a consequence of an episode of infection? Epidemiological and pathological data cannot be translated to provide definitive answers to the question asked by Isobel and echoed by the majority of the other women.

*"Is my insides totally clear now or is it a little bit damaged, could it affect me having a child later?"*

However it does not stop them from asking the question, and in the absence of definitive answers from medical 'experts', they are compelled to use information available to them from a variety of sources to draw their own conclusions and make their own interpretations.

### **7.8 Uncertainty**

The term uncertainty is used in different settings and different contexts such that Atkinson has described it as a linguistic wastebasket (Atkinson, 1995). Penrod proposes that uncertainty is a perceived inability to assign probabilities to outcomes (Penrod, 2001). Echoing the voices of the respondents in this study, what is the probability that this episode of infection has resulted in damage to my fallopian tubes to the extent that it will prevent me from conceiving? Uncertainty is recognised as a central component of any illness experience (Babrow and Kline, 2000) where a number of components including unpredictability, and lack of information are considered to underlie the process (McCormick, 2002). The rise in surveillance medicine, of technologies that detect disease at progressively earlier stages and present probabilities of disease development, together with advances in disease management that extends the illness career of those with chronic disease, have collectively contributed to an increase in the amount of uncertainty and a consequent focus on its

impact (Howell et al., 2003, Brashers, 2001, Hedestig et al., 2003). Diagnostic or screening tests are presented as the means by which to enable a rationalistic approach to diagnostic information. In this respect, they are conceptualised as a means by which to gain control, to be able to do something in the face of the threat that potential or actual disease presents (Lupton, 1995).

Bradac distinguishes between the theoretical frameworks of uncertainty reduction and uncertainty management (Bradac, 2001). He proposes that rationality is the standard to which we are expected to aspire. This is based on the three scientific criteria of the mechanistic paradigm which continue to dominate thinking in society and provide the promise of uncertainty reduction. Deterministic causation is established through the 'crucial experiment' and produces objective knowledge that exists independently of the beliefs, attitudes or values of the observer. This provides us with the second criterion, the objective/subjective dichotomy. It is an approach that is apparent in medical science where disease processes are considered to be understandable with certainty, determined by a single or by multiple causes. The third criterion is the definitive test, the means by which to establish this cause-effect relationship. The knowledge generated through this means is considered to be objective, fully independent of the subjects involved, both patient and doctor (Bursztajn et al., 1990). Technological advances in medical science are increasingly defined and driven by the biological determinism that characterises the "power-charged discourse of molecular biology" (Rose, 2000 p 74). As such they serve to reinforce societal expectations that if we look hard enough and for long enough, the cause of disease processes can be discovered, that the answers and solutions for all medical problems can be found. They produce the epidemiological conceptualisation of risk which describes objective, depersonalised and quantitative cause-effect relationships (Lupton, 1995).

Mature and responsible behaviour is considered to be based upon actively seeking information and acting upon it (Katz Rothman, 1994). Information and the degree of personal control that it affords is commonly cited as the means by which to reduce uncertainty (Deane and Degner, 1998, Lemaire, 2004, Eisinger et al., 1999). These beliefs support the ideology of uncertainty reduction by the supply of information. However, although uncertainty reduction is a desirable outcome for some people in some situations, it is not the only valid approach and the assurance of definitive information that biomedical science promises is rarely forthcoming. The portrayal of diagnostic information as objectively derived and used does not reflect reality and the

information that is presented is rarely applicable in an individualistic and unambiguous way.

### **7.8.1 Uncertainty management**

Bradac presents the concept of uncertainty management as an alternative approach which diverges from this biomedical construction. Whilst it encompasses uncertainty reduction as one possible outcome, it also embraces the two other outcomes of uncertainty increase and uncertainty maintenance as both legitimate and acceptable (Bradac, 2001). It is increasingly recognised as a valid response, particularly in relation to chronic illness (Crigger, 1996) and in conditions where treatment or cure is not an option. Uncertainty in these situations provides opportunity for hope and optimism (Brashers, 2001), a form of resistance to the threat of our created narrative of the self (Rose, 2000). Information in this context is a tool to manipulate uncertainty in a desired direction, both in the context within which it is presented and that within which it is interpreted. The probability-evaluation complexes that are commonly derived from statistical analysis and epidemiological data are complex, difficult to both convey and interpret. In understanding the implications for health of a specific diagnosis, both quantifiers and evaluative adjectives are variously used which may either reinforce or contradict one another (Brashers, 2001). Thus a poor prognosis in statistical terms may be balanced by a verbal example that presents the exception to the rule (Bradac, 2001).

A recognised strategy in the management of uncertainty is the use of information that is drawn from a variety of sources, both professionally defined and lay knowledges which appear sometimes distinct and separate whilst at other times interwoven and multi-layered (Miller, 1998). The interpretations that result are emergent. Influenced by prior interpretations, other events and consequences, they may produce one set of meanings initially only to be reworked subsequently (Riessman, 1989). Some sources will be favoured over and above others because they either concur with or contradict current beliefs and may subsequently be rejected in the light of subsequent information. In estimations of effect and outcome, the way in which some information influences personal health outcomes is evident. For example, the prioritisation of acute and severe health problems in hospital care is a recognised approach to health care delivery and is evidenced by target setting in referral times for suspected cancer (DH, 2000). Waiting times for hospital appointments may therefore be interpreted as an indication of disease severity. In a population of those diagnosed with type 2 diabetes mellitus, the time interval between referral and hospital appointment was interpreted by

the patients in order to substantiate their expectations of severe or mild disease (Parry et al., 2004).

An alternative marker is the experience of those who have gone through or are going through a similar series of events. In a detailed analysis, Roth (1963) charted how the collective experiences of those hospitalised as a consequence of tuberculosis contribute to an illness career where certain events are expected to occur at certain times. In this group situation, there is consensus agreement as to what events will occur and when. The collective experience of those who have trod the path before contribute to the creation of signposts or reference points along the way which enable progress to be measured (Roth, 1963). In this way it forms a framework against which to measure and chart one's own progress and outcomes which Roth proposes contributes to uncertainty reduction. However self evaluation against the experiences of others may not be desirable, particularly in diseases with poor prognoses when the desire is to be the exception rather than the norm (Bradac, 2001). An additional difficulty with this approach is the representative nature of the information upon which one draws in making comparisons and constructing careers and outcomes. The hospital setting for Roth's study provided a number of people who collectively represented the spectrum of disease thus enabling the establishment of parameters and norms. In a community setting where people and their individual experiences are widely dispersed, the sources against which one can monitor one's disease are limited to a small number of acquaintances in comparable situations or to those that are portrayed through the media. When the social construction of a disease such as chlamydia largely negates information sharing, there is a consequent over reliance on media portrayals.

### **7.9 Uncertainty of outcome in chlamydial infection**

In relation to chlamydial infection, one key aspect of uncertainty centres upon the question of whether tubal damage has occurred and the consequent long term effects. However this is an area where there is much uncertainty, where the association of infection and infertility is based upon estimations of probability and biomedical science is unable to provide the definitive answers that the women seek. These difficulties however do not preclude an individual from making these estimations of association using self selected markers, of constructing attributions of causality. This was evident in the data, where the dominant approach to the rationalisation of the likely long term effects was the construction of causal relationships using the markers of longevity and severity.

### 7.9.1 Sources of information

In constructing their own interpretation of the causal relationship, the women drew upon two key information sources. The first of these was the professional information. In written form this is exemplified by health promotional materials which establish a link between infection and infertility in a vague and non quantified way. The second was lay information acquired either through personal communication or through the media. In the main this is characterised by case studies of those who discover they are infertile as a result of chlamydial infection that they contracted some time previously. It is this second source of information that largely formed the basis of such estimations in those who did draw upon identifiable information sources. When infection is diagnosed the commonality of experience brings them to mind. The underlying anxieties whether they be longevity, severity or probability are reflected in the report of these accounts.

*"On the tele, this woman said that she'd been trying for kids and wasn't able to have any and the doctor had asked her if she'd had chlamydia before and she said no and then when they did tests on her they found out that it [had affected her]. Previously she had had chlamydia and it had gone away on its own and that's what had stopped her from having kids. So I was worrying if anything, if you know how long I've had it for because I didn't really know if it had done anything to me insides, anything like that."*  
(Liz)

and

*"I've read these awful ads, in one of my magazines that I read, and this lady, she got pains in her stomach, she thought she was pregnant and she was only 15 and she'd actually got chlamydia and now she's had a hysterectomy, she can't have kids and she's 15 years old"* (Jodie)

and

*"Erm, more than 75% of women that get chlamydia can't have babies.....*

*It was in a book in the library, I went and had a read and erm, I thought I'd best go and have a look up and went to the library."* (Kelly)

These accounts exist in a relative vacuum of social discourse as a result of the social connotations of the infection. Consequently few people will know of others who have had the infection and subsequently conceived without difficulty. It is the personal and emotive nature of these accounts that makes them so powerful and memorable, all the more so because they are largely unchallenged. When there are additional perceived similarities between self and the subject of the account these serve to further

strengthen the conviction that the infection has caused long term damage which appears to be unshaken despite professional challenge.

*"I am worried because my neighbour next door, she can't have any children anymore and the reason for that is that she's had chlamydia as well, and when she had her first baby, her little lad, she went down to 6 stone and she went to the hospital and they tested her and she had chlamydia and I've lost quite a lot of weight rapidly, it's just dropped and I've asked the nurses and they said that it's got [nothing to do with it]. Chlamydia doesn't really have anything to do with your weight but it's funny how she lost quite a bit of weight and so have I and we've both had the same disease." (31)*

The two assumed causes of tubal damage were the duration of infection and the severity of symptoms. Both concepts were utilised independently of one another and in conjunction with one another. In both respects there was an underlying assumption of a direct proportional relationship between cause and effect. This proposes therefore that the more severe the symptoms, the greater the probability of damage having occurred. Similarly the longer the infection was estimated to have been present, the greater the probability of tubal damage.

The question however remains; what duration of infectivity and what degree of severity were considered to result in the production of damage? What constituted the knowledge base upon which these estimations were made? Although there was an implied objectivity in this causal relationship, the absence of any empirical data necessitated the objectification of subjective information, assessments and interpretations. In a small number of cases the basis of assessment was not evident; it was presented as simply commonsense that an infection that was estimated to have only been present for a few weeks was unlikely to cause damage. In most cases however, it was evident that assessments were made against the benchmark of information available to them. The direct reference to lay sources of information made by several of the respondents positioned this information as the empirical and objective standard against which they interpreted their own experience.

### **7.9.2 Determining the duration of infection**

Two basic assumptions were evident in the explanations that considered the duration of infection. The first was an association between the appearance of symptoms and the duration of infection. A number of the respondents referred to the possibility that someone could have the infection for a considerable length of time and be unaware of

the fact, often until they attempted to become pregnant. A range of information sources were quoted to support such explanations including television chat shows, magazine articles, health professional accounts and the experiences of friends and acquaintances. The end result of these accounts was detection by some means or another. The implication of this is that infection will eventually become manifest.

If there is an underlying assumption that infection will eventually become manifest at some time or another, whilst it was accepted that an asymptomatic stage was a characteristic of this infection, there was an expectation that at some point symptoms would occur. Implicit in this was an expectation that they would appear after a certain, but largely unspecified, period of time which may be of considerable duration. Consequently if they were considered to have appeared sooner than expected, measured against this benchmark, they were viewed positively.

*"I think before, I don't know if it was because I caught it so soon, before and this one has been, I've had it for a few months and that's why it's doing what it's doing, I really don't know, because I know when I've read leaflets that it says women can carry it for years without having any symptoms at all, well for a long time anyway, but I know that I hadn't had it that long and so I really didn't expect to get the symptoms as soon as I'd got them, I mean I'm glad that I had because I, now I've found out that I've got it but ...." (Jane)*

and

*"In the past 11 months sort of thing [estimated duration of infection], but it can go undetected for years can't it, I have caught it relatively quickly compared to some people." (Jodie)*

The benefit of symptoms occurring in this respect is to enable treatment thereby shortening the duration of infection and the consequent implications. However whilst this is a positive effect, it does not necessarily result in an assumption that symptomatic presentation will always occur in time to enable treatment prior to the occurrence of damage as Robert observed, reflecting upon his girlfriends' possible situation.

*"It might not flare up for 5 years and it's too late then, before you know."*

Therefore whilst the appearance of symptoms, particularly if they occur within what is perceived to be a short time subsequent to infection, are viewed positively, they do not result inevitably in complacency as to the probability of having escaped tubal damage.

### **7.9.3 Duration as an indication of damage**

The second assumption was that the longer the infection had been present, the greater the probability that it may have caused damage. Although there is no data to support this claim and indeed, ethical considerations would preclude the possibility of gathering such data, this would seem a reasonable assumption on two counts. Firstly if damage occurs at an indeterminate point in the infection process, the greater the duration of infection, the greater the opportunity for damage to have occurred. Secondly, if damage is assumed to occur as an ongoing process and to accumulate on an incremental basis, a longer duration of infection will result in a larger amount of damage having occurred. Although this would seem at first glance to be a reasonable assumption, it does not address the question as to how long an infection has to be present in order to cause damage such that it affects fertility. In contemplating how long it takes for damage to occur, the working principle adopted by those who assumed that they had escaped damage was that the length of time that it takes is greater than the time that they estimated that they had been infected, whether this was weeks, months or years. This was the basis upon which Shirley made her estimation of risk and upon which Robert, who was in a stable relationship, considered the possible effect of damage to his girlfriend.

*"I just assume that because I could only have had it for a few weeks sort of thing that it can't really have done much damage but I don't know, whether these things can do much damage in a couple of weeks, I just assume that it didn't." (Shirley)*

and

*"I'd read up that it could cause infertility, but mainly in women, and I thought it was more high risk, do you know what I mean, a more high risk of being infertile over a short period of time, but it does actually take some time doesn't it? I found that out as well." (Robert)*

### **7.9.4 Severity as an indication of damage**

The range of symptoms experienced and attributed to the infection was very variable, ranging from those who reported a total absence of symptoms through to those who required hospitalisation as a result of severe abdominal pains. For several of the respondents, severity of symptoms was taken as an indicator of the extent of damage. However such linkage was not evident in relation to all symptoms. Whilst other symptoms, particularly bleeding and a malodorous vaginal discharge may have been judged to be significant enough to merit graphic description and prompt health seeking behaviour, they were not associated with long term tubal damage. Their significance

lay in their role as indicators of the presence of infection. For Isobel the appearance of symptoms indicated a lack of severity because they had enabled diagnosis.

*"And it's obviously a case of you've had some form of symptoms and so it can't be that bad but you just don't know." (Isobel)*

Similarly their absence was identified as sinister and a cause of concern precisely because of the consequent lack of facility for detection that they afforded.

*"The fact that there's no symptoms puts you off thinking that it can do any damage, to not know that you've got it and the effects that it can have on you, it's pretty frightening really when you think about it. Because I like came here three years ago, there's no saying that I couldn't, because they say it can do damage all the time, but how much time does it take to do damage, you see you don't know that, and then you think how long could I have had it before we found it so you don't really know if everything is still O.K do you?" (Judy)*

In this respect therefore, an asymptomatic infection may well be a greater cause of anxiety than one that produces symptoms.

The linkage with severity was confined to one specific symptom, namely the level of pain experienced, which was interpreted either as a direct indication of damage or as an indication of duration of infection which was in turn associated with damage. For Liz the level of pain equated directly to concerns of infertility.

*"That [infertility] did worry me especially like with the pain that I was having."*

Jane made the same linkage although as this was the second episode of infection, she had opportunity to compare experiences. Subsequent to her first episode, which was asymptomatic, she became pregnant thereby confirming tubal patency. On this basis the pain associated with her second episode of infection was a matter of particular concern.

*"I know from the time before when I had it that it didn't leave me infertile because I did get pregnant, I mean I had to have an abortion so I was alright then, but this time because of the severe pains that I've had in my tubes, it worries me more this time than it did last time."*

Julie who did not know how long she had been infected but had experienced severe symptoms, sufficient to merit hospitalisation, assumed a threefold linkage. Firstly she linked severity and longevity on the basis of her own experience

*“Obviously if I was in that much pain it could probably have been there for a while... the pain that I’ve had, is that because I’ve had it a long time?”*

Secondly she constructed a link between longevity and infertility on the basis of anecdotal information.

*“It really worried me, not being able to have children, it really did ..... because my mum said, oh, this woman’s been on the telly, she’s had it for 12 years and she can’t have children.”*

These factors contribute to the way that a retrospective assessment of the infection is used to form an expectation of damage. In this respect it is the basis of explanation in two oppositional constructions. For those who considered that they had had a long or severe infection it formed the basis of anxieties surrounding infertility whilst for those who considered themselves to have had a short or mild infection it was used as a means of relieving anxiety.

#### **7.9.5 Catching it in time**

A number of the respondents equated the value of diagnosis with the opportunity to receive treatment and eliminate the infection. Several described this as ‘catching it in time,’ the implication being that the treatment and cure served as a safeguard against tubal damage. The infection has been found sooner rather than later. Sooner equated to early and by this means was taken to imply soon enough to diminish the probability of consequences. Whilst it was used in conjunction with considerations of duration, in effect this was a prospective view of the situation as opposed to the retrospective measures of duration and severity. In so far as this viewpoint was a product of diagnosis and treatment it was the one most closely associated with and resulting from the health consultation. Treatment represented the means by which to protect oneself from damage in contrast to those case studies portrayed in the media, the women who had not been afforded this opportunity with the apparently inevitable consequences of not being treated.

*"I'm glad that I'm getting it treated and not to leave it because if not I would be infertile ... in time to come if I ever want children if I don't have it treated I'll not be able to have any." (Kate)*

A perspective that focuses on the potential damage that has been prevented as a result of treatment rather than on the unquantifiable and unalterable damage that may have occurred previously represents positive action. In relation to the body problem of control, it represents a means by which to reclaim control, to re-establish the predictability of a body-self that was threatened by the presence of infection (Frank, 1995).

#### **7.9.6 The professional perspective**

The health consultation within which the infection is managed provides essential opportunities for information and emotional support of those who have been emotionally traumatised by the experience of the infection. A patient who is anxious about the effect of infection on their future fertility is highly likely to seek information regarding these longer term concerns. Requests for information represent a response to uncertainty. The health professionals afford a means by which to acquire such information, either directly in their capacity as a safe and expert source of knowledge or indirectly as an access route to information that becomes available through diagnostic testing.

In a mechanistic paradigm of medicine in which diagnostic testing is the link between cause and effect, the prospect of definitive tests that could provide unequivocal information presented a tantalising proposition for several of the respondents.

*"I did ask them when I came last time, I said is there anything that can, any way that you know [that I can become pregnant], and they said no, you can't test for it can you?" (Michelle)*

However in this situation there are no technological procedures available to provide such information, no tests that can unequivocally resolve the uncertain issue of fertility. The only way in which someone can definitively determine that they are fertile is by becoming pregnant. This leaves medical opinion as the only source of information on this matter, an opinion which occupies a largely unquestioned position of dominance by drawing upon both common sense and technical explanatory models (Oakley, 1984).

### **7.9.7 Communication of risk**

The communication of risk on an individual basis is a common aspect of medical practice, however it is intrinsically problematic. A discussion of percentage probabilities that relates to a group of people has little relevance for the individual who wants to know specifically about their own life chances. People are generally considered to apply a bimodal model of risk in which they see themselves as either high or low risk which bears little relevance to the mathematical models used by doctors (Misselbrook and Armstrong, 2002). In communicating risk, it is proposed that strategies are employed that under-communicate messages of potential risk and attempt to individualise test results (Lauritzen and Sachs, 2001). However limited risk communication can produce serious negative outcomes as was evident in the Bristol enquiry (Iliffe and Manthorpe, 2002) and it is therefore important to communicate the facts as far as they are known. The challenge is to provide understandable information that has personal relevance and that reflects the probable health effect in a comprehensible form. There is evidence to suggest that patients prefer probability information in the form of words not numbers and it is recommended that both forms are used together to improve clarity of meaning (Ohnishi et al., 2002) although it is recognised that the concepts and language of risk are commonly imprecise (Iliffe and Manthorpe, 2002).

Whilst the way that information is presented is highly relevant in this respect, arguably the way that it is received is of greater concern. The specific terminology and approach used by the health professionals are important however patient's beliefs which are often indeterminate influence the interpretation of the health messages and the way that they are assimilated into the wider understanding of the infection. It is the 'take home message' that they glean from that consultation, and the extent to which it either reinforces or extends their own interpretation of the situation which is of particular relevance in this respect.

The respondents reported a health professional viewpoint that largely mirrored their own although with an emphasis on the importance of treating and eliminating infection. In answer to the central question 'am I infertile?' all the respondents reported a non committal response that neither confirmed nor rejected the possibility. The question of fertility and conception was one for the future, to be answered at some later indefinite time.

*"She told me just to forget about it for now because what worried me the most was when later on, if I want to have children and that's the one thing that's really worrying me, but she said just to forget about it and when the time comes and you want to try, she said you'll just have to keep trying, that's what worried me the most."* (Jacky)

In several accounts, the way that the health professionals' viewpoints were recounted suggests that they largely concurred with the observations of Lauritzen and Sachs (2001) with an emphasis that was optimistic, suggestive of a favourable outcome. However this was not necessarily construed as reassuring in the absence of definitive information as Liz indicated.

*"I just said, I said to her that I'd heard it could stop you having children and she said oh that's only if it's gone on for a very long time but I didn't know how long I'd had it for or anything."*

The health message may also fulfil a secondary role by focusing on the importance of ensuring that the infection is eliminated. This has particular significance when there is a two stage infection management policy, when diagnosis in a primary care setting results in an individual being required to attend a specialist facility in order to be treated. An emphasis on the prospective benefit of treatment suggests its use as a motivational factor in attempts to ensure attendance at a GUM clinic which carries negative connotations for many. In this context the presentation of an optimistic assessment is conditional, contingent upon full and effective treatment.

*"They kept saying oh, we picked it up really early and you should be alright and as long as you go to the hospital at such and such a time, it'll all be alright and it should all have gone and there should be no problem."* (Marion)

Although it may not adequately address the anxieties and concerns of the respondents, optimism is arguably the most pragmatic approach in this situation. In reality it is no more possible for a health professional than for a patient to be sure that damage has not occurred. However, statistical data indicates that although a significant number of people do have tubal infertility subsequent to chlamydial infection, this is not the majority experience. Only a fraction of those with chlamydial infection will develop PID and a proportion of those will go on to experience tubal infertility (Cohen and Brunham, 1999). Therefore, whilst it is not possible to make a statement about someone's ability to conceive subsequent to chlamydial infection, the majority experience is that they will

not have problems and a statement that reflects this is likely to be correct for the majority of patients. Equally it is not possible to know the fecundity of any patient in the absence of chlamydial infection although the majority experience again is the ability to conceive. In an arena fraught by uncertainty and in the absence of any definitive information, patients interpret health messages as cautiously optimistic, an approach that in all probability reflects their own viewpoint. However if there are unanswered questions, such as the duration of a particular infection episode, that the professional judgement does not appear to take into account, the extent to which the professional opinion is considered reassuring is questionable.

#### **7.9.8 Responding to the possibility of damage**

It has been suggested in the literature that a fear of tubal damage will prompt women to test their fertility and in effect resolve the uncertainty by attempting to conceive (France et al., 2001). However the basis on which the claim is made is largely unsubstantiated in so far as it refers to a single account that lacks context. A second concern voiced in medical circles is that those who have had Chlamydia will assume that they are infertile and therefore see no necessity for contraception (personal communication). This data does not support either claim. Several of the respondents discussed in some detail their contraceptive intentions subsequent to infection, particularly with respect to condoms as discussed in chapter ten. Similarly none of the respondents reported any intention to try and conceive, with the exception of Angela, who reported harbouring such thoughts for a short and transient period of time.

*“A couple of weeks ago we thought, shall we have a baby in case I’m infertile and when I found out that I wasn’t pregnant I thought I might be infertile, I might be infertile, then we thought that we were being a bit silly so it was a good job that I wasn’t pregnant after all that.”*

A common approach to the management of uncertainty was to distance oneself in temporal terms from the problem. In so far as pregnancy was a matter for the future, so too were the potential problems associated with it. It is not known whether anxieties that were apparent in the immediate period surrounding infection persist or whether they reoccur when attempts to conceive are unsuccessful. Equally it is a matter of conjecture as to whether infection episodes that occurred years previously would influence family planning decisions including requests for infertility investigations at an early stage in the process of attempting to conceive. However as Jane identified, it

may well be that this will become a matter of concern at the time of attempted conception.

*"I know if I think we'll try for a baby, I know roughly when and if I don't get caught then I think first month I'll panic and second month I'll panic even more and the third month I don't know what I'll do."*

For the majority of the respondents, pregnancy was very much in the future. The most common approach to the uncertainty, as summarised by Jill was to wait and see, to deal with the matter as and when it occurred.

*"I suppose the major thing was, you know, I hope I don't become sterile, but again, as I've said I'm not going to know for another 10 years and so it's a waste of energy to worry about stuff like that now."*

#### **7.9.9 The promise of technology**

A few of the respondents who reflected on this issue envisaged that a solution to their potential problem lay in the New Reproductive Technologies (NRT's). The promise that this offers has resulted in increased numbers of women seeking specialist fertility care even though the absolute proportion of the population affected by infertility appears to have remained relatively constant for the past century (Evers, 2002). The proliferation of NRTs represents a medical industrialised approach to the problem of infertility where new techniques reconstruct an unachievable pregnancy as a not yet achieved pregnancy. Although this belies the reality that for many is beset by unattainability, enormous personal cost and frequent failure, the image of endless possibilities is portrayed in the media which reinforces the authority of biomedicine (Whiteford and Gonzalez, 1995). It is unsurprising therefore, that respondents identified NRT as the means by which to resolve the problem. The degree of reliance that is invested in technological advances of medical science is a common feature of other conditions where medical cures are elusive. For example, the cure for Cystic Fibrosis that was promised 20 years ago when genes and molecular mechanisms were elucidated has not materialised. However those living with the condition continue to place their hope in the possibility of a cure (Gjendal et al., 2003). Similarly pre-implantation diagnosis and selective implantation is presented as the means by which

to bypass genetically carried conditions (Egozcue et al., 2000). This reliance on technology was apparent in the data, in some instances reflecting a naïve faith in current processes whilst others, particularly Angela, did acknowledge the limitations of current technology.

*"In the future if I want to have kids, I would hope that technology has progressed and that things like infertility treatment would be better hopefully"*

NRT offers a means by which to fulfil the social desire to have a child, a way in which to bypass infertility (Shildrik, 1997). Reproduction in these terms is a technological process, produced and sanctioned by the authoritative knowledge of biomedicine. NRT's offer a degree of control over those life choices and cultural expectations that are threatened by a susceptible and potentially damaged body. If technology cannot provide definitive answers at present to the central question of fertility, it does promise a resolution to the uncertainty that chlamydial infection creates by bypassing the problem of infertility.

### **7.10 Conclusion**

Symptoms acquire a considerable degree of significance in both physical and social terms in an infection that is predominantly asymptomatic. However, the often vague and non specific nature of symptoms associated with chlamydial infection and the capacity to absorb alterations in body signs into explanations of normal variability can make it difficult for individuals to determine whether or not there is something wrong. This becomes even more problematic when reticence in discussing intimate body function reduces shared understanding of normality and when the background variability is altered by imposed medical control of the body and its reproductive functions.

Symptoms represent a source of danger, however within the context of a largely asymptomatic infection they also represent the means by which to protect oneself from danger. They may therefore be considered in a positive sense in so far as they provide the means by which the infection becomes apparent. When symptoms do occur, they are used as the means by which to determine the duration of infection. To consider that the two events may have occurred at separate times with a considerable period of time between them is conceptually difficult. The concept of dormancy is one way in

which to resolve this apparent anomaly, however other explanations including that of contagion may also be recruited in order to make physical and social sense of personal experiences.

Women understand the possible long term implications of chlamydial infection solely in terms of its effect on fertility. This concurs with the focus of attention in the health promotion literature which both reflects and reinforces a view of women who are defined in terms of their reproductive capabilities. Women manage the resultant uncertainty regarding their fertility status by drawing on a range of physical indicators and social comparisons. These provide benchmarks against which they estimate the likelihood of tubal damage. Their assessments of severity and duration of infection are particularly significant in this respect. Pain is commonly taken as an indication of both severity and duration and is therefore viewed as considerably more sinister than other symptoms. Health professionals similarly use the same indicators as a means by which to reassure women that damage has not occurred. However their emphasis in this context is located within medical management and serves to try and ensure compliance with treatment regimes and attendance at specialist service facilities.

These techniques of uncertainty management appear to be effective in reducing the anxieties associated with infertility that occur around the time of infection. However their effectiveness may well be challenged when circumstances change and women attempt to conceive. There is little evidence to support the notion that women try to conceive after infection in order to test their fertility. However it remains to be seen what the impact of previous infection will be in women when they attempt to conceive, the extent to which they will interpret delays in conception as an inability to conceive and the readiness with which they seek to access the promises of assisted reproductive technologies.

## **Chapter 8: The embodiment of infection**

### **8.1 Introduction**

Sontag suggests 'that it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped.' (Sontag, 1991 p. 3). In the same way it is scarcely possible to acquire an STI without also acquiring, albeit temporarily, the social constructions that have surrounded it for centuries. The cultural significance that is attributed to certain illnesses and disorders marks them out from the host of other disorders and in this respect STI's have come to occupy a position that is separate and distinct from almost all others. The moral significance which has come to be associated with these infections over the course of history has written a discourse that presents them as disreputable and immoral and their presence is taken to be indicative of breaching the moral code. Perpetuation of these attitudes occurs because they are formulated within the shared social construction of such infections, and it is through the continued shared understanding and conveyance of ideas and understandings that they continue to proliferate.

### **8.2 The otherness of STI's**

Sexually transmitted infections are located in otherness. They are associated in the public consciousness with people and behaviours that are outside the moral code and who therefore represent a threat to the social order. Whilst such a viewpoint may seem to reside in the historical legacy of such an infection and therefore have little currency in the present time, the data indicates that it is far from redundant. Whilst many individuals may not subscribe to such a position, nevertheless it is apparent that it remains a prevalent societal view, resistant to the passage of time and the impact of public health efforts. Certain kinds of behaviours continue to be considered to predispose to infection and these behaviours are particularly associated with certain kinds of people.

STI's are categorised as being associated with specific people and behaviours. This type of general categorisation on the basis of physical appearance, where presentation is taken to indicate moral character, is commonly used as the basis of speculation as to who may be infected (Stanley, 1999, Duncan et al., 2001a) and the type of person who frequents genitourinary clinics (Scoular et al., 2001). This locates them elsewhere; in behaviours other than those associated with oneself and in those judged by appearance to be different and inferior to oneself. It is on this basis that physical appearance forms a key element upon which concepts of safety from infection are

based (Skidmore and Hayter, 2000, Gold et al., 1992). Whilst it has been proposed that the basis of such a rationale, particularly in relation to HIV, is the length of incubation and the absence of physical indications of infection, I would suggest that the explanation is more fundamental. If infections are associated with those who are dirty and scruffy, it follows that those who are clean and smart cannot be infected.

### **8.3 Bodily discomfort**

To discover that you have contracted an infection that 'shouldn't have happened to me' presents a direct challenge to a theoretical perception that STI's are something that other people get. To come face to face with the reality that you have an infection is problematic because it does not correspond with the perception of self and those things that should and do happen to self. For many this was experienced and expressed as a strong sense of contamination and a challenge to their sense of self as Paula and Steve so vividly described.

*"I felt dirty, I felt dirty, I just felt really dirty and that it shouldn't have happened to me"*  
(Paula)

and

*"I thought I was dirty, I thought, I can't be dirty"* (Steve)

This general sense of bodily discomfort was a very common response, reflected in the accounts of the majority of the respondents. Although it was often a relatively transient feeling, the strength of response and the sense of discomfort was commonly profound. A number of the respondents described such feelings in conjunction with expressions of upset and distress and several of them were reduced to tears on discovering the diagnosis. Some linked the concept of dirtiness to that of pathogenicity, the thought that they had a disease. This may have been expressed in vague terms, the discomfort of knowing that there was something there.

*"You feel a bit dirty at the time don't you, you think that you've got something"* (Mike)

and

*"I think people think it's disgusting that you've caught something, I think people find it repulsive"* (Kelly)

In other cases it was specifically their realisation of the presence of disease or infection in their own body which was identified as producing such a response.

*"I think it's most because it's a disease, you feel sort of dirty with being diseased"*  
(Andrew)

and

*"That's what I'm trying to get at, picking something up, people think it's dirty don't they"*  
(Steve).

This feeling persisted even in the face of logic and reason that recognised the non-specific and non-discriminatory nature of such an infection.

*"I know that bacteria is not picky who it goes to but it just makes you feel so dirty."*  
(Zoe)

For most of the respondents however it was simply an internalised feeling that was difficult to express in any more specific terms. When asked where it came from, most were not able to clarify the issue in any way or to articulate the source of discomfort that had been evoked. For them, it was a distinct and identifiable feeling of bodily discomfort that simply escaped further elucidation. Although their feelings were difficult to articulate in any more specific terms, they were nevertheless highly significant, particularly as their first responses to the infection. It affected the way that they felt about themselves and it affected the interpersonal relationships with others that surrounded the infection, either health professionals involved in diagnosing and treating the infection, or those people to whom they felt an obligation or a desire to disclose the diagnosis.

*"I just feel so dirty is the only word I can use to describe it. I just feel unclean and not nice, I don't know and I don't know where it comes from"* (Jenny)

and

*"Because it were a sexually transmitted disease, I don't know how, it doesn't bother me now, but at the time I were like, Oh my God, it just makes you feel euurghhh!"*  
(Michelle)

#### **8.4 A spoiled identity**

The association of disease and dirt is understandable given that our current thinking of dirt is tightly associated with the existence of micro organisms and pathogenicity, with ideas of hygiene and aesthetics. Since the discovery that microorganisms caused disease at the end of the nineteenth century, personal hygiene has increasingly become a focus of public and private activities to control disease. However the term

dirty precedes and far exceeds this narrow and rather recent interpretation and this is also apparent in the way that the respondents verbalised their feelings. The majority of diseases are not presented as being dirty even though they may be considered to result from 'dirty conditions', for example to suffer from a gastrointestinal condition arising from poor food handling techniques would not generally be considered to be dirty. Even though the feeling of dirtiness may have been described in terms of pathogenicity, it was specific to the type of infection and the means of transmission, a distinction that Michelle made in identifying the difference between infection types.

*"Because its sexually transmitted I think, if it had been a water infection or like, I don't know, it's just the stigma, that's what it is, people think you're dirty or something, if you know what I mean." (Michelle)*

It is the nature of the infection and the means of transmission, rather than the pathogenic element of it, that justifies the attachment of the label. It is not the bacteria but the moral categorisation of the disease which is important in this respect reflecting Douglas' theorisation of contravention of the state of ordered relations (Douglas, 1966).

The underlying concepts are firstly a breaching of the physical and social boundaries, realised through the diagnosis of infection, and secondly the associated internalisation of dirtiness. Feeling dirty and the bodily discomfort that results therefore represents an internalisation of the prevalent sociocultural view of STI's in which the infection is a demonstration of breaking the pollution rules. It is by implication an indication of transgressing the moral order and much of the discomfort that results is associated with attaching meaning and significance to the resultant social situation in relation to one's own behaviour and that of others who are implicated. It reflects a sense of discordance between one's virtual and actual identity, the discrepancy between seeing STI's as something that happen to other people and the reality that they can and do happen to self.

#### **8.4.1 The shock of the diagnosis**

One of the consequences of locating STI's in otherness is the impact that diagnosis of the infection in self produces. For the majority of the respondents in this study, the diagnosis of chlamydial infection was unexpected and unanticipated despite the fact that many, although not all, had known that one of the primary purposes of the testing to which they had submitted themselves was the detection of sexually transmitted

diseases. This discrepancy is a recognised phenomenon. The largest study of its kind, the Department of Health funded study of chlamydia testing undertaken between 1999-2000, indicated that the majority of those interviewed in the qualitative component of the study expressed shock and distress at their result (DH, 2001c). The authors of that study highlighted a paradox in the discrepancy between acceptance of a test and the apparent lack of understanding of the consequences of a positive test result. Such a conclusion suggests that when people submit themselves to medical investigations for a specific condition, they do so in anticipation or expectation that such a condition will be identified.

#### **8.4.2 The purpose of testing**

This is an oversimplification of the situation. People consent to testing and even request testing for a range of other reasons. In routine testing instigated by the health service as in the case of cervical screening, many women conform to the programme largely as a result of normalcy and correctness, because it is the expected thing to do (Bush, 2000), founded upon a sense of responsibility and obligation to self and others (Howson, 1999). Even in relation to patient requested testing, for example in the case of HIV antibody tests, the justification for such a request relates to a variety of reasons, the majority of which are largely symbolic, associated with the commencement or closure of relationships, in conjunction with discontinuation of condom use in a developing relationship, or as a demonstration of personal responsibility (Lupton et al., 1995a).

In a climate of increased public and personal awareness of infection, fuelled by media campaigns, there is an increased sense of personal vulnerability which may be further heightened if acquaintances are known to be infected. Within this context, testing provides a means by which to re-establish control in the face of danger. However, whilst testing is viewed as the 'rational' thing to do, it is done in the expectation of a negative result with little anticipation of the unthinkable, namely a positive result (Lupton et al., 1995b, Lupton et al., 1995a). On this basis, it suggests that for many, the purpose of a chlamydia test is to provide the security of demonstrating that the infection is not there, not to prove that it is.

For the majority of respondents in this study, it was the presence of symptoms which provided the impetus to health seeking behaviour. This suggests that there might be a heightened awareness of the possibility of infection. However this situation did little to counter the feelings of shock which stemmed from facing up to the knowledge that one

had an infection. Thus whilst it may have been considered a possibility in an abstract sense, to be faced with a positive diagnosis remained unexpected. In part this was based upon the use of the test for ontological security and the consequent anticipation of a negative result.

*"I'd been tested last week, didn't expect to find anything ....as I say, I was hoping that they were going to be all clear." (Jodie)*

Even when it was the presence of symptoms that led to the request for testing, there was little indication that a clear link had been made between the symptoms and infection, the hope was that they were due to something else.

*"It was still a bit of a shock, I was sort of hoping that I didn't have anything." (Carol)*

In part this may have been due to the vague nature of symptoms, when they seemed to be a deviation from normal rather than something highly untoward and sinister. As a result they were not evaluated as the type of symptoms associated with infection.

*"It's just a normal [discharge], there's just a lot of it. It's not, I wouldn't say it had an odour, not a bad one, there's just a lot of it and I weren't used to it. There was no pain or anything, I was really shocked when I found out." (Gail)*

The primary reason however, for the degree of shock that many respondents experienced, emanated from a discrepancy between preconceptions of the types of behaviours and people associated with STI's, and the perception of self and one's own behaviour and relationship status. The reactions that occurred were the result of coming face to face with the reality that they had this infection. If STI's are clearly located in other people and other behaviours, then there is a fundamental difficulty in accepting that you can become infected yourself. The categorisation system established and maintained to ensure the proper ordering of things in which STI's are clearly other has been challenged. The sense of personal vulnerability, promoted through increased public awareness, for which testing is supposed to produce a counter-offensive in the form of a negative result, is instead confirmed through those means that were intended to refute it. As a consequence, they were confronted by the discrepancy between their virtual identity as someone who does not get STI's and their actual identity as someone who has an STI. The reality provides a direct challenge to

one's classification system forcing a reappraisal of the situation and a re-evaluation (Strauss, 1959).

### **8.5 The comparison of behaviours**

A common response to the disruption of the categories was to examine one's own behaviour and to compare it with those behaviours that were considered to constitute other, as a means by which to make some sense of the situation. Such a comparison is founded upon the assumption that there are behaviours that are strongly associated with STI's. These are evident in descriptions of specific behaviours and of general categories that are taken to imply such behaviours. Whilst the shock of diagnosis and the feelings of bodily discomfort that result were common to both males and females in this sample, it is significant that the comparison of behaviours and the social categorization of those types of people who may be associated with STI's were confined solely to the females in the sample. This then constitutes a gender specific aspect of the infection experience that is traceable back to the historical associations of venereal disease.

As a source of contamination, an STI represents pollution. The role of pollution rules is to reinforce the internal structure and maintain the stability of society by buttressing the moral code (Douglas, 1966). Moral codes by nature are general and their application to a specific situation is often obscure and contradictory. Pollution rules by contrast are unequivocal, they are clear cut and the effect of breaking the rules is evident in the consequences that result.

#### **8.5.1 Social expectations**

The social structure of Western and fundamentally Christian society is founded upon the family unit maintained through the institution of marriage, an organisational structure which was socially constructed as a means by which to channel and constrain sexual activities in order to maintain social stability (Turner, 1996). Social tolerance of sexual relationships outside of this became increasingly suppressed over time (Elias, 1994). Whilst there may have been some relaxation of social views in recent times which are reflected in demographic trends in marriage and divorce rates, the two fundamental principles of monogamy and fidelity continue to form the basis upon which the legislative and political rulings of our society are founded, and as such continue to be socially constructed as the moral code of sexual behaviour.

Individually owned attitudes towards sexual relationships both reinforce and are reflective of wider social values. Data from the National Sexual Attitudes and Lifestyles survey (NATSAL), the largest study of this kind to be conducted in Britain, quantitatively demonstrated that these two elements continue to underpin both practice and attitudes. Trends in sexual behaviour over the past few decades indicate a decreasing age of first intercourse and an increased number of lifetime sexual partners. However, despite a common pattern of multiple partnerships in those aged 16-24, the dominant context within which this occurs is of serial monogamy (Johnson et al., 1994). This is further reflected in attitudes to extra-marital sex and other non-exclusive sexual relationships. In this NATSAL study of nearly 19,000 people aged 16-59 years, whilst pre-marital sex was generally viewed with leniency, this attitude was not extended to other extra-marital sexual practices. The majority of people (78.9% of men and 84.3% of women) considered that extramarital sex was always or mostly wrong, an attitude that was largely extended to sex outside a live-in relationship. Over half the men and more than two thirds of the women in the sample similarly considered sexual relations outside a regular relationship as always or mostly wrong, although it is not clear what constituted a regular relationship in this context. As the authors of the study conclude, these findings, which did not contain age related trends, clearly indicate that the majority view, across all age groups, is that monogamy is the correct form of behaviour (Johnson et al., 1994).

### **8.5.2 Breaching the moral code**

Behaviours that have come to be associated with the risk of infection are multiple and concurrent sexual relationships. To some extent, these are born out by epidemiological data and therefore they remain the dominant identifiers of infection risk in health surveillance strategies (DH, 1998, LaMontagne et al., 2004). Whilst there may be scientific justification for such an approach, its effect is to reinforce the perception of STI's as pollution, whereby their presence provides an unequivocal indication that the moral code has been breached. Indeed the term venereal disease connotes metaphorical meanings of immorality, evil and infidelity (Brandt, 1987) and although the name has been replaced, the connotations that stem from synonymous association of the two remains.

This moral code as any other is vague and ambiguous at times. Whilst the primary concepts of fidelity and monogamy may appear clear cut, their interpretation is at times poorly defined, conditional on circumstances and intent and subject to debate as to what constitutes right and wrong. Thus a person will not necessarily view their own

concurrent relationship as a breach of fidelity, for example if there is a lack of emotional investment associated with it, or if it occurs with a previous partner. Alternatively if there is a very temporary break up within a relationship, this may create a brief window such that any sexual consequences that occur in that time will not necessarily be construed as infidelity. The cases of Sheila and Anne who both described themselves as in stable relationships at the time that the described incidents took place illustrate the inherent ambiguities that exist.

*"I'd slept with an ex-partner, one of those silly things that you do. (Sheila)*

and

*"My partner and I had a massive row, split up for a day and a half, I slept with someone on the rebound." (Anne)*

Whilst the moral code appears to be implicitly considered in terms of monogamy and fidelity, its outworking demonstrates that it is not specifically confined to this definition. It is extended to encompass those social standards implicit in the construction of deviant categories and classifications which are then ascribed to those who are considered to have breached the code. In many of the accounts STI's as proof of pollution were described as synonymous with 'slappers', with 'promiscuous behaviours', 'tarting around' and 'those who were scruffy.' Similarly, expressions of feeling dirty were extended to considering and subsequently rejecting the possibility that one was 'a dirty cow.' These were the categories that provided a source of comparison with self perceptions of type and behaviour.

### **8.5.3 The gendered construction of the moral code**

These category groups and their comparisons with self were gender specific. Behaviours such as multiple partners and concurrent sexual relationships, that were considered to be associated with these infections, were attributed to both men and women by male and female respondents. However the labels that were used to categorise people who engaged in such behaviours, the slappers and those who were promiscuous, were specifically confined to women and applied to them by both men and women alike.

Lees (1993) identifies how widely used and pervasively abusive terms such as 'slag' and 'slut' have a shared understanding of meaning which primarily relates to the accusation of 'sleeping around' although they may be used in general terms to describe appearance and behaviour which in reality may bear little relation to actual

behaviour. These terms are gendered in so far as they have no male equivalent; derogatory terms for boys are milder because they do not refer to social identity. They function as a continual threat to a girl's moral reputation about which she has to be ever mindful and therefore position girls in a state of continual vulnerability, in terms of what they do but also who they associate with.

These terms are unique as deviant categories in so far as they are never accepted by the recipient themselves or applied to their social circle (Lees, 1993). Similarly promiscuity is a term in common usage, but it is itself a subjective and pejorative label applied to the behaviour of others and has little personal meaning. Whilst being promiscuous is perceived as a risk behaviour in relation to STI's and specifically HIV, few young people associated such behaviour with themselves or anticipated participating in such activity (Breakwell, 1996). The existence of such categories are always applied to others, the shifts invariably being socially downwards and therefore mixing with those whose reputation is suspect represents a potential source of contamination (Lees, 1993). They are therefore 'dirty categories' located in otherness and it is on this basis that they form a suitable reservoir within which to locate STI's and from which to distance oneself.

*"I knew about them, but I don't put myself in that group, do you know what I mean, like you put them in a group, like people that get diseases. At that age I weren't in that group. I didn't consider myself that type of person, I thought you had to be tarting about all the time to get owt like that." (Judy)*

and

*Because they looked scruffy, I just thought they had to have something, I know its awful but you do, you think they must have something, the slappers don't you, but it's not all slappers that get Chlamydia is it?" (Zoe)*

#### **8.5.4 Individualised comparisons of behaviour**

Comparisons of behaviour also occurred on a more individualistic basis, drawing examples from one's own previous behaviour or that of friends and acquaintances. In these situations, it is notable that behaviours were cited as the point of comparison in contrast to the social categories described previously. In the same way as one does not categorise self as a 'slag' or 'slapper', equally one cannot consider one's friends in these categories because of the inherent difficulty in conceiving oneself as associating with such people and the possibility of contamination that it presents to one's own reputation.

Whilst short term relationships and frequent partner change may be associated with likelihood of infection in general terms, in practice the exact number of partnerships considered in this way were imprecise; however comparisons were made. The predominant feeling prior to diagnosis was one of safety and invulnerability. Their current behaviour was not associated with the acquisition of STI's, whatever the length of the present relationship or the number of recent partners. Rather, it was this current behaviour that served as the benchmark against which other behaviours were assessed, either the behaviour of other people, or their own past behaviour if this was not a first infection.

To be faced with the prospect of a second infection provided opportunity for an evaluation of current behaviour against past behaviour. This was the basis of Jane's reasoning in explaining the circumstances by which she became infected on the first and the second occasion.

*"I think I was shocked more this time because there was only 2 people that it could of possibly have come from or from that time period. From December, I've only slept with 2 people."*

Her explanation of the current situation suggests that she did not consider her recent behaviour as being the sort of behaviour that could result in infection, an evaluation that was made in comparison with her behaviour on the previous occasion, within the context of her changing attitudes and values that had occurred in the interim.

*"I had it [chlamydial infection] 3 or 4 years ago, I went on holiday and I was a bit stupid and didn't use anything ..... since I've had my daughter I've changed a lot with partners and things, like before when I was younger I suppose I was a bit of a wild one, when I was younger."*

The passage of time and the change in circumstance that had occurred enabled a reflective account of previous behaviours. These provided a rational explanation for how she came to have an infection using the benchmark of current behaviour. Within such an assessment, STI's are associated with a specific behaviour of unprotected intercourse with casual holiday acquaintances and a general behaviour of having multiple partners. In comparison, two partners in recent months was considered safe and responsible behaviour and was therefore not associated with the risk of an STI.

This understanding provided an explanation of how she came to have an infection previously, without compromising her concept of who and how one gets STI's. However it also preserves the sense of invulnerability in terms of current behaviour. Consequently, the diagnosis of infection on this second occasion produced intense emotion.

*When I got outside [from the doctors surgery] I was just that shocked I just burst into tears*

An alternative form of comparison was the measuring of one's own sexual behaviour against the presumed behaviour patterns of others, either in a largely theoretical sense where the other is a general term applied to unspecified people, or in a more personal sense where comparisons are drawn against the behaviour of friends and acquaintances. If the accepted rhetoric is that those people who have multiple partners are the ones who get STI's, then it leads to the expectation that friends and acquaintances who are perceived to lead a more sexually free lifestyle than oneself, generally considered by the scrutinor as more promiscuous or less careful with contraception, are the ones who should be getting the infection rather than oneself.

If this is not seen to be the case, the result may be a degree of anger and resentment, a general feeling that one's own behaviour does not merit the infection.

*"I was quite mad, I thought out of all the people, why has it got to be me?" (Marion)*  
and

*"It does make me angry. People sort of sleep around and apparently not get anything and I feel as I am [careful] and I get this, because we've always been brought up, you know not to do things like that so yes, I'm angry" (Alison)*

and

*"I know it's mean, but I think of all my friends who've been with loads of men and they're fine and it annoys me and I think I got caught out and had a baby, get a infection, and I just think they've been with loads and they're just fine and it really annoys me but, yeah, it seems unfair." (Jean)*

These comparisons were significant in that they indicated the sense of invulnerability that existed prior to the diagnosis of infection. They were also significant in the way that they were exclusively confined to the female accounts. Women's moral character rests upon their sexual reputation in a way that is not mirrored in men (Lees, 1993).

The implicit consequences of this upon their social identity created a degree of vulnerability that was singularly absent from the male accounts. The effect was a perceived necessity in the women to justify their sexual behaviour by comparing it with others. It was this comparison that provided the contrast and enabled them to feel that the infection was something that their behaviour did not merit, thus enabling the preservation of a vulnerable and damaged identity. Whilst the men did express similar feelings of dirtiness, they did so as an internalised feeling of discomfort. Because they were not vulnerable to the social connotations of reprobation and derogatory labelling, they did not demonstrate the same imperative for justification of behaviour that was so evident in the female accounts.

## **8.6 Considering the possibility of infection**

### **8.6.1 The invulnerability of self**

In considering the possibility of an STI, there is a strong sense of invulnerability, a feeling that it cannot happen to me. Attempts to understand the basis of such an attitude are variously used to develop health interventions which are aimed at increasing the adherence to protective behaviours. This sense of invulnerability also contributes to the explanations offered when such interventions do not work. Young adults appear to have unrealistic optimism about the avoidance of health problems, expressed as an expectation that their own chances of experiencing harm were less than those of their peers. This attitude seems most pronounced in relation to those health problems that are seen to be controllable and is proposed to be based predominantly upon an exaggerated confidence in one's own ability to protect self (Weinstein, 1982). Whilst exposure to infection has been most closely associated with those who are vulnerable and unable to negotiate their contraceptive needs (Hillard et al., 1993, Thomson and Holland, 1994, Hutchinson, 1998), sexual risk taking in casual relationships has been shown to be directly and positively associated with sexual self-efficacy, defined as the belief that one has the ability to exert personal control (Seal et al., 1997). Conversely rather than feeling that they have the ability to protect themselves, Moore & Rosenthal (1993) suggest that this sense of invulnerability is based upon a non personalisation of risk resulting from "a kind of cognitive egocentrism, or belief that one is special, unique and invulnerable to the risks and hazards that befall other people" (Moore and Rosenthal, 1993 p. 129). This viewpoint, which centred on self and lacked any cognitive perception of risk, was reflected in the data as illustrated by Jean.

*"You think it's not going to happen to you but it does." (Jean)*

The basis of this viewpoint however, rather than resulting from a sense of uniqueness, appeared to be founded upon a fundamental inability to conceive of oneself in such a situation.

*"But you don't go around thinking it'll never happen to me, it just never even pops into your head. You don't think it'll ever happen to me because the whole idea doesn't even enter your head it'll never happen to me because the whole idea, you can't comprehend the fact that you could catch something" (Margaret)*

and

*"I don't think I even thought about them [STI's] at that age, I didn't think about them at all" (Helen)*

and

*"No, it didn't cross my mind, the only thing that crossed my mind was getting pregnant which I went on the pill for, I didn't even think of infection." (Laura)*

To suggest that this represents a non personalisation of risk is to suggest that risk is considered in some way and then rejected on the basis that it is not relevant, either because of one's ability to protect oneself or because of a special kind of immunity. This appears to overstate the association between self and risk. It also fails to acknowledge the relational component which is central to sexual activity.

### **8.6.2 The assessment of others**

One of the ways in which people feel able to protect themselves is by determining the type of person with whom they have sex. The assessment they make is egocentric, using knowledge of self as the yardstick against which others are judged, and the framework within which the biographies of others are interpreted (Skidmore and Hayter, 2000). Thus assessments are made on the basis of physical appearance or previous knowledge of the individual and then used as justification of non condom use, even in populations with a high prevalence of HIV and in sex with street based prostitutes (MacPhail and Campbell, 2001, Ramos et al., 1995, Gold et al., 1992, McKeganey and Bernard, 1996). Additionally the concept of trust and commitment to the relationship is presented as justification, although it may be that its primary purpose is to sanitise risk, as the time taken for development of trust can be extremely short (Skidmore and Hayter, 2000) and has been shown to occur within the context of what

might be considered the high risk activity of commercial sex (McKeganey and Bernard, 1996).

In the data, the assessment of risk within a relationship was presented retrospectively as the explanation for perceived protection from infection. It formed the basis on which decisions to discontinue condom usage were justified, because protection of self from one's partner was not considered necessary. As in the previously cited studies, the respondents in this study also cited physical appearance and previous knowledge of the person as the justification for their decisions.

*"I haven't in the past because you never think it's going to happen. I think everyone does to be honest, you think they look alright and that's it basically, you think I'll not get owt, but this just goes to prove that you can." (Michelle)*

and

*"I've been on the pill anyway and I knew him before, we were like friends before we started like having a relationship together and we've got engaged and so it's like a permanent thing, so I didn't use any other sort of contraception." (Sarah)*

For Isobel, who described herself as coming from a middle class background, appearance was extended to include social class. Describing herself as previously assiduous in protecting herself, she explained her recent lack of protection.

*"I thought no, he won't have anything, the type of background he's come from and everything. I thought no, he'll be, he's switched on, he knows what's what... a lot of lads that I've been with, they've got their own house, they've been, well, 2 of them have been married before and have kids or whatever... I don't know and when you get to speak to those, those lads, you get on really well and then you go back to their house which is council estate or the house looks a right tip or they just can't afford to go out this weekend."*

### **8.6.3 Assessment of the relationship**

The element of trust was also provided as an explanation, commonly described in terms of a developing relationship, in which perception of safety was based upon anticipated fidelity and commitment to the relationship.

*"We'd been together for quite a while, we wanted to stay together because we were getting on really well and living together. I was on the pill and I thought I knew, I thought I knew him." (Jacky)*

and

*"This boyfriend I was with, we'd been together for 2 years you see, we did use condoms at first, but then when you get really close and that and then you don't use them" (Helen)*

and

*"it's just when you stop, when you've been with someone quite a while you just think oh, you know, and they are a bit, when you start feeling close to somebody and loving somebody, you don't want that [the condom], because there is a difference isn't there." (Jane)*

In this situation any sense of vulnerability that may have been present at the outset of the relationship appeared to diminish rapidly as a consequence of the emotional investment, even though the length of time over which such a change took place may have been very short.

If confounding factors such as alcohol or a lack of supplies resulted in a discontinuation of condom usage, it was unlikely that usage would be re-established.

*"No, to be honest no, we were both drunk and I didn't really think about it. I've talked to some of my friends about it, you look at them and you think oh, they look all right and I think that's what I thought. You shouldn't really think like that but when you're drunk you think anything don't you?" (Jean)*

and

*"Well, the guy I was seeing, I was seeing him for 6 months. We did [use condoms] for a short, we did for quite a while, to start with and the, we just, I don't know we just went out drinking and things happened and one thing leads to another and you just forget and we just forgot." (Gail)*

#### **8.6.4 Insiders and outsiders**

This sense of invulnerability may influence any decision making in respect of protective behaviours, however it does not of itself appear to provide a complete explanation of the difficulty one has of conceiving oneself as having an infection. The explanations of risk perception and non personalisation of risk are founded upon the precept that one considers oneself to be at risk of infection and to be engaging in behaviours that may

expose oneself to infection. Previous studies have suggested that this is the case (Skidmore and Hayter, 2000, Gold et al., 1992), however they are invariably retrospective studies in which responses reflect explanations modified by hindsight and the passage of time. As has been previously discussed, infection is viewed very much in terms of specific behaviours and specific people. Yet the classifications of behaviour that are considered to predispose someone to an STI are measured and evaluated against the benchmark of one's own current behaviour. It follows therefore that one cannot view one's own behaviour in this way. Equally the way in which partners are viewed is as insiders rather than outsiders. Whilst casual relationships and one-night stands with outsiders may be conceivable, this sense of invulnerability is less likely to occur in such a situation which is consequently more likely to be associated with protective behaviours if circumstances permit (Evans et al., 1997, Anderson et al., 1999). Meaningful and emotionally invested relationships occur with insiders who do not represent a threat even though the length of the relationship may be very short. Within this context, the sense of shock that results from finding that one has become infected with an STI is the product of acknowledgement and acceptance, on the basis of the evidence, that one's actions or those of one's partner have broken the moral code, that there has been a crossing of the internal lines or a breaching of the boundary and that pollution in the form of infection has resulted.

### **8.7 The impact of diagnosis**

In Goffman's terms, a stigma is considered to be the possession of a discrediting or discreditable attribute. The stigmatising effect of an STI rests upon the social discredibility of the infection which is in turn predicated upon the social constructions of the types of behaviours and people that acquire such infections. Such a viewpoint is so widely accepted in society, permeating through every conceivable communication method, that there has been ample opportunity to learn of the stigmatising nature of the infection long before finding oneself in this situation. At the point of diagnosis therefore, one acquires the legacy of the social packaging of the infection. The effect of this is a re-identification of self and a consequent likelihood of developing disapproval of self (Goffman, 1990). As a result there will be an increased sensitivity to the response of others based upon an expectation that they will be censorial as "the stigmatised individual is too ready to read unintended meanings into our actions" (Goffman, 1990 p. 29).

### **8.7.1 Communicating the diagnosis**

In this respect the health client interface is a highly sensitive one. The reactions of those health professionals who are involved in all aspects of the infection management, those who initiate investigation and impart the diagnostic information, as well as those who manage the treatment process, come under intense scrutiny. The information that they convey is not bio-medically neutral. It is charged with moral significance to the recipient who is highly sensitive to any inference of culpability or social labelling of behaviour at this time. The way that information is conveyed at all stages, the subtleties of communication and the content of explanations have a considerable effect upon the way that such information is received and the resultant impact upon the individual. The sensitivity of this situation has the effect of magnifying experiences. Insensitive communications produce bad experiences that appear to have a devastating effect, whilst sensitive communications produce experiences that are positive in their effect, neutralising many of the initial concerns associated with diagnosis.

As several of the respondents had received their diagnosis in primary care prior to referral whilst others had received their diagnosis in the GUM clinic there was opportunity to draw some degree of comparison between the experiences in general terms whilst acknowledging variability within any one collection of responses. In the vast majority of cases, primary care was confined to testing and diagnosis with informal or formal referral to the GUM clinic for treatment and management. This consequently limits the opportunity for comparative analysis. However the emotional response to the diagnosis was a significant component of the whole experience. It was determined to a great extent by the perception of the way that such information was imparted and the contextual information that accompanied it.

### **8.7.2 The effect of insensitive management**

Insensitive management of this situation in primary care centred round a perception of social condemnation by the service provider that produced and intensified feelings of bodily pollution. These resulted from the way that the initial diagnosis, either in general or specific terms, was presented. For several of the respondents, the effect of this was a deeply distressing experience.

*"I was not expecting that at all, not at all, and I just think that she [the doctor] could have erm, said it a bit nicer to me instead of making me feel so cheap and dirty, because she made me feel that way." (Jane)*

and

*“Everytime I just felt so dirty, like when they [ the primary care providers] was talking to me, like really really bad. I don’t know, I just felt like a slapper, and I’d not done anything wrong really and that’s just the impression that they were looking over me, wagging a finger at me sort of thing and I’d not done anything wrong.” (Sian)*

With a subject as emotive as the diagnosis of a sexually transmitted infection, it is the way in which the information is presented as much as the information itself that produces such a response. For the majority of people, the diagnosis was unexpected and was therefore a shock. However whilst an unexpected diagnosis is likely to produce an emotional response, it was the way in which it was presented that amplified that response. If presented as stark information without any accompanying information, or if there was an attempt to locate the infection in the behaviour either of the patient or their partner, then the effect was to absorb not only the diagnosis but the social construction of it. Although the health professional may not have intended to convey a moral context when they were communicating the diagnosis, the sensitivity of the information heightened the significance of what was said and what was implied. This resulted in meaning being read into what was said and what was not said with the consequence that its impact was magnified considerably. In those who described extreme distress, the primary perception was of a diagnosis of an STI as a stark piece of information delivered in a detached and matter of fact way.

*“She came out basically oh yes, it looks very sore inside, well she said you’ve either had a miscarriage or it’s chlamydia. Well, I’ve never, the way that I felt when she told me that was unbelievable. I thought she was very callous in the way she said it.” (Alison)*

and

*“When she said oh, I think it’s a sexually transmitted disease, if you’ve got any pain in your ovaries it’s a sexually transmitted disease and I was shocked, I cried.” (Jane)*

It was this that was considered to be so traumatic. When the diagnosis was presented without any accompanying opportunity for discussion or clarification, it was the lack of any explanation that contributed to the emotional effect.

*“She said, oh, it might not be, I’m only surmising, I thought oh thanks, she didn’t offer me any sort of explanation, she didn’t tell me about chlamydia, I didn’t know anything about it.” (Alison)*

Alternatively, attempts by the primary care provider to locate the source of the infection may be equally distressing in so far as they potentially impact upon the relationship status by making inferences on the basis of the information supplied

*“They said that I’d got chlamydia and basically, have you been with anyone else, and I told them what I told you [a stable relationship for 6 years] and they said well, it can’t be from you then, it must be from someone else. Is he seeing someone else?” (Sian)*

It is difficult to imagine that those health professionals who made such statements could have any conception of the effect that their dismissive attitude or their conjectures had upon the recipients of such information. However it indicates how important the communication is at this point and the imperative of considering the impact of what is said upon someone in such a sensitive state.

### **8.7.3 Challenging the stigma effect**

The stigmatising effect of this infection was not inevitable and when it was apparent, it was transient for the majority of the respondents in this study. Similarly diagnoses were not always conveyed in a stark and insensitive way and the responses to diagnosis, although unexpected and upsetting, were not inevitably traumatic for all respondents. The spectrum of responses was influenced by a variety of individual factors including pre-existing knowledge and relationship status. Additionally the role of the health professional was important in contributing to minimisation or elimination of the stigma effect. Imparting the diagnosis provided the means by which to challenge the imputation of moral culpability and thereby to restore their spoiled identity.

As the stigmatising effect is founded upon specific constructions of the social and biomedical aspects of the infection, challenges to either or both of these will effectively undermine that effect. This occurred in one of two ways. Firstly explanations provided by a minority of respondents indicated that they dealt with the situation by locating the infection in the other person, their sexual partner. Secondly it occurred through the explanations provided by the health professionals. In particular certain key pieces of information appeared to have specific significance in terms of challenging the stigma effect and they therefore represented a tangible way of undermining the concept of bodily pollution that accompanied diagnosis.

#### 8.7.4 Locating the source in others

A minority reaction to the diagnosis was to locate the infection in someone else. In so far as dirtiness stems from a sense of one's own breach of the moral code, this represented an alternative perspective by portraying the other person as the source of infection and therefore as the dirty one. In this way the association of the infection with people and behaviours remained evident but was not applied to self. The effect of not internalising the infection and its associated connotations was that their own identity could remain intact. This was evident in the case of Gemma who clearly saw her partner as the source of infection and was anticipating a re-infection several months after the initial diagnosis and treatment.

*"I wouldn't have felt dirty, I would have thought that I got it back off him, something like that."*

For Sue, there was no previous history of infection that informed her position. Rather it was a personal conviction of the morality of her own behaviour that provided the basis upon which she preserved her identity, placing the culpability firmly upon the other person whom she considered had been responsible for passing the infection on to her.

*"I didn't feel dirty because I knew that I wasn't and the reason why I got them [the infections] was because I'd slept with the wrong person and not slept around."*

The tendency to locate the infection in the other was evident in male and female accounts and the two examples above are both drawn from the female data. Overall however, the data suggests that the males subscribed more readily to the location of disease in others as the means by which they had become infected. There is insufficient data here to make definitive statements regarding gendered explanations. However, it is worthy of note that whilst the males represented only 20% of the total sample, they provided the majority of accounts in this respect. As discussed previously, the threat to social identity was not as great for the males and there was therefore less imperative to locate this specific infection in others. However there was an indication of a male readiness to locate females as the source of infection in conjunction with the pejorative labelling explored previously.

*"When you wait for your test you sort of look back at girls that you have been with, because you were in a relationship with them for like 2 months, and then someone says why were you with her, she's a bit of a slag and all this and you look back at all*

*this and you think well, maybe she was a slag, maybe she was going around behind my back because you don't know do you?" (Tom)*

Alternatively in the explanation of social attitudes to STI's, it was implicit by the choice of personal pronoun

*"If something has been brought up in a conversation about someone else, they'd say oh, she had chlamydia, and say it in a way to put them down, rather than just stating facts. It's a derogatory statement." (Peter)*

The gendered differences in the way that infection was located in others was striking. Whilst Sue described the person who infected her as 'the wrong person' her explanation was limited to a neutral term. There was no allusion to his character, his morals or his behaviour. His wrongness lay simply in the fact that he was carrying an STI and was not explained in terms of what he was or what he did. By contrast when Tom reflected back on a similar situation and considered the woman from whom he may have picked up an infection, he not only assassinated her moral character by labelling her as 'a slag' but also called her behaviour into question.

## **8.8 Providing key information**

The process of imparting the diagnosis provided an opportunity to contextualise the infection in a biomedical way. As demonstrated previously the effect of presenting a stark diagnosis was considerable. However if it was presented in a contextualised way, many of the initial concerns and anxieties could be allayed and the information also provided the means by which to rebuff the accusations of others. The importance of such information lies in the fact that it addresses the very common questions asked at the time of diagnosis and it provides the means through which to challenge the preconceptions that become highly significant at such a time. The significance of these common assumptions in the context of the relationship is considered separately in chapter nine. However it is important at this stage to examine the specific information that appeared to be most important in this respect. This can be identified as the three key elements of duration, commonality, and transiency.

### **8.8.1 Duration**

The indeterminate length of an infection that is largely asymptomatic leads almost inevitably to the questions where did I get it from and how long have I had it? The indeterminacy can be both reassuring and threatening at one and the same time. The

security comes from provision of the opportunity to dissociate the infection from the threat that it poses to the relationship. If there is no means by which to accurately determine the length of infection, there is no means by which to attribute its presence to the possibility of a concurrent relationship and the potential threat that this may pose to the relationship. To offer an indeterminate duration of infection enables it to be understood as something that was brought into the relationship at the outset rather than introduced at a later stage. For Yvonne, who had been in a stable relationship for seven years, the possibility of a long duration was important because of the safety that it offered to her relationship.

*"We were fine once we'd come here and they explained that it could lie dormant for quite a few years, it's not forced to be anyone playing away or anything."*

The significance of a lengthy duration of infection in this situation lies in its potential facility to protect the relationship. Such safety however may bring with it a potential cost. As discussed in the previous chapter, alternative readings of duration of infection would consider it a cause of concern in so far as it increases the possibility of long term complications. Safety in relationship terms may consequently represent risk in health terms and the meaning attributed to a possible lengthy duration of infection is likely to be determined by the context within which it considered.

### **8.8.2 Commonality**

When the respondents found that they did have such an infection, the sense of discomfort that it generated generally precluded any wish to discuss the diagnosis with others. This issue of secrecy and information control will be considered in greater detail in chapter ten however it is important at this point to acknowledge the contribution that it makes to the sense of contamination.

For many people, the realisation that this is a common infection was unexpected. Although the amount of public information about chlamydia has increased considerably over the past few years as a result of media coverage and health information campaigns, it remains a predominantly secret condition. There is a considerable degree of secrecy surrounding any STI. This is not information that is readily shared. There is a lack of public dialogue and a tendency of individuals to strictly limit the degree of disclosure. The effect of such tight information control is that even if it is a very common infection, it is not very common for someone to know of someone else who has had that infection. This situation creates the illusion that acquiring the

infection is a rare occurrence. Consequently, in the absence of any other information, those who found that they had the infection assumed that it was rare. The resultant feeling of isolation further contributed to their sense of dirtiness or otherness.

*"Because I think at first, if the doctor says that to you [the diagnosis of infection] and you just feel so dirty as though you're the only one that it's happened to." (Jane)*

To discover that this infection was common was crucial in undermining feelings of contamination because it challenged its location in the category of other and provided a means by which to re-establish a degree of order through a restructuring of categories. In some instances this was experiential through the discovery of friends or acquaintances who had also had the infection. Liz described how knowing someone who had had this infection three times had made her feel better, whilst Paula identified how nice it had been to find someone else to talk to who had also been through the experience.

In other cases the relief came simply from being told that these infections were common. A metaphor that was commonly adopted in this respect was that of likening chlamydial infection to the common cold. This metaphor was used frequently by many of the staff in the GUM clinic and particularly by the Health Advisor and was recounted by a number of respondents. The term 'common cold' subtly portrays the significance of this comparison. Although the cold is recognised as a contagious condition passed from one person to another, it is an everyday occurrence, accepted as something to which we are all susceptible and to which we all succumb; there is no blame and culpability associated with its transmission.

The effect of understanding that this is a common infection challenges the whole social representation of the disease and may therefore reduce the perceived necessity for secrecy. As a result there may be those who have had the infection and are happy to discuss details with others in general conversation. In these terms it is simply an infection, little more than a minor inconvenience, and investigation and treatment carries little social value. When this is the predominant view in one's social circle, it presents an alternative interpretation to the predominant sociocultural one. This was evident as a minority viewpoint in the data however it demonstrated the way in which this attitude normalised the infection thereby diminishing feelings of isolation and stigmatisation.

*"I think they find it easy to talk about, it's not such a big thing, I've got one friend that comes regularly, every 6 months and she's not bothered, she says well, come here and get sorted, it's a bit strange like, but, surely it would be easier not to get it in the first place but, people are a lot more open about it now. They do, people talk about it, it's not such a big thing anymore." (Tracy)*

and

*"I work on a building site so basically everything is shouted out. I took the letter on site and it fell out of my pocket and one of the lads picked it up and read it and then within about 30 minutes everyone on the site knew about it, it doesn't matter does it, there's no point worrying about it." (Wayne)*

### **8.8.3 Transiency**

The third element is that of transiency of the stigmatising effect. In Goffman's terms, stigma is a permanent state and whilst it can be managed and minimised, there is little consideration of the circumstances relating to non permanent stigmatisation. In the main this stems from the fact that the underlying conditions upon which his discussion was based are permanent. However a study of those in long term remission of epilepsy, which for many is a short lived and self limiting condition, demonstrated perceptions of felt stigma that far outlasted the occurrence of seizures (Jacoby, 1994) suggesting that the stigma may have a lifespan that exceeds that of the underlying condition. In relation to STI's there does not appear to have been any work that explores diminution or elimination of felt stigma. Those studies that have considered this issue have confined their focus to anticipation of diagnosis or first response on diagnosis (Duncan et al., 2001b, Fortenberry et al., 2002, Liu et al., 2002). However in terms of a condition that is treatable, and which can therefore be effectively eliminated, factors which contribute to both the production and the elimination of feelings of stigma are fundamental to understanding effective management of the condition from a psychosocial as well as a biomedical perspective. If one acquires the social packaging of the infection at the time of diagnosis then it might be possible to shed that packaging at some point, either in terms of rejecting the stereotypical image of someone with an STI or by elimination of the infection itself. However it is important to note that the social labelling is not inevitably and exclusively tied to the confirmed presence of infection. Existing as it does in the realms of social reputation, people are imputed as being infected on the basis of reputation. It is therefore likely that in certain situations, knowledge of having had an STI may taint one's reputation beyond the time that the infected state exists.

The knowledge that this infection is extremely responsive to treatment and can be rapidly and effectively eliminated in the vast majority of cases, notwithstanding the possibility of residual pathological damage, played a key role in undermining the extreme emotional responses that were experienced at the point of diagnosis for a number of respondents. Given that many respondents reported a singular lack of understanding of the infection in terms of treatment and management and that the most high profile STI is undoubtedly HIV for which there is treatment but no cure, it is perhaps not surprising that several of them expressed extreme anxiety as to the consequences of being diagnosed with this infection. To then discover that the infection could be relatively easily eliminated by the administration of antibiotic therapy effectively undermined the majority of those initial responses.

*"But they said we'll give you some treatment, some tablets, they told me that over the phone, so it like calms your nerves when they say it's just tablets to cure it." (Robert)*

With the elimination of the infection goes the feelings of dirtiness and the expressions of bodily contamination. Many respondents expressed a need to feel clean again subsequent to treatment, a need to be sure that the infection that been effectively eliminated.

*"Well, when I knew it were easily treatable, it stopped me worrying about it as much once I did realise that I'd got it" (Shirley)*

The feeling of dirtiness emanated from knowing that they had the infection, that the infective organism was resident within their body. It is perhaps not surprising therefore that for some, taking the medication that was expected to remove the organism and therefore the diagnostic label was all that was required in order to eliminate those feelings.

*"At the end of the day, I've taken some tablets and I've changed my mind, thinking differently, and now I've got a big smile on my face.... people think its dirty don't they, most people do anyway, teenagers and some young adults, it's not really, you have treatment, you shift it." (Steve)*

and

*"I don't know how, it doesn't bother me now, but at the time I were like oh my God, it just makes you feel euurgh." (Michelle)*

For some the imperative in terms of eliminating the pollution effect was knowing that the infection had been eliminated and it was therefore sufficient for them to receive treatment. However this was not sufficient for everyone and the availability of a retest post treatment provided an additional facility by affirming both the effectiveness of the treatment and confirming the elimination of the infection.

## **8.9 Retesting and the test of cure**

### **8.9.1 The purpose of the retest**

From a medical management perspective, retesting is recognised as a means by which to ensure re-attendance (Dale et al., 2001). However even if testing is provided, not all patients requested to attend for follow up do so and non attendance rates are a recognised aspect of genitourinary medicine care provision. The data on rate of return is highly variable ranging from 55% in a review of Gonococcal infection conducted in a London hospital (Lewis et al., 1999) to approximately 75% in three Chlamydia studies from America (Hillis et al., 1998, Fortenberry et al., 1999, Orr et al., 2001) and 85% in a retrospective study of chlamydial infection in a District General Hospital (Jarvis et al., 1999). Many factors are likely to affect return rates, including location of the clinic and population profile. Three of the five studies cited are American rather than British data and their context as research studies may also influence return rates. However these do concur with data from the study clinic at the time of data collection when the Health Advisor estimated that approximately 25% of those treated for chlamydial infection did not attend the follow up visit (personal communication, 2003). It is reasonable therefore to assume that this process is not universally considered as valuable enough to go through the processes involved, nevertheless for three out of four clients it appears to have been important enough to justify the time and effort.

The standard procedure in the study clinic was to offer a retest approximately 4 weeks after treatment. The recruitment and interview procedure adopted in this study meant that the majority of interviews that took place in the GUM clinic did so at a follow up visit with just two taking place at the time of initial diagnosis. Clinic activity at the majority of these visits therefore included retesting although in some instances, possible re-exposure to infection or non completion of medication resulted in re-treatment rather than retesting at that visit. Even those interviewed in the second study centre (the FP clinic) reported having been retested, either in the GUM clinic or at the GP's. The sole perspective in this study therefore is that of those who chose to return for a retest and it is not possible to comment on the perspective of those who may have

elected not to attend the follow up appointment, the factors that contributed to such a decision and whether perceptions of bodily pollution were a consideration either at the time of diagnosis or subsequent to treatment.

### **8.9.2 Functions of the return visit**

Retesting is only one of the functions of the return visit which also provides facility to fulfil the public health functions of contact tracing and prevention of re-infection as detailed in the clinical guidelines (CEG, 2002). However when the respondents explained the purpose of their return visit, they focused almost entirely upon the testing that had been conducted, upon the physical examination, the microbiological test and its role in establishing that they were no longer infected. It would appear therefore that they viewed the purpose of their visit almost exclusively in terms of this test. Any other discussion and activity that would in all probability have taken place was not considered sufficiently important or relevant for them to mention.

There are two possible explanations why the purpose of the visit was consistently viewed only in relation to the retesting. Firstly activities such as contact tracing and health education which are verbal interactions taking place as part of a consultation are viewed as very much less relevant by the respondents and not worthy of note. Whilst discussion may have been part of the total package, it was the physical aspect of swab taking which was of prime importance.

An alternative explanation for their sole focus on testing as the purpose of the visit is that this may have been the way in which the visit was justified to them. There was some indication in the data that this was the situation. Some respondents were interviewed immediately after they had been treated for infection, either because they had just received their initial infection diagnosis or because of possible re-exposure. They had therefore just been advised of the return visit and it seems likely that their explanation in the interview would have reflected the way the retest had been justified to them. Their understanding, which concurred with that of those who had attended a follow up visit, was of a test undertaken to ensure that the infection had been eliminated, a test of cure (TOC).

*"I've got to come back in 4 weeks time to check that the chlamydia has cleared up"*  
(Andrea)

and

*"I've got to come back in 3 weeks, I think it's 3 weeks, and then they'll do some more tests to make sure that everything is cleared up and then that's it as far as I'm aware."*  
(Sarah)

### **8.9.3 Being rid of the infection**

There was a remarkable degree of similarity in the language used by the respondents to describe the test and its purpose. Three words or phrases were repeatedly used in the explanations, either individually or in combination. These were 'make sure' 'gone' and 'clear'.

*"I've come along today for my check-up, for them to do some more swabs to make sure that it's cleared up and gone."* (Jane)

and

*"[I came] for the tests to see if I'm clear from it now."* (Liz)

and

*"I just had 2 swabs to make sure that I'm clear of it because I've had like antibiotics, so it's mostly to make sure that I'm clear."* (Michelle)

There are two things that appear to need checking in terms of elimination of the infection. Firstly whether it has been fully eliminated in quantitative terms and secondly whether sufficient time has elapsed for it to be eliminated. The phrase 'make sure' is confirmatory. There is an implicit expectation of what the outcome will be and the purpose of the test in this circumstance is to provide confirmatory data. However it appeared to carry an additional connotation in this context which related to the treatment.

*"I had 2 swabs to make sure that I'm clear of it because I've had like antibiotics"*  
(Michelle)

and

*"Today is a follow up from the first time that I came ... it's called a test of cure, to see if the treatment's worked."* (Peter)

The purpose of the test in this respect was to confirm the effectiveness of the medication and its ability to eliminate the infection. The inference here is that the medication does not always work and therefore that there is a need to ensure that it has been effective. These descriptions were used whatever medication was used, either a course of tablets or a stat dose administered in the clinic, suggesting that the

issue in question was the effectiveness of the medication itself rather than adherence to regime.

*"Came back today and found out that it's all gone."* (Anne)

and

*"They gave me the tablets and they gave me the tests to check whether it had all gone away."* (Isobel)

The second suggestion in the data was that elimination of infection is a fairly lengthy process and therefore there was a possibility that insufficient time may have elapsed since treatment. The purpose of the retest in this reading was to ascertain whether the end point in the process had been reached yet.

*"Last time I came I got given some antibiotics and so they were just checking to see if it was gone or not yet."* (Jacky)

Given that there is a considerable time lag between completion and the retest this seems somewhat surprising. However in the clinic drug treatment was accompanied by a recommendation to abstain from sexual intercourse for the four week time span between treatment and the follow up visits. Although infectivity is not considered to be an issue seven days after treatment and the advice on abstinence relates more to prevention of re-exposure and re-infection, the attachment of a time interval produced an understanding of the elimination of the infection as a lengthy process.

#### **8.9.4 The surveillance role of the clinic**

From the perspective of the GUM clinic, the primary function of the return visit is to enable it to fulfil its public health role. It provides opportunity to ascertain that the patient has followed instructions regarding both medication and sexual activity, that they have not become re-infected and it enables the staff to check on the process of partner notification. The fulfilment of these roles exemplify the function of the GUM clinic as a site of surveillance (Pryce, 2001, Armstrong, 1983). The progress of infection is tracked as it courses its way through the social body and measures are instigated to stem its progress. Surveillance of necessity operates upon and through those individuals who come under the medical gaze, those who are recruited as active patients (Pryce, 2001, Armstrong, 1983) adhering to the medical regime that includes the return visit as part of the process.

The operation of biopower acts upon the body of the individual in order to realise its effect upon the social body. In the interest of health, behaviours are shaped largely through a process of self policing, through mechanisms of guilt, anxiety and through the admonition of others (Lupton, 1995). However in regard to STI's that are already suffused with anxiety, guilt and secrecy, such mechanisms are unlikely to operate in the same way. Yet it is the patient in the clinic who provides the means by which the clinic can exercise its surveillance role and in order to do so it is necessary that the patient returns to the clinic after treatment. Those public health activities that constitute the primary purpose of the return visit for the clinic are unlikely to constitute sufficient motivation to ensure a return visit, on the basis that people are unlikely to return purely for the purpose of 'checking in.' The offer of a retest therefore presents justification for the investment of time and effort and is used as a way of increasing the likelihood of attendance at the follow up visit (Dale et al., 2001).

The technical details as to whether the retest functions primarily as a test of cure or of re-infection was discussed in section 3.7. However as identified previously, in the way that the patients described its purpose, it was apparent that they understood it to be a test of cure. This is not strictly inaccurate although the most likely causes of infection at retest are either re-infection or non adherence to medication. However whilst failure of treatment may be statistically less probable, it is considerably more socially acceptable as a cause of a positive result at retest. Within this study, re-exposure to infection or non completion of medication was a common occurrence. Eight of the respondents (16% of the total) described their need for re-treatment and one of them had had three courses of treatment. It is a matter of conjecture whether they would have returned to the clinic for re-treatment if the facility of a sanitised reason had not been made available to them.

#### **8.9.5 The difficulty of complying with health instruction**

Adherence to specific instructions concerning aspects of behaviour and lifestyle choices characterise health promotional activities. This creates a moral imperative upon the individual to assume personal responsibility for their health and behaviour (Lupton, 1995). However the health rhetoric often belies the complexity and difficulty of adopting specific behaviour patterns. Abstinence from intercourse or condom use in the interval between treatment and retesting may well be problematic. As a minimum it requires that infection status be disclosed to and discussed with one's partner. However the ability and willingness to make such a disclosure requires a level of communication and a degree of trust within the relationship that cannot be assumed.

For those such as Amy who found the task of disclosing their infection to their partner insurmountable at the time, re-exposure to infection was almost inevitable.

*"I was scared to tell, in case, because I didn't know him right well at the time as well, scared about what he would say and I just didn't want to lose him."*

Re-exposure to infection constitutes non compliance with the instruction to protect oneself and is therefore subject to self-policing and expectation of recrimination from others. Whilst a return visit to the clinic provides the means by which to rectify matters, it also necessitates disclosure of non-compliant behaviour to those who are the most powerful advocates of compliance. Conflict between the two options was apparent in the case of Wayne who initially defaulted but subsequently made a further appointment because he *"felt a bit of a prat"*. Anticipation of recrimination was also a concern for Carol although it did not prevent her attendance and was subsequently largely unrealised.

*"The second time I came back she asked me if I'd had unprotected sex and I said yes and I thought she'd have a go at me and everything but she was really nice about it, it's good like that, I thought I'd get told off but I didn't."*

An infection management structure that includes a retest therefore appears to provide the facility to deal with re-infection which carries connotations of moral culpability. Pre-booked return visits routinise the process of return visits although they commonly result in a high non attendance rate. Calling the retest a test of cure rather than a test of re-infection simultaneously offers a socially acceptable means by which to deal with re-infection in those in whom it is an issue and increases the likelihood of re-attendance in those in whom it is not an issue.

#### **8.9.6 Personal significance of the retest**

It was apparent from the data that for many people the retest had a personal significance that served as sufficient motivation to assure their re-attendance at the clinic. This purpose was related to but distinguishable from the medical rationale. The function of a re-test is twofold, either to confirm the presence or the absence of the infective organism. Notwithstanding the source of a positive result, the overall medical purpose of testing is to identify infection in those in whom it is present. Its significance for the patient however lay in not identifying infection when it was not present.

Retesting provided the means by which to establish definitively that they were free from infection in so far as they had been tested and the test results were negative.

Test results provide the means by which someone can know rather than assume that the treatment they have taken has been effective. It was this knowledge that was particularly important for some including Helen, for whom the uncertainty of waiting for the results of a test of cure produced a degree of anxiety.

*"I'm still a bit on edge, whether it has worked, whether it has gone or not."*

One of the probable reasons for the value that is placed on a test of cure relates to the high probability of asymptomatic infection. Symptoms as a physical indicator serve two important functions. As the physical manifestation of infection, the presence of symptoms indicates the presence of infection. Equally the absence of symptoms indicates the absence of the infection. The lack of symptoms associated with chlamydial infection make it equally difficult to identify the presence of infection and its subsequent elimination which may be difficult for some.

On this basis one might expect that the retest would have greater significance for those who did not experience symptoms attributable to chlamydia as part of their infection episode. The data supports this association to some extent. The test of cure was identified as particularly important by Jill, Jacky, Becky and Jenny, none of whom felt that they had experienced significant symptoms (see appendix I). Jill considered it to have particular value in this respect even though the infection itself was not a cause of great concern and the retest was viewed almost as a foregone conclusion.

*"The chlamydia, I don't know if it's a good idea, but you can almost put it to the back of your mind. You've had no symptoms, the treatment, some pills I think that I took on the day and that was it and I've had a retest today and the results will come through and fingers crossed, you know it'll be clear, but there was very little to occupy your mind with that."*

For Jacky the infection was a cause of considerably greater concern and the retest was considered essential in providing assurance that it had been eliminated.

*"It's been a month since I finished my tablets and I'm still worried that I could still have it .... I think I will believe it [the test of cure letter] and try and forget it. Yes yes, I wanted the test."*

As discussed previously in this chapter, treatment alone provided sufficient assurance for some that the infection had been eliminated. For others however the retest had particular significance in this respect because of its ability to provide definitive information about the microbiological detection or non-detection of the organism. As such it occupied a pivotal position marking the symbolic boundary between an infected and an uninfected state. It could therefore be viewed either as the end of the infected state or the beginning of the uninfected or 'clear' state. Within either of these understandings the test of cure functions as a form of ritualistic cleansing.

van Gennep (1960) draws attention to the way in which the life of any individual within society is marked by a series of passages from one phase of life to another. These rites of passage exist wherever there are social distinctions such that life is constructed from a succession of stages. Many of these are readily apparent such as birth, puberty and marriage and marked to a greater or lesser extent by formalised rituals, however, they are not confined to such culturally defined significant life stages, and may accompany any change from one state to another (Turner, 1967). He identified how rites of passage, whatever their context or purpose are characterised by the three stages of separation, transition and incorporation. Separation which marks the detachment of the individual from a fixed point in the social structure leads to a liminal or transitional period, during which the state of the subject is ambiguous whilst the incorporation marks the consummation of the passage. In a health context, Forss et al identify how the cervical smear which women expect to confirm their state of cervical health projects them into an unintentional transition of liminality when they receive a diagnosis of cellular abnormality, a situation that is 'betwixt and between' (Turner, 1967), neither confirmed health nor confirmed disease (Forss et al., 2004).

In terms of chlamydial infection, the infected state is a liminal state within which the individual represents danger both to self and to others. Danger to herself resides in her physical state of infection and her social state of otherness. Simultaneously she represents a potential source of danger to others, as a source of infection. Whilst the treatment is the pharmacological means by which the infection is eliminated, it is the test of cure, the evidence of freedom from infection that constitutes the postliminal rite. It provides a ritualistic process that marks the transition from the state of liminality to

the incorporation phase. For some, its importance lies in its position as the end point of liminality, the end of dirtiness, whilst for others it is significant as the beginning of incorporation, the beginning of being clean again.

#### **8.9.7 The end of dirtiness**

Knowing that the infection had gone and that they were now 'clear' was an important piece of information for several of the respondents. For others the significance of the information extended to incorporate the symbolic significance associated with the infection. Given that the presence of the infection was repeatedly expressed in terms of contamination, knowing that it had been eliminated provided the means by which to deal with the bodily pollution. It enabled them to know that they were clear of infection and therefore clean. The retest in this circumstance had ritualistic significance as marking the end point of the cleansing process.

*"I did for a bit [feel dirty] but not now, because now I'm thinking all clear." (Andrew)*  
and

*"I don't know in the back of my mind if I'm 100%, if they think I've got it because I've not heard that I've not, last time when they said that I had, I'm not clean from it yet." (Beccy)*

The ability to draw a line under this episode of life and the role of the test in enabling them to do so did appear to be very important for some as is clear from Jenny's account.

*"I need that [the letter giving the results of the test of cure] to feel that I can, it's just like closure, I just need it to say this, this and this, it's done. I couldn't have come and had my antibiotics and then never come back again."*

#### **8.9.8 The beginning of cleanness**

As well as marking the end of the infected period, the pivotal positioning of the test means that it also provides the facility to mark the beginning of the clear phase and for some it was this that appeared to have greatest significance. For those who were not currently in a sexual relationship it was seen as important in terms of being able to move on and contemplate a new relationship in the knowledge that the possibility of transmitting the infection to someone else no longer existed.

*"Another urine test, just to see that it has completely gone, and then I can start having a sex life again, when it's all gone." (Tom)*

and

*"I want to find out, to know that I'm clear and then if I want to start a new relationship with someone, then I'll feel more confident to do so." (Beccy)*

Within an ongoing relationship, when both partners had been treated and retested, the knowledge that both were now free from infection provided particular significance in terms of the safety it afforded. The demonstrated lack of infection within that relationship enabled decisions to be made about future contraceptive usage and provided sufficient justification for cessation of condom usage.

*"C and I have been tested for lots of things and we know we've not got anything else. I think as soon as this is cleared up I don't think we'll be using condoms again. I know that everything is cleared up and we don't like using them anyway." (Angela)*

and

*"When we've both been cleared and we both know that we haven't got anything, if I'm on the pill we don't necessarily have to use condoms all the time, because if we both know that we're clear of everything ...." (Margaret)*

For those that considered themselves to be in a stable and ongoing relationship this was viewed as a positive outcome of the situation given that condoms were largely viewed in a negative way. However given that knowledge of the absence of infection effectively removes one of the main arguments for the use of barrier contraception, it could be viewed as undermining personal choice in contraceptive usage. For those who might prefer not to use hormonal contraception or those such as Tess who favoured dual method usage for contraceptive effect, it might be expected to produce consequent difficulties.

*"Now that we've been cleared up and having all these tests is it going to be a case of oh, but we've been tested now, we've got the all clear, we don't need to worry about that. Again I'm going to have to put my foot down and say well, I don't care, tough, use one [a condom] least of all because one of the things that came into my mind when I was waiting for the results of the urine tests a week ago, I thought oh, what if they've done a routine pregnancy test and what if I'm pregnant and I'm on the pill."*

For those in a relationship, confirmation of the absence of infection that comes with retesting effectively draws a boundary around that relationship. The safety that this boundary provides remains intact for as long as the relationship is sexually exclusive. It marks a point of transition from an infected to uninfected state both for the individual and for the relationship. As such it forms the benchmark against which any subsequent infection that may occur within that relationship can be interpreted. The occurrence of the infection in either partner subsequent to a negative retest would indicate that the safety boundary and therefore the sexual exclusivity of the relationship had been breached. At the initial diagnosis of infection, the asymptomatic and variable duration of infection provided the facility to locate its source as being at some indeterminate time prior to the commencement of the current relationship. This was a common strategy adopted in order to diminish its impact on that relationship as discussed earlier this chapter. A negative result at retest in both partners effectively removes that explanation for any subsequent infections that may occur within the relationship. As such it provided a visible indication of extra-relationship sexual activity as several of the respondents identified.

*"When my partner's all clear, we're both all clear now and that if one of us got it again it means that one of us has been sleeping with someone else so we'd know." (Anne)*  
and

*"He told me he'd had chlamydia before and he told me just before we got together that he'd come here and been cured of it, so from that point of view it shouldn't be in our relationship and it is." (Jodie)*

### **8.10 Conclusion**

Sexually transmitted infections continue to be closely associated with breaches of the moral order and sanctioned standards of female behaviours that are highly reminiscent of Victorian attitudes and values. These not only perpetuate social stereotypes and double standards of morality but they also make it problematic for individuals to consider themselves as being susceptible to such infections because of the fundamental distinction between self and other. They therefore contribute to perceptions of invulnerability which have not necessarily diminished when someone agrees to be tested for infection.

The extent to which a diagnosis is anticipated and expected, even in someone who has been experiencing symptoms suggestive of infection, cannot be assumed. Resulting from the sense of invulnerability that arises from categorising these infections as

something that other people get as well as the social connotations of having an STI, there is a magnified sensitivity to the response of others. This arises from disapproval of self and consequent expectation of disapproval by others. It needs to be recognised and acknowledged within the context of the medical consultation in order to reduce rather than increase the emotional and social impact of this diagnosis.

The sense of body pollution that occurs as a result of realisation that one has an STI can be profound and produce a spoiled identity. Although it may be expressed in terms of pathogenicity, its roots lie in social ordering and the sociocultural concepts of dirt. The amenability of this infection to effective treatment means that it can be considered a transient episode. Although the knowledge that they have been treated seems to be sufficient for some to consider that they are free of infection, for others it was important to know that they had been effectively treated in order that they could feel clean. In this respect the retest performed a valuable role serving as a ritual process marking the transition from infected to uninfected.

## **Chapter 9: The Hierarchy of infections**

### **9.1 Introduction**

Whilst the mode of transmission produces a stigmatising effect that is common to this group of infections which are collectively categorised as STI's, the location of each infection relative to the others is not equal. Although all STI's are stigmatising, some are more stigmatising than others. In effect there is an apparent hierarchy of infection that was evident in the data. Those elements that contribute to the experience of the infection constitute the means by which the hierarchical positioning is determined. Thus chlamydia occupies a position on the scale as a result of the specific characteristics of the infection itself as well as its representation within the media and health educational programmes and initiatives. This rating scale also appears to extend to the strength of emotion elicited, and the degree of fear, anxiety or disgust that was associated with specific identified infections. In part this drew on hypothetical circumstances whereby participants compared what was with what could have been. However, several of the participants had been diagnosed with more than one infection, co-presentations being chlamydia with genital warts, scabies, and gonorrhoea. This provided an opportunity for them to reflect upon the comparative effect of these infections. In this respect therefore, part of the data draws on first hand experience.

### **9.2 Order of magnitude**

A general aversion and disgust was expressed in relation to STI's in general and a clear distinction was drawn between STI's and other infections that affected approximately the same anatomical area and which could conceivably be diagnosed through the same means, for example urinary tract infections. However, the strength of response elicited varied considerably from one infection to another. Chlamydia was commonly described in relative terms in comparison with other infections. The majority of participants that identified and discussed this comparative element did so in terms of the magnitude of infection whereby chlamydia was described as being a little infection. In the majority of cases, the comparison was drawn between HIV and chlamydia, however, a number of other infections were identified and discussed in this respect. Duncan et al (2001) similarly identified this phenomenon in their qualitative study of seventeen women who had had chlamydial infection. They propose that the diminution of chlamydia occurs as a means by which to restore a soiled image. Whilst this seems reasonable, my data would suggest that this is only part of the explanation. The categorisation process occurs on the basis of specific aspects of the infection which

have a clear and rational explanation and which show considerable consistency between individuals.

### **9.3 The historical legacy of venereal diseases**

The legacy of sexually transmitted infections stem from the traditional venereal diseases of syphilis and gonorrhoea. Chlamydia has acquired that legacy because of its categorisation as an STI, however as a relative new comer it does not carry the same connotations. In relative terms therefore, the social impact of this infection is not as pronounced as it is with the traditional infections where the name alone was sufficient to conjure up distasteful associations.

*"I don't know, things like gonorrhoea just sound horrible, the word, it sounds eeuurgh."*  
(Liz)

For those who found that they had an STI, there was a general reluctance to disclose and discuss the infection with others. A variety of considerations influenced these decisions as will be discussed in chapter ten. However in general terms the degree of reluctance was not equal. There was a greater degree of reluctance to discuss one infection over and above another that reflected the degree of distaste associated with each of them. This decision of selective disclosure was expressed from a hypothetical point of view in relation to HIV and from actual experience in the case of gonorrhoea when Gemma was found to have both gonococcal and chlamydial infection. Although both infections were diagnosed at the same time, and in all probability had been contracted at the same time, one was clearly more acceptable than the other.

*"I didn't tell her [mum] I had gonorrhoea, I just told her I had chlamydia, I didn't want to tell her anything else... because she'd be like oh, you've got gonorrhoea, I think it was shyness more than anything else."*

Feeling able to disclose the diagnosis to another person appeared to be related to the extent of personal discomfort that accompanied a specific diagnosis. The connotations associated with the diagnosis of an STI were more pronounced in the case of gonorrhoea than chlamydia because of its historical location which created an increased sense of personal discomfort. This in turn was translated into a decision to selectively disclose one diagnosis and not the other. The basis of such a decision was firstly the degree of personal discomfort associated with each of them, and secondly anticipation of the reaction of the other person where it was expected that a disclosure

of gonorrhoea would elicit a more negative response than chlamydia. However decisions about selective disclosure are egocentric. They can only be based upon personal views and opinions. The responses of others to different infections that determine information sharing can only be speculative and will remain unrealised if the information is withheld. As a result there is no facility to challenge these preconceptions.

#### **9.4 The relative magnitude of STI's**

Many of the respondents expressed severe emotional responses to the diagnosis of chlamydia that included distress, bodily pollution, self disgust, and anger. These have been explored in chapter eight. However it was common to also express relief that it was chlamydial infection rather than any other sexually transmitted infection. A number of characteristics of the specific infections were cited in this respect to explain a classification that predominantly categorises chlamydia as a small infection. It occupies this position not only in relation to HIV, which has assumed a degree of magnitude that places it above all other STI's, but also in relation to other STI's.

##### **9.4.1 The visibility of infections**

One factor that determined the scale of magnitude was visibility, whereby infections and infestations that produce a visible effect were considered worse than those that are largely invisible. For Jill, this was founded upon the bodily impact of having such an infection.

*"The warts, because they're visible and you can see them and they make you feel euurgh whereas the chlamydia, it's something you can, I don't know if it's a good idea, but you can almost put it to the back of your mind." (Jill)*

It was also a factor that determined the degree of perceived discomfort in disclosing and discussing the presence of such an infection. The visibility of an infection and the imagery that it conjures up is seen as distasteful, a matter for concealment on the basis of the negative responses that it elicits in others.

*"I think it would actually be worse and more embarrassing for people to talk about things like crabs and things like that. If I'd ever got that I wouldn't really have wanted to talk about things like that but this [chlamydia] doesn't bother me." (Liz)*

and

*“You can’t mention warts, any other disease you can mention, but if you mention that, I don’t know, it seems to be euurgh ... if you say you’ve had warts it’s ‘you dirty cow, or dirty whatever’, do you know what I mean?” (Judy)*

The level of visibility serves to promote an infection up the scale. Therefore warts are rated above chlamydia because they are visible and cause feelings of self disgust, however it is unlikely that this distinction would be extended to include other non visible infections, most notably HIV. The categorisation on this basis is founded upon the presence of cosmetically unacceptable lesions. The visibility of them serves as a constant reminder and forms a tangible indicator of their presence to others. Their psychological impact has been demonstrated to be considerable. Those with visible warts commonly report emotional upheaval and anxiety with a negative effect upon self-image and a consequent adverse effect on both the frequency and spontaneity of sexual activity (Clarke et al., 1996).

Arguably, the inclusion of pictorial images of STI’s into educational packages further compounds this response. Such an approach is a recognised educational strategy. In historical terms it was widely used with the armed forces and in more recent times has become a common approach adopted within educational programmes for young people. The purpose of using slides of clinical presentations of certain infections is emotive. Whilst they may serve to inform individuals of the possible appearance of lesions such that they may be able to subsequently recognise them, they also serve an additional function as a deterrent and scare tactic in order to reinforce key health messages as identified by Mike.

*“In the 6<sup>th</sup> form where we were they hit it hard with us, because she used to show slides of genital warts and that and everyone used to eurrh but it hits you, it just shows you that if you’re not careful what can happen and it’s not nice and so it hits you hard.”*

The use of such images is highly selective, firstly by being confined to those infections that have a visible effect and secondly by selection of those images that are worthy of note. Although Human Papilloma Virus (HPV) may produce visible lesions, namely warts, there is considerable variability in the scale and site of presentation and therefore the degree of visibility. However, those photographic images chosen as a visual illustration will inevitably be at the more extreme of the scale and therefore create a sensationalist effect that overstates the reality of the situation for many.

The use of visual imagery techniques are powerful in so far as they are the images that come to mind on learning that either oneself or someone else has an STI. However these techniques serve to reinforce and perpetuate the collective stigma effect of STI's and particularly those of the visual infections by focusing on their visibility to elicit feeling of disgust and horror as Tess explained.

*"Like I say, there does seem to be a stigma associated with chlamydia because its sexually transmitted diseases, like in school with sex education, STD's is always the gory pictures and slides and lots of leaflets and everyone goes euuuurgh so I suppose there's still that sort of attitude that people who you talk to might have about you."* (Tess).

Whilst undoubtedly well intentioned, the educational value of such a strategy is questionable, if only because one of the key messages commonly conveyed is the invisibility of those infections that arguably represent the greatest threats to health. However it is also likely to contribute to the exaggerated response to visible infections. In consequence genital warts produce a marked feeling of dirtiness which justifies their ranking on the scale above chlamydia.

It is important at this point to note the ironic nature of this classification. Those strains of the wart virus that carry the most sinister threats to health, specifically cervical cancer (Londesborough et al., 1996) are those that do not produce the visible condylomatous lesions that are associated with wart virus. Similarly the long term health consequences are likely to be more significant with chlamydial infection than the wart infection. The visible warts are unlikely to be anything more than cosmetically unpleasant, associated as they are with the non malignant strains of the human papilloma virus (Steadman, 1998). This categorisation is formulated fundamentally upon the concepts of dirtiness and bodily contamination rather than the gravity of health threat.

However whilst the concept of contamination is clearly related to the visibility of the infection, it does not rest upon visibility alone but stems from its mode of transmission. A comparable circumstance which highlights this point is that relating to acne vulgaris another visible condition which is strongly associated with negative emotions. The occurrence of acne carries strong connotations of hygiene and this aspect together with its common occurrence on the face, the most visible part of the body, contributes to its considerable impact on psychosocial well being (Koo, 1995). However whilst this

is evident in the accounts of those with this condition, acne does not evoke feelings of contamination in the way that genital warts do.

#### **9.4.2 The curability of infections**

Sexually transmitted infections include both viral and bacterial infections, each of which has its own aetiology and pathological effect. The responsiveness of bacterial infections to antibiotic therapies means that they are treatable and in the majority of situations the causative organism can be eliminated. In contrast the action of antiviral therapies is limited to reducing their effect by shortening the episode of infection in herpes, by removing the visible lesion associated with HPV infection, or by reducing viral load in HIV infection. Elimination of the viral agent as a result of treatment does not occur in any of these cases. Viral infections are therefore to a greater or lesser extent considered to be chronic and associated with either unpredictable and variable recurrence or permanent infectivity.

To discover that chlamydial infection was curable was an important factor in undermining the initial feelings of anxiety associated with diagnosis as previously identified in section 8.5.8. In effect, its treatability and the facility to demonstrate its subsequent elimination from the body by retesting enabled it to be viewed as a time limited infection. This was an important contributory factor in its classification as a small infection, both in its own right and relative to other STI's.

*"I look back and I think gosh, I'm lucky, it could have been anything, it could have been AIDS, it could have been anything and I'm lucky that it was something as mild, well, it's not mild, but it's something that's easily treatable and not life threatening." (Margaret)*  
and

*"I thought oh my God, I've got this vile disease and its horrible and then I sit down and I think about it. I think well, there are lots of people that are so much worse off, I've got something that can thankfully be treated and there's people that ...a friend of mine has, is it genital herpes that recurs all the time or whatever it is and she said it's just dreadful, she says she meets someone and it's there at the back of your mind all the time, and you daren't be with anybody." (Jenny)*

The curability of chlamydial infection therefore is important in two respects. In comparison with HIV infection that is equated with incurability and mortality, chlamydial infection is considered to be mild and therefore small. In so far as it is not life threatening it justifies categorisation as small. This is an understandable viewpoint

when the contrast is presented in such a clear cut way. However it is notable in this categorisation, as in the previous one, that the potential long term effects of chlamydia were rarely alluded to. Infection was equated with the possibility of infertility by a number of the respondents who spoke at some length about this issue, many of them identifying it as one of their greatest anxieties associated with the infection. However this in itself does not seem sufficient to merit raising it up the scale above those infections that are not curable but are considered to constitute less of a long term health risk. The positioning on the scale is related exclusively to the current infection itself and the ability to be rid of it rather than the possible consequences of that infection. There is a single exception in the data that represented this alternative viewpoint.

*"I think the chlamydia [is worse] because I know the warts will stay but they do go and they come back only if you have unprotected sex or something like that, but with the chlamydia it's a lot more dangerous if you don't get it treated. I know you can treat it but I know it can make you infertile and all different things." (Sue)*

From a relationship perspective, the overriding factor is the time limited effect of an infection that can be effectively eliminated from the body. The issue of infectivity with this organism is similarly time limited. If the infection has been effectively treated, the possibility of subsequently transmitting infection to someone else has been eliminated. There is therefore no imperative to discuss previous infection with a new partner. This contrasts with viral infections and particularly herpes for which the issue of infectivity is a consideration in all new relationships.

As a consequence of its treatability, the bodily effect is eliminated relatively readily with chlamydia. Several respondents described how their feelings of dirtiness disappeared with elimination of the infection, either at the point of treatment or as a result of a retest. For those who were not in a stable relationship, the importance of feeling clean before embarking on new relationships was identified as an important effect of treatment management as discussed in chapter eight. In contrast, this cleansing effect is not afforded to those with herpes infection. One might therefore anticipate an ongoing stigma effect although the data does suggest that most people adjust psychologically to recurrent herpes infection (Brooks et al., 1993). However, in a condition such as herpes where the possibility of recurrence is unpredictable, the extent to which it does recur appears to be significant in ongoing psychological impact (Carney et al., 1993). The suggestion is that the adjustment is due, at least in part, to an increasing time interval

from the infectious episode which reflects an apparent if not actual resolution of the infection. In this hypothetical categorisation, it is the dormancy and recurrency elements of herpes that are important. Similarly in relation to HPV, the impact of infection upon relationships also appears to be important, particularly in the formation of new relationships. In a study of 489 respondents who had HPV, the majority of whom had had the infection for three or more years, 86% reported that the infection had affected their ability to approach a new sexual partner and 9% reported rejection by a potential sexual partner on the basis of their HPV infection (Clarke et al., 1996). The placement of chlamydia below herpes and HPV on the scale is justified upon the ability to eliminate the infection and categorically state that it has been eliminated. The relational considerations that result from this situation are particularly significant in this respect.

#### **9.4.3 The commonality of infections**

The discovery that there is a high prevalence of chlamydial infection and therefore that it is a common infection, particularly in relation to the prevalence of other STI's, was an additional component in establishing its ranking. For the majority of the respondents this was an unexpected piece of information. The previous lack of public dialogue around this topic and the tendency of individuals to strictly limit the degree of disclosure in this respect creates the illusion that acquiring this infection is a rare occurrence. Consequently, to discover that one has an infection that affects many other people is to reduce the threat associated with it and therefore reduce the anxiety associated with it.

*"I thought when they first told me, I thought it was worse than it actually were, and then I came here, they gave me tablets and a leaflet on it, and it's very common now isn't it, very common, so I haven't been worried about it really."* (Julie)

and

*"Chlamydia sounds better, it's the most popular disease, the infection that most people get ....."* (Gemma)

The more common an infection is, the less it is considered to be threatening because it is an experience that is shared with many other people. Although it can be considered to be big in demographic terms, it is this demography that justifies its categorisation as small. In this respect it is placed on a par with genital infections such as thrush (vaginal candidiasis) which are recognised as being common and as a consequence are considered a minor irritation rather than a serious health problem.

### **9.5 The public health implications of being a little infection**

Efforts to increase the public awareness of chlamydial infection have resulted in a number of health educational campaigns. The focus of these has been to increase public familiarity with the infection in terms of its existence, but also to promote key health messages such as the commonality and the curability of the infection. Public representation of this infection in this way is intended to diminish associated anxieties and is considered an essential component of efforts to increase the acceptability of chlamydial screening. However, the media portrayal of chlamydia may result in an interpretation of this infection as not serious. This aspect has been identified as a factor that contributed to delays in seeking treatment in those notified by their partner of the presence of the infection (Darroch et al., 2003). Whilst there are likely to be other contributory factors that determine treatment seeking behaviour, the public health considerations of representing chlamydia as a small infection should not be overlooked.

### **9.6 HIV as a separate entity**

HIV was presented as being in a league of its own, separated from the other infections linguistically and in terms of order or magnitude. HIV is always presented as a separate entity, in medical literature and policy documents and in everyday speech. Thus the Education Act (1994) describes a requirement to address HIV and STI's within the secondary school curriculum and the Department of Health outlines its strategy for sexual health in the document entitled "Sexual Health and HIV strategy." The implication in both is that there are educational and health provision issues specific to HIV that require separate consideration and need to be addressed differently. Whilst the necessity for separate medical consideration of a chronic infection that requires complex therapeutic intervention is not disputed, the rationale for this linguistic separation merits consideration as does the consequences of such a representation.

#### **9.6.1 Similarities and differences**

Implicit within the terminology are two fundamental assumptions. Firstly that HIV stands alone from all other STI's and secondly that all other STI's can be grouped together. This suggests that the differences are greater than the similarities between HIV and other infections, whilst conversely the similarities are greater than the differences between all other sexually transmitted infections. However closer examination brings this premise into dispute. The term STI is used to encompass a collection of infections that differ considerably from one another in terms of causative organism, clinical presentation, systemic effects, treatment, and outcome. As has been

discussed previously, the way in which they are viewed also differs considerably. The only common element between them is the primary means by which they are contracted, a feature that is also shared with HIV.

The approaches and interventions used to prevent and detect STI's including HIV have considerably more similarities than differences. From a preventative perspective, the health messages surrounding safer sex also apply equally to the prevention of transmission of all these infections, including HIV. Similarly the diagnosis of one infection raises the possibility of co-infection with any of the others. This is the basis of the recommendation that those attending the GUM clinic for one infection should be screened for all others including HIV (Harindra et al., 2002, DH, 2001a).

Despite these similarities, the separation of HIV from all other STI's has contributed to a situation where it has come to be viewed as a separate entity. In comparison with HIV, other STI's are unlikely to be considered to be serious medical conditions (Barth et al., 2002). In terms of the public representation of this infection, it is presented as the explanation and justification for protective behaviours, dating back to the health education campaigns of 1988 that entreated the population "AIDS: Don't die of ignorance." This representation of HIV as the primary infection consideration in relation to sexual activity was clearly apparent in the data. It was a common issue identified by the majority of respondents which arose spontaneously in a number of contexts, in explanation of protective behaviours, as the primary health concern and in some instances in terms of requests for health screens. The separation of HIV from other STI's was reflected strongly in the data. Whilst this incorporated linguistic separation, in many instances it also extended to comparative orders of magnitude whereby HIV was described as 'the big one' with all other infection collectively categorised as small in comparison.

### **9.6.2 Awareness of HIV**

The data reflected a considerably greater awareness of HIV than of any other infection although a number of the respondents did identify other infections in discussing their anxieties surrounding diagnosis. For many of the respondents however, any consideration of infection was confined exclusively to HIV.

*"I don't think I've ever thought about infections, probably apart from AIDS." (Michelle)*

Over the past 15 years, HIV has come to permeate all social discourse pertaining to sexual health and has become deeply embedded in the public consciousness as a consequence. In the data, it was acknowledged as being the primary element in any public sexual health messages and as an ever present force in the media.

*“Obviously you remember HIV because that’s like, obviously one thing that you’re worried about all the time, so obviously you remember that one but nothing else really ... it’s such a big thing, and it’s always in the paper and it’s around you and it’s common knowledge isn’t it, they make a right deal of that one.” (Marion)*

As well as the media coverage of HIV, it was also commonly cited as the predominant or exclusive component of sex educational programmes by those who recollected educational coverage.

*“We didn’t really talk about sexually transmitted diseases at school, it was just wear a condom and that was it really, we didn’t actually, they did cover HIV but they didn’t go into the smaller ones, like chlamydia.” (Andrea)*

and

*“There was never, it were all about HIV and AIDS and the rest of it.” (Wayne)*

Whilst this should not be taken to represent the actual coverage of educational programmes at the current time, it provides insight into the impact of such programmes. The average age of the sample was 21.5 years with a median age of 17 years, therefore sex education for the majority would have occurred within the last ten years and for the majority who referred to their educational experiences, it was likely to have taken place within the last five years. It can therefore be assumed to have taken place within the statutory educational requirements that required coverage of both HIV and STI’s (DofE, 1994, DofE, 2000). However there was little reference to coverage other than that pertaining to HIV. There are two possible explanations for this. The first is that the recollections of the respondents reflected the actual delivery in terms of both content and emphasis of educational content. Alternatively, educational coverage may have been much broader and incorporated other STI’s, however the passage of time resulted in recall that was confined almost exclusively to HIV, perhaps because of its higher social profile. Learning and recall is a complex process influenced by familiarity of the topic as well as the quality of teaching both of which will contribute to the amount of learning and recall that takes place. This is reflected in the account of Mandy, a sixteen year old whose experience in this area was very recent.

*"They covered AIDS and things like that, the bigger things, and I think like the smaller things were done in like year 7, we did that but I can't think of what they said because they don't teach it well, they think they do but they don't."*

### **9.6.3 HIV as the explanation for condom use**

The impact of such a process is that HIV becomes the primary or sole consideration in any behaviours that are undertaken for sexual health protection. Thus HIV was identified as the primary reason for condom usage at the outset of a relationship.

*"I suppose in the beginning when you want them to use a condom and everything, I suppose the big one is your HIV isn't it." (Jane)*

and

*"The only reason why I ever thought 'use a condom' was AIDS really, that was the big thing at the back of your mind, that's the one thing that you don't want." (Judy)*

From a theoretical perspective, the rationale on which such behaviours are based is immaterial in so far as the result is the same regardless of the basis of such a decision. It does not matter whether one uses a condom to protect oneself from HIV or chlamydia, protection from the other occurs incidental to the primary purpose. However, such a result is only achieved if personal concerns regarding HIV are translated into consistent self-protective behaviours. By definition the participants in this study had engaged in behaviours that had theoretically exposed them to the risk of HIV. Their fear of HIV had not translated into consistent self protective behaviours. A high level of awareness of HIV, to the extent that it overshadows any other consideration in personal behaviour, could be considered to be a two-edged sword in a Western culture where the levels of HIV have not reached the epidemic proportions that were originally forecast.

### **9.6.4 Perceived personal risk of HIV**

Several contributory explanations for not needing to protect oneself from STI's, which include their association with specific peoples and behaviours and a personal sense of invulnerability, were discussed in detail in chapter eight. These effects are more pronounced with HIV than with any other sexually transmitted infection. There is a perpetuation of the association of HIV infection with specific groups of people and behaviours. To some extent the assumption that this infection is a matter of consideration only in conjunction with homosexuality persists and was clearly apparent in the account of Wayne.

*"I'm not homophobic but I reckon that gays get it mainly so no, it's no problem to me."*

Increasingly however it is considered in terms of those of other nationalities as the scale of HIV in the African sub continent has continued to increase largely unabated and reached pandemic proportions. This is the coverage which dominates the HIV scene in the media representation. This coverage reflects the reality of the situation in demographic terms, however in so doing it reinforces the view that HIV is located in the otherness of cultural difference. HIV is more fully located in otherness than any other infection. Therefore the gulf between a theoretical fear of HIV and a perceived necessity to protect oneself from the possibility of becoming infected is greater for HIV than any other infection as Paula explained.

*"They just think that there's HIV, they don't think that there's the little ones out there, they just think that it's the big , but we'll not get that anyway because it's really hard to get and nobody's got it round here anyway."*

The magnitude of HIV in this context reflects the impact of becoming infected. In the majority of cases, the bigness of HIV describes the public representation of the infection and the consequences of being infected with a viral infection for which there is no cure. Its size is related to the personal consequences of infection rather than the statistical probability of becoming infected which would result from high prevalence of HIV infection. Indeed, it is the low prevalence that creates a lack of proximity which diminishes the immediacy of the danger. On the one hand therefore HIV can be categorised as big, whilst simultaneously it can be presented as small thus explaining behaviours that could produce exposure to infection. This was well described by Tom.

*"You just don't think about STI's as being big where you are, coming from X, no one sort of talks about it and you don't see people dying on the street, not like in America where people have got AIDS and you don't know anyone with AIDS, whereas in Africa everyone knows someone who's got it because it's quite big over there. I think if it gets to that level here people will take more care."*

This reflects a representation that disconnects the risk from one's own health. In this respect the anxieties expressed could be considered to equate more to those responses that are associated with feelings of detachment generated in response to rare and tropical diseases such as Ebola virus (Joffe and Haarhoff, 2002) rather than those that one is likely to be personally familiar with. Whilst the level of anxiety

provoked in relation to HIV is high, the perception of it being a disease of others creates a sense of personal invulnerability in this respect (Wyn, 1994). Protective behaviours that are assumed to have come about as a result of perceiving a need to protect self from HIV have been waning in recent years and have been cited as a contributory factor in the unprecedented rise year on year since 1995 in the prevalence of the majority of STI's and particularly chlamydia (HPA, 2004). If the threat of STI's is the threat of HIV, and HIV is known about in a theoretical way but considered the concern of others, predominantly those in other Continents, then one does not consider oneself to be at risk in any real sense.

#### **9.6.5 Fear of diagnosis**

One consequence of the anxiety surrounding HIV is the fear of being diagnosed with the infection. HIV is an infection that does not make itself readily identifiable in so far as it is largely asymptomatic until the appearance of opportunistic infections that occur secondarily to the primary infection (Mindel and Tenant-Flowers, 2001). The public health consequences of an asymptomatic infection and the improved health outcomes associated with detection and antiretroviral therapies (op cit) have resulted in the screening of identified populations. One such population is GUM attenders. It is policy in the GUM clinic to offer HIV testing for all those who present with STI's in recognition of the possibility of co-infection. This practice is supported by the Sexual Health and HIV strategy which set targets for the uptake of HIV testing in this setting (DH, 2001a). The majority of the respondents that had attended GUM as part of their infection management accepted HIV testing. In several instances this was perceived as a valuable thing because it provided opportunity to obtain a clean bill of health.

*"I came in here for chlamydia but I've had tests for absolutely everything and now I know that everything is fine. I can walk out of here today and go right, I know I'm not HIV positive, the test has come back negative, all my other STD tests have come back negative."* (Karen)

Some however declined HIV testing, primarily as a result of the anxiety associated with the possibility of a positive result. The majority of those who request HIV testing do so on the basis of symbolic purpose and there is little serious consideration of a positive result (Lupton et al., 1995a). In common with other types of medical screening, the primary purpose of requesting testing is to confirm the absence of infection. However to be offered HIV testing within the context of an STI screen in a specialist GUM clinic requires someone to face the possibility that they have been exposed to the virus as

this is the basis on which the testing is offered. The reality of testing positive, however small, needs to be confronted although a move towards routinisation of testing in this setting may decrease this effect (Stanley et al., 2003). Whilst the issue of HIV testing was not an issue for many, and indeed was viewed in a positive light by some, this was not a universal response. Several of the respondents explained their decision to decline the HIV test. In part this was explained in terms of anxiety surrounding the procedure, specifically the necessity for venepuncture.

*"I would have liked to have done it [HIV testing] because I would have liked to have known for sure, but I just couldn't." (Marion)*

In another case the reason for declining the test was more clearly based on the possibility of a positive result. For Tracy, the acceptability of the test lay in the probability of a negative result whilst the possibility of a positive result which had become a reality in the light of recent experience served as an effective deterrent.

*"I haven't had an AIDS test yet, but I plan to have one, but I daren't, I know it's completely irrational because I probably have not got AIDS but I just don't want .... It makes you realise, if you can catch chlamydia, then you can catch other things even though I know it's not highly possible that I've got it, but I've still not had it done, I'm not keen."*

### **9.7 Conclusion**

Although chlamydia is viewed as a stigmatising infection by virtue of its classification as a sexually transmitted infection, it arguably represents less of a threat in comparison to all other STI's. A categorisation system exists which provides the means by which to create a hierarchical structure of STI's. This derives from a number of assessment elements and relates to a range of characteristics which span epidemiological considerations such as commonality as well as medical determinants such as treatability and the cultural concepts of abjection that relates to the visibility of effect. Given the multifaceted construction of this system, the high degree of consistency with which it was used by almost all the respondents indicates a considerable level of robustness.

## **Chapter 10: Threats and Dangers**

### **10.1 Introduction**

A diagnosis of chlamydial infection carries with it a number of threats. These require management both in terms of the danger that they pose and the development of strategies and intentions designed to minimise their effect. There are three separate but interrelated ways in which their effect has an impact, firstly at the level of the individual body, secondly within an intimate relationship and thirdly within the wider social context.

In the first instance the diagnosis raises the inevitable question of where the infection has come from. The public health imperative to trace the route of infection in order to treat sexual contacts necessitates the sharing of information which includes personal disclosure. This requirement to share one's diagnosis with partners has the propensity to produce speculation about the source of infection which carries the risk of recrimination.

In a wider context the sharing of information carries with it a degree of danger. This resides in the possible reactions that it may generate in others and the impact of that upon an identity that may already have been made vulnerable by the diagnosis itself. The sharing of information with others results in a loss of personal control both in the way that it is spread and the way that it is used. When the information carries social consequences its impact may expand beyond the limits of the infection itself in both magnitude and temporality. The decisions around information management therefore have considerable importance in the social management of the infection and preservation of identity.

On a bodily level the presence of an infection is evidence of its vulnerability and susceptibility to invasion. The expectation that this 'won't happen to me' has been replaced by the reality of 'this has happened to me.' Those physical and social safeguards that were assumed to protect oneself have been shown to be fragile and inadequate. As a consequence, previous behaviours and activities are examined and a number of behavioural intentions are generated on the expectation that they will provide more comprehensive and effective protection thereby preventing a recurrence of the experience.

## **10.2 Information management**

### **10.2.1 The importance of information control**

The power of information lies in the way that it is used and the effect that this has on both the subject and the recipient. One key aspect of managing a stigmatising condition is that of information control, determining how much information is divulged and to whom in order to preserve sense of self and protect oneself from the anticipated negative reactions of others. "To tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where " (Goffman, 1990 p. 57). The stigmatising effect of STI's lies in their social location and considerations of information control are largely concerned with a reluctance to be categorised as someone who has an STI and the anticipated impact on social identity. There are two possible effects that one would wish to avoid. Firstly the immediate effect of possibly being judged by those to whom the information is divulged and secondly the loss of control that arises from sharing information.

### **10.2.2 The sharing of information**

For those diseases recognised as stigmatising, decisions around information control centre round the benefits and risks of disclosure. Secrecy is a common feature which often extends well beyond that of the medical condition. Strict limitations are imposed in terms of whom to disclose to for fear of stigmatisation and discrimination (Scambler and Hopkins, 1986, Jacoby, 1994). However the sharing of information can provide a means of accessing emotional support and concealment therefore carries an emotional burden. In the case of HIV this has been shown to be emotionally exhausting because it deprives the individual of social support (Alonzo and Reynolds, 1995). When decisions are made about informing family and friends they largely hinge upon a recognition of the need for emotional support, but are tempered by the possibility of rejection and condemnation (Katz, 1997).

### **10.2.3 Wider moral effect**

When a moral reputation is considered to be at stake, the tenacity of such an association presents a threat to self that extends well beyond the episode of infection, particularly when combined with a loss of control over information spread. It is the temporal dimension of a stigma that renders it ineradicable and irreversible (Alonzo and Reynolds, 1995). The threat of the information coming into the possession of someone who is an unsafe receptacle (Goffman, 1990) and the consequent potential dissemination through a social group provides a powerful disincentive to disclosure.

When the stigmatising effect of the condition stems from its moral construction, an opposing moral imperative exists in relation to these decisions. From a historical perspective, the emergence of infectious disease theories had a profound effect upon public health morality, the responsibility that individuals were expected to assume in protecting themselves and others against infection (Tomes, 1997). In relation to STI's, the structures and processes of partner notification reflect this imperative. It serves to challenge any personal inclinations to maintain secrecy and may therefore produce a degree of conflict in terms of decisions about who to share the information with and from whom to actively withhold information, in terms of one's social contacts, including current and previous sexual partners, friends and family. Whilst the predominant response was to limit the number of people who knew about the infection, a number of factors influenced these decisions and led to information sharing in certain situations. This was justified in relation to identified rationale; however it carried with it a degree of risk to self both in the immediate and the longer term.

#### **10.2.4 Carriers and sign-vehicles**

The primary purpose of keeping the diagnosis of an STI secret is to protect oneself from the possibility of assumptions being made about one's social and moral behaviour. It requires decisions to be made about disclosure. These decisions are controllable in as far as the individual can determine whether to tell or not and if so to whom. Through other means however, disclosure may occur indirectly and unintentionally. In social settings the accessibility of many different sources of information and their transmission through sign-vehicles enables a composite picture of the person to be constructed (Goffman, 1990). Sign-vehicles are the means by which information is conveyed, they provide clues which allow assumptions and predictions to be made. Whilst these include body gestures and facial expressions, they may also include other pieces of information that are accumulated incrementally and interlinked to form an increasingly complex and comprehensive picture. The meaning of one piece of information, its significance and interpretation is determined by its context which in turn is considered in relation to other pieces of information. In this way information may inadvertently be disclosed that one might otherwise have chosen to keep secret. These pieces of information function as indicators, in so far as they may inadvertently disclose the diagnosis, or produce circumstances that force a disclosure which might not have happened otherwise. These pieces of information may therefore need to be safeguarded or managed in order to protect oneself from those judgements that the infection is taken to indicate.

### 10.2.5 Indicators of infection

A number of pieces of information may make an infection that is largely invisible more visible. Attendance at a specialist GUM clinic is one example that will be discussed in more detail in chapter eleven, however a number of other indicators were also apparent in the data. These related to all aspects of the infection, from the appearance of symptoms, to the testing and treatment. Their function as indicators was variable. It depended upon the extent to which they were shared with others, the expertise of the recipient in being able to interpret this information, and the willingness of the respondents to acknowledge linkage between the indicator and core information. Their role as potential causes of the disclosure of diagnosis was generally less clear cut than attendance at the GUM clinic because the linkage was less apparent. Consequently they may have been less of a danger in terms of information leakage, however their significance lay primarily in their variability and the extent to which they were controllable.

When physical symptoms cause concern, a natural inclination is to tell someone about them. Lay knowledge sources are commonly used for reference purposes, either to allay anxiety and determine a cause (Johnson, 1991) or determine the significance of symptoms by providing boundaries of normality (Chasse, 1991). When the appearance of symptoms does not suggest the possibility of an STI, there may be no apparent reason to refrain from sharing symptom information on the basis of what it may mean. Indeed being unable to identify a possible cause may increase the likelihood of sharing information with someone else in order to decide what to do and whether to seek medical advice. The vague and non specific nature of the symptoms will decrease the likelihood of the confidante making the link with the diagnosis unless they have specialist knowledge, however sharing the initial information may produce an expectation that subsequent information, including a diagnosis will also be shared. Decisions may therefore have to be made as to whether to disclose or to conceal the diagnosis. As a consequence others may become aware of the diagnosis who may not have done so under other circumstances as was the case with Michelle.

*"I told her [mum] because she knew that I'd been bleeding and everything. Perhaps if I hadn't told her that, perhaps I wouldn't have told her [the diagnosis]."*

A number of aspects of infection management served to function as indicator information including attendance at the hospital, diagnostic tests, and medication which required temporary abstinence from alcohol. These activities do not directly disclose

the infection; however they do increase the possibility of disclosure and may therefore necessitate protective activities. Hospital attendance may be discussed with friends or colleagues, perhaps in order to negotiate time from work. Whilst there is no imperative to disclose the purpose, it may produce an expectation to do so. For Jacky this resulted in the disclosure of information that she might otherwise have chosen not to divulge.

*"I decided to tell my friends because it was actually because I had mentioned that I had to go to the hospital, otherwise I don't think that I would have told them"*

Alison who also needed to take time from work in order to attend the GUM clinic felt it necessary to construct an alternative explanation to protect this information.

*"When you say I'm going to the hospital people want to know why, and of course, I'm having time off work, I'm not going to tell them I've got chlamydia, it's not something you say, I was embarrassed ...I've had to tell a few porkys at work, I've just got to, I said I've got a water infection."*

Diagnostic tests function similarly in this respect. For those who underwent testing, particularly in the absence of symptoms, it was not necessarily unacceptable to tell others that they had been tested for infection because to be tested for infection is a responsible thing to do. However this information sharing did not necessarily extend to sharing a positive result with friends or family. The difficulty lay in managing a situation where others who had known of the testing expected to be informed of the results, a matter of greater secrecy, subject to careful and discriminating disclosure.

*"They know I've been but there's only certain ones that I'm going to tell, the rest of them I'm going to say that I've not got anything because I feel safe like that, it's not going to get spread around, it doesn't look very good if it gets spread around, so just keep it to certain people." (Mandy)*

The social acceptability of being tested for infection does not extend to the possibility of having that infection. This phenomenon is evident in other related aspects of health. Cervical screening is so widespread that it is the majority experience; testing is largely considered a moral obligation and non compliance is viewed as deviant (Howson, 1999). However the high level of acceptability of the test does not extend to abnormal

results which are commonly associated with a range of negative feelings including self-blame and carry fears of social sanction (McKie, 1995, Quilliam, 1992).

Similarly, whilst it may be socially acceptable to request testing for chlamydial infection because it is considered a responsible action, this acceptability does not necessarily extend to being diagnosed with the infection as 17 year old Beccy explained.

*"We do talk about the possibility of getting checked out but I never told anyone that I did have chlamydia, we don't talk about it but we did talk about testing..... I suppose it's not OK [to tell them that you have an infection] because I think people will think that it's dirty, that they'll look at you differently, and they'll think she's a slag or whatever because she's dirty, I don't want people to know that."*

#### **10.2.6 As an indication of unprotected sex**

The diagnosis of an STI itself also acts as indicator information revealing core information about sexual activity. In a pragmatic sense, all that an STI indicates is that someone has engaged in an act of unprotected sexual intercourse with someone who already has an infection and that the organism has been transmitted from one person to another. Even within this limited context there was considerable reluctance to disclose the diagnosis because of the moral significance of the information that it indicated.

In current sexual health terms the moral imperative, persistently and powerfully represented by more than a decade of high profile health promotional messages in the wake of HIV, is to ensure that all sexual activity is protected by the use of condoms (Edgar, 1992, Metts and Fitzpatrick, 1992). In this construction, unprotected sex is considered to be both dangerous and irresponsible. Consequently to reveal oneself as someone who has an infection is to open oneself to such a charge, all the more so, if this is known to be the viewpoint of the person to whom it may become apparent. It was on this basis that both Tess and Peter made their decisions to ensure that they did not disclose their diagnosis.

*"One of my colleagues, she's just starting a new sexual relationship and she's not had one for a couple of years and so she was all excited about that and the subject of condoms and STDs did come up and she was saying how she was so adamant that she wouldn't have sex with a strange bloke unless he was wearing a condom and so*

*that has kind of made me not want to tell her because she'll think, stupid, you didn't use a condom." (Tess)*

and

*"I haven't told parents for example, I wouldn't want them to know because they would probably be disappointed in me or something, for having unprotected sex." (Peter)*

### **10.2.7 As an indicator of moral character**

The social and moral assumptions that have come to be associated with STI's over the centuries mean that their presence is taken to indicate much more in terms of sexual behaviour and moral character than simply acts of unprotected intercourse. These concerns formed the basis on which active decisions to maintain the secrecy of the diagnosis were primarily made. On a bodily level there was some concern that one might be spurned and avoided as a result. In part this reflected the sense of bodily discomfort that accompanied feelings of dirtiness but it also incorporated considerations of contagion which were evident in several accounts. One respondent had been advised to avoid using the toilet facilities in the GUM clinic whilst another described how a friend ritualistically disinfected the toilet after it had been used by another friend with genital herpes. On a more general basis, contagion was expressed in concerns that one might be distanced from friends, that *"you're going to be left out and that they'll not talk to you."* (Paula)

Concerns also related to the possibility that others may make judgements about one's behaviour, that one might be considered to 'sleep around'. This was less of a concern with close friends because their knowledge of one's sexual behaviour and number of partners would modify their opinions. It was more of a concern in relation to the wider social circle on the basis that one might acquire a reputation among those who did not have such personal knowledge, a reputation that would prove hard to dislodge.

*"If I told someone they'd think, oh, it's because you've been about a bit, but I haven't, but it's just like it can get passed around quite easily and people don't know and you think, oh, I'll get a right reputation if this gets out, but it's not like that at all."* (Julie)

and

*"Well, it's a personal thing isn't it, if you label yourself with that once, people will just think that you're dirty, do you know what I mean, people spread rumours and Chinese whispers, and from having that it will turn into bigger things."* (Tom)

Once information has been shared with someone, there is a consequent loss of control over its subsequent spread. Whilst some may be expected to keep the information to themselves, others may be considered less reliable in this respect. Decisions as to whom they chose to share this core information with were largely influenced by considerations as to whether or not they were likely to keep it to themselves.

*"I'm not sure whether to tell ex-boyfriends or not, because I know that they'll probably end up spreading it around." (Mandy)*

### **10.2.8 Confiding in others**

When information was shared with others, in the majority of cases it was with previous sexual contacts and current partners. As this situation raised specific considerations it will be dealt with separately later in the chapter. In all other situations, decisions to share the diagnosis were largely determined by the degree of emotional support that they could be expected to provide. This commonly translated into sharing with close friends and family even though such disclosures may not have been originally intended. The most valuable support however came from those who had previously had the infection and could therefore empathise and share the experience in a way that arguably no else could, an experience that has also been identified by those with genital warts (Hammarlund and Nystrom, 2004). These are 'the own', those who know what it is like to have this experience and who can provide instruction, moral support, comfort and acceptance (Goffman, 1990) transforming personal experiences into collectivized experiences (Bulow, 2004). One of the inherent difficulties with sexually transmitted infections is the degree of secrecy and consequent lack of information that surrounds them. Whilst it is a fundamental right of the individual to determine how much personal information they decide to divulge, the effect is a high level of information control by the majority of people. As was previously identified, this created a sense of anxiety around the rarity of the infection and a consequent feeling of isolation. To know of someone else who had had the infection was considered helpful. It reduced the feelings of isolation and provided opportunity to allay anxieties regarding all aspects of the situation, from symptoms, to treatment, service access and even as a means by which to rebuff implications of sexual behaviours.

*"S said well, tell D about it .....and anyway I told her and she were in stitches, she were laughing and I said what, and she said, I've got it as well. I said oh my God, how's that possible and we were just laughing about it and it were just that it were funny that we'd got it but that we hardly knew each other and I'd just told S and I thought well nobody*

*else can have it. So it made me feel a bit better and we talked about it, and then when we were clear we were like oh, I'm clear now and then she'd be clear and it were like somebody to talk to about it that had been through it so it were nice." (Paula)*

and

*"My sister, who's also had it, she's never had any symptoms for it and she found out she'd got it and my sister, she's been, she's had very very few partners..... that helped, my sister, because I said to my partner, even X and Y have had it and he knows my sister's not been with many." (Jane)*

### **10.3 Contact tracing**

The most obvious people with whom information needed to be shared were sexual partners, as the means by which they could rid themselves of infection, and in order to protect oneself from subsequent re-infection. Contact tracing is the mainstay of public health measures to reduce the prevalence of infection and has been a formal part of GUM clinic activity since the 1940's (Wigfield, 1972) although it was first documented as a method of STD control in the nineteenth century (Cowan et al., 1996). As outlined in chapter two, the legal framework and the organisational structures of the GUM clinic enable notification to be done by health professionals. However the majority is carried out by the patients who take it upon themselves to inform their partners (Jarvis et al., 1999, Clarke, 1998, Stokes and Schober, 1999). In relation to chlamydia, it is generally recommended that all sexual partners in the six months prior to infection should be informed of possible infection and advised to attend the clinic for testing and treatment (CEG, 2002). The process of partner notification is both supported and overseen by the clinic staff and forms one of the objectives of a follow up test (op cit). In this respect it represents a particularly overt example of surveillance where retesting provides the incentive and the justification for asking people to return (Dale et al., 2001).

The vast majority of the respondents described having notified current and past partners. For a small number of the respondents the task proved too difficult in the first instance. For Chris who had recently embarked on a relationship, having been treated and charged with the responsibility of informing her partner of the situation, she found herself unable to do because she *"was just too scared of how he would react"* with the result that she exposed herself to re-infection. Many others also found it difficult for a variety of reasons. Some of these related to the quality of the relationship itself although the effect of this was variable. For some, such as Sue, an established and intimate relationship appeared to make the disclosure easier because *"if you've got*

*someone who you know you can trust, it's easier to tell them" whilst for others such as Paula it was the emotional attachment that made it more difficult to inform a current partner in comparison with past partners "because I care about him".*

### **10.3.1 Concern for partners**

Several described how they had gone to considerable lengths to ensure that current partners attend the clinic by reminding them and by making appointments for them. Many also described how they had contacted partners from the distant past, rather than confining themselves to the recommended six month period. When face-to face communication was difficult due to geographical separation or communication breakdown, it necessitated extra effort and the use of alternative methods. These ranged from telephone calls to letters and text messages that enabled the information to be transmitted without the necessity of a two way dialogue. Despite these difficulties there was a strong sense in much of the data that contacting partners, current and past, was a requisite activity. A small number of respondents reported their decision not to inform some past partners, for fear that they may spread rumours. However this was very much a minority view.

What then was the basis on which these decisions to inform were justified? The primary concerns that permeated through the accounts were for the welfare of those to whom they were or had been emotionally attached. The discovery that they had the infection, and that it was therefore highly probable that their partner would also have it, produced an imperative to tell that person in order that the infection could be dealt with. This was the basis of their decision despite, in some instances, considerable anxiety about the personal cost of doing so as is evident in Tom's account.

*"It's dirty isn't it, I've got to go and tell L today and tell her that I've got chlamydia and that's terrible ....it's not nice, it's embarrassing and it's humiliating and it makes you feel dirty as though it's your fault ... it's important to get it sorted, that's the main thing, it doesn't really matter how I feel about it, I'd rather not tell her, but I've got to, there's no two ways about it."*

### **10.3.2 Concern for others**

The basis of decisions often extended beyond this immediate effect and encompassed concerns for the long term effect of having this infection, both on the partner and on others to whom they might subsequently transmit it. A sense of personal vulnerability was a significant element that ran through the experience of having this infection and

largely determined the thoughts and actions that resulted. This was evident in the initial response to diagnosis, in the necessity of ensuring that treatment had been effective, in declared strategies that would protect against re-infection and in concerns round the possibility that long term damage may have occurred. Their personal experience had highlighted for many the insidious and pervasive way in which this infection can spread through a sexual community with the result that they felt obliged to stem its progress, despite reservations about the effect of doing so, and negative feelings towards the person who they considered may have given it to them.

*"When I found out what it was, I thought I'd best tell him in case he's got it 'cos if he goes with someone else, he could be passing it on." (Helen)*

and

*"I was at first like well, I'm not telling him because he deserves all he gets but I think with the other girls and what not, I think they should be contacted ...it would make my conscience better, knowing that I've let him know." (Andrea)*

and

*"I didn't want to [tell him] but they have a right to know haven't they, if they pass it on to other people, it's not really fair ... I texted him." (Laura)*

For this group of people the morally responsible thing was clearly to do what they had done; to get themselves treated and then facilitate and encourage others to do so. This is reminiscent of the sense of obligation displayed by women towards others to ensure that they complied with the cervical cytology programme (Howson, 1999). It was clear that they felt that they had to pass on infection information in order to fulfil their moral obligation and that they felt positive about their actions, that they had done the right thing. Although some appeared to have found it difficult to do so, the process of contact tracing provided a means by which to dissipate any feelings of guilt and shame that may have occurred as a response to the infection, a finding that concurs with the work of Faxelid & Krantz (1993). In the case of Steve 'doing the right thing' produced a clear sense of pride.

*"I've warned her like, do you know what I mean? I've told her. I can't make her go to the hospital, I can't drag her up to the hospital, all I can do is warn her or tell her to get herself checked out, I hope she does, I'll be proud if she does."*

When those whom they informed did not appear to be acting in like manner, it provoked feelings of anger, on the basis of the social irresponsibility of spreading this

infection to unsuspecting others for whom the consequences may be considerable. This was one aspect within which several of the respondents presented themselves as the responsible self. For example Angela, who considered that she had been infected by a previous partner, displayed a strong sense of outrage at his apparent irresponsibility on the basis of his disinterested response when she informed him of her infection status.

*"It's upsetting really because I know he's one of those people that does sleep with a lot of girls and he's just passing it on and passing it on and I can't go round everyone and say he's got this and he's got that. I can't do that. it's upsetting really that a girl could be in my situation, could be here next week finding out that she's got chlamydia and could be infertile. It's just upsetting really that he's infecting everyone without telling anybody." (Angela)*

### **10.3.3 Presenting a responsible self**

Accounts of thoughts and actions that constitute the research interview provide a means by which to compose an impression and project a definition of who we are, what we do and why we do it. In their telling they create order and structure in past events and render future ones less threatening (Kelly and Dickinson, 1997) and in so doing they enable a particular self to be constructed through them (Riessman, 1990). Illness narratives commonly have a moral component which links the personal and the social, where narratives of culpability combine with those that exonerate self from blame in order to preserve self worth. They provide a means by which the self can be presented as virtuous (Bury, 2001). These accounts of contact tracing decisions similarly represented a means through which the respondents could present a particular image of themselves as socially responsible, a means by which to redress the balance and make reparation. It provided an opportunity to create an account in which one can define self as 'good' in the light of prevailing social constructions that define self as 'bad' (Stanley, 1999).

Frank has suggested that bearing responsibility for others has been largely lost, a casualty of modernity (Frank, 1995) however these accounts challenge such a statement. Notwithstanding the possibility of some tendency to present a moral self, this was the basis on which many of the contact tracing decisions appear to have been justified. In this respect it shares commonality with other health surveillance activities which are particularly associated with women. Mothers are constructed as moral guardians for the health and well being of the family (Lupton, 1995) and women

frequently report the active recruitment of others into cytology programmes in the conviction that it is in their best interest (Bush, 2000, Howson, 1999). For women who are HIV positive, activities such as spreading a message or undertaking a mission provides opportunity for moral management and represents a strategy for reconstruction of a moral self (Stanley, 1999).

It is noticeable that in relation to partner notification, whilst both males and females considered it a personal responsibility to undertake this role, they all justified it in terms of their own partner and the wider female circle. Thus if women thought their partner was unlikely to attend for treatment, their concerns largely centred round the impact of infection transmission to other females. However there was no comparable concern among the men that their partners would not attend and that they therefore represented a risk to other unsuspecting males. This may reflect a greater expectation among men that women would attend for treatment, or a greater concern among women for women's health that is reminiscent of their active involvement in health screening processes (Bush, 2000, Howson, 1999). However it appears to be more strikingly a reflection of the dominant view of biomedicine that portrays this infection almost exclusively as a problem for women's health. Whilst men are recognised as transmitters of the infection, the focus of attention rests on its possible long term effects on women. This conjures up fundamentally different roles for men and women where men are constructed as vectors and women as reservoirs for the infection. In doing so it disadvantages men by failing to acknowledge the possible impact upon their long term health and disadvantages women by reinforcing the historical representations of STI's.

#### **10.4 Sourcing the infection**

The decision to inform a sexual contact that they required investigation and treatment for infection was important for the management of moral identity. Inevitably this would require the individual to share their own diagnosis with that person. However the process of doing so represented a threat to the precarious preservation of that moral identity.

##### **10.4.1 The risk to self**

The spoiled social identity that defines this as a stigmatising condition, albeit temporarily, formulates the individual as discredited. To have to then present oneself to one's sexual contacts runs the risk of creating conditions that have social consequences, a situation Goffman (1990) describes as 'tensionful.' The primary

conflict that resulted from telling a partner about the chlamydial diagnosis was the immediate impact it produced in terms of the partner reaction. For many the diagnosis elicited feelings of bodily pollution which were difficult to deal with. To see oneself as contaminated, and then to have to disclose the diagnosis to one's partner is to open oneself to the possibility that they will also view you in this way.

*"I wanted to see what his reaction would be as well I think, because I felt horrible and dirty I didn't want him to feel like that about me." (Paula)*

Even though these concerns may not have been born out in reality, they contributed to the level of anxiety that permeated many of the accounts of this process. The sociocultural construction of this infection makes the question of 'where did it come from?' relevant. It is within this understanding that disclosure becomes a potentially vulnerable situation. There are two possible interpretations of the situation. Either that they transmitted it to their partner or that they received it from that partner. Within this construction both may become valid matters of debate invoking the concepts of culpability or blame.

In some cases the sexual histories of themselves and their partner lead to a clear assumption of where the infection had come from. This was primarily based on the number of previous partners, particularly if it was a first relationship for one or other, or if one or other had been previously tested and confirmed clear of infection. Whilst these may have been suppositions in some cases, when they were accepted by both, there was little attempt to lay blame at the feet of the other. In other cases, it was much less clear. When the route of transmission was contested, it provided opportunity for an unequal apportion of culpability which fell predominantly upon the person in whom the infection had been first identified. This person was liable to the charge that they were the source of infection within that relationship.

#### **10.4.2 The significance of symptoms**

The appearance of symptoms in one person and not the other, or prior to the other, may be viewed as highly significant from a lay perspective and lead to an assumption that this pattern reflects the chronological passage of infection. This logic cannot be extended to chlamydial infection because it does not follow a predictable pattern in terms of the appearance of symptoms. However it is the basis of medical and lay understanding in relation to a number of other infections and it formed the premise on

which a number of the respondents made assumptions as to who had passed the infection to whom.

*"Because she's not had any symptoms and I'm the one telling her, I mean, if she came to me and told me that she had chlamydia, then I would probably feel that she gave it to me." (Tom)*

*and*

*"Because I found out first that I had it and not him, he was funny to me ..... but he said you've got it first." (Gail)*

Although founded on a faulty logic, it is not the inaccurate application of scientific principles that is relevant in this respect, but the potential interpersonal consequences of this type of reasoning in respect of a morally constructed infection. The assumption that the person in whom the infection has manifested itself, or in whom it has been first diagnosed, is the source of infection within that relationship provides opportunity for the second person to occupy the moral high ground. It enables them to present themselves as 'the innocent,' the one who has become infected and in so doing it exposes the other person to the possibility of recrimination. Whilst this is not a foregone conclusion, the possibility of it may be sufficient in itself to produce anxiety and form the basis of concern in someone who is infected, fearing and anticipating such a response from a previous partner that she has to contact.

*"What I'm scared of is him blaming me and I know it can't be but I think that's it that's worrying me the most." (Jacky)*

Whilst such fears were sometimes unsubstantiated, in other cases this was exactly the type of response that a partner invoked. In some instances this was expressed by inference in a reaction that clearly denied the possibility of him being the source. By asserting that it was *"not from me and that was it really"* Jean's partner effectively rejected the possibility that he was the source of infection thereby implying that it was she who was culpable. In other instances it provoked overt accusations from partners, not only that the respondent had transmitted the infection and was therefore to blame, but also that there had been a degree of intention attached to such an action.

*"He's one of them people that he blamed it on me for giving it to him." (Helen)*

*and*

*"I can't believe you, you've done it on purpose." (Shirley)*

These responses illustrate the effect of revealing the presence of an infection that is largely constructed within a specific social and cultural context, where the source of the infection is considered to be important enough to dispute the issue because of the imputation associated with it. What is in dispute here is not conduct within the context of an established relationship, but a retrospective scrutiny of past relationships and behaviours in a situation where both partners are, at least theoretically, aware that there is a past sexual history. However it creates opportunity for one person to exercise considerable moralistic power over the other, to make accusations which are grounded either in the intimate details of her sexual response or her behaviour by implying intent.

*"When I spoke to the lad he was like where did it come from, are you sure it wasn't from you because you know, you're really juicy when you get going." (Isobel)*

There is no defence to either of these. How can one counter an accusation that the physiological changes that occur during sexual arousal are in some way indicative of the fact that she must have infected him, or answer the charge that one has deliberately passed on an infection of which one had no knowledge? Both reflect those constantly reverberating historical precepts of women as reservoirs of infection (Spongberg, 1997, Connor, 1996). They are deeply disempowering to the individual. She is placed in a vulnerable position as a result of the disclosure and is then required to defend her position and her moral reputation in order to counter the accusations and mollify her partner as Shirley felt obliged to do.

*"I can't believe you, you've done it on purpose, but I convinced him and he's happy again."*

#### **10.4.3 Bringing previous activity to the fore.**

Within a relationship, sexual history is not generally discussed in detail even though both partners may be aware that there have been previous partners. Much of the evidence that relates to perception of infection risk in relation to these respondents indicates that there was little examination or consideration of past behaviours. If self protection measures were adopted at the outset, the likelihood of their usage diminished rapidly with time. The increasing level of familiarity and emotional commitment that accompanied a developing relationship and led to a rapid diminution in the perception of infection risk served to distance that person from their sexual past. This situation changed with the identification of infection. It caused the person with the

infection to re-examine their sexual networks in order to determine where the infection may have come from. It also brought those networks under the scrutiny of others, notably their current partner for whom the physical proof of previous relationships was unsettling and upsetting.

*“But it sort of upset him, the whole thought of me being with someone else and that sort of thing.” (Margaret)*

This created an unequal focus of attention upon one partner rather than the other again producing an imbalance in the way that past behaviours are viewed and moral judgements are made.

The distancing of oneself from one's past relationship at the start of a new relationship assumes symbolic meaning in terms of new beginnings. The establishment of trust that is considered an essential element in many such situations is founded upon an expectation of monogamy and sexual exclusivity in both males and females (Flood, 2003, Thompson and Holland, 1994). The appearance of infection re-establishes this link with the past. By reinforcing the existence of this kind of sexual history to their current partner, it provides the opportunity for past behaviour to be seen as an indication of future behaviour with a consequent imputation of distrust by one's partner.

*“He's heard things about my past and then for me to go and tell him that I've found that I've got this, I just felt as though it would put a strain on the relationship thinking oh, she's got this and I've heard about her past, she's not going to be faithful to me.” (Jane)*

This constitutes another example of the unequal power distribution in this situation. The future behaviour of one partner is now anticipated on the interpretation of her past behaviour which has also acquired this additional morally charged component. The onus now rests upon her to prove her fidelity whilst leaving her partner in a relatively invulnerable position.

This tendency to apportion blame was not confined to the male partners of females who found that they were infected. Similarly those who expressed concerns that they would be subject to such accusations were not exclusively females as Tom's account in section 10.4.2 indicated. However, by far the majority experience was for the men to apportion blame and the women to expect that they would be blamed. This was evident even when there was little doubt as to how infection had been introduced into

the relationship. The sample did contain a disproportionate number of women, and in the majority of cases, the infection had been diagnosed in them prior to their partner which influences interpretations of chronology as identified previously. However the extent to which culpability was evident, both in terms of magnitude and intensity, suggest that the primary cause of such responses was socially constructed gendered differences in the way that STI's are viewed.

#### **10.4.4 As an indication of infidelity**

The degree of importance associated with non-monogamy is likely to carry more significance within the context of a stable relationship. When this is coupled together with a personal conviction of one's own behaviour patterns it may produce accusations which are levelled at one's partner even prior to establishing whether or not they also carry the infection. When there is suspicion of infidelity in a relationship, this produces a very powerful piece of information that can be used as evidence to support an accusation even though it may be met with denial.

*"... I know the person that I think he cheated on me with and you hear a lot of stories and background related to her ..... He won't admit it, he keeps saying he hasn't done anything wrong and I know that I haven't, so someone has got to have done something." (Jodie)*

What is particularly striking in this respect however is not the way in which testing is used as a proof of infidelity but how the infection is located. Whilst for Jodie it served as an indicator of her partner's behaviour, the source of the infection remained firmly located within a woman with a reputation that clearly categorises her as someone who gets STI's. This is the historical legacy of a prevailing discourse that persists in vilifying the woman as the site of infection whilst simultaneously presenting the man as the victim whose crime lies in straying from the straight and narrow path of monogamy. It has been internalised so fully, it is reinforced and reflected by both men and women alike.

#### **10.5 The protection of self**

In someone who has had a chlamydial infection, an immediate and readily understandable reaction is an intention not to repeat the experience. Diagnosis provides concrete evidence of a specific behaviour and the consequences of that behaviour, namely the realisation that at some point in the past, unprotected sex has resulted in the transmission of infection. A common response to this realisation was a

reflection on what may have contributed to the occurrence, a regret of past behaviours and a determination not to repeat the experience. This resulted in a resolution to make modifications or amendments to behaviour to ensure that it didn't happen again and a declared intention to adopt specific protective strategies. The majority of accounts contained some description of those strategies that the respondents intended to adopt in order to protect themselves.

Much of the data collection took place at a stage of the process when the respondents were awaiting and anticipating confirmation of the resolution of infection. The experience of infection was relatively recent for the majority of them. Expressions of intention should be considered as largely theoretical and conjectural reflecting a number of elements, a sense of vulnerability and a wish to protect oneself as well as a means by which to construct and present a responsible self. One participant however was interviewed twice. The first time was when she attended with her first episode of infection. She was interviewed for the second time approximately thirteen months later towards the end of the data collection process when she returned with a repeat infection. This unanticipated opportunity provided a small insight into the association between her actual and intended behaviours. A comparison of her two accounts illustrates the conflicts that emerge in relation to the issues around intention and protection of the self. Therefore, Jean will be presented as a short case study at the end of this chapter.

In general there are three possible self-protection options available to an individual. The first two of these reduce the possibility of contracting the infection from someone else either by ensuring that a sexual partner does not carry the infection because they have been tested and if necessary treated, or by preventing the onward transmission of infection by the consistent use of barrier contraception. Both of these strategies were consistently identified as behavioural intentions in the data, either separately or in combination.

A third option that was apparent was the decision to undergo future testing oneself. The intention to be tested at some date subsequent to the current episode of infection was identified by many of the respondents, either separate from or in conjunction with one or both of the other strategies. Testing is clearly a means of identification rather than prevention and in this respect it differs fundamentally from the other two options. The presence of the organism can only be detected if one has already become infected. The danger of chlamydial infection resides primarily in its invisible presence

and the potential effect of this both in the short term and the long term. In this respect therefore, testing may provide a means by which to reduce the threat of the infection because detection enables it to be treated and eliminated. The value of testing however extends beyond that of detection. Its primary role in self protection resides in its capacity to confirm the absence of infection and the consequent security that such information provides.

Decisions which are made at the time when one is being treated for infection may influence future behaviour patterns. However it is by no means certain that they will do so. Indeed, epidemiological data relating to re-infection rates would suggest that intentions are frequently not translated into sustained action (Mardh and Persson, 2002, Xu et al., 2000). However this type of speculation is not the focus of enquiry. The significance of these deliberations lies in their construction as a product of the dominant public representations of risk and health behaviours, and their outworking within a personal and inter-relational context.

The behavioural decisions and the way that they were envisaged collectively represent two fundamentally separate and distinct approaches to the concept of self protection. The first of these is a routinised approach where the risk of infection is portrayed as an ever present possibility. This requires a response that is standardised and consistent. In relation to condoms this consisted of intentions to use them as an ongoing and consistent aspect of behaviour for the foreseeable future and in some cases, for ever after. In relation to testing for infection it translated into a routine of undergoing testing for infection at regular and defined intervals. Such actions are largely dissociated from the interpersonal considerations of a sexual relationship. Therefore this could be considered a safe and unthreatening approach to the concept of self protection. It is also reflective of dominant health messages around risk and of those health activities which are characterised by regular testing.

The second approach was to link the testing and contraceptive activities to sexual behaviour and to partners. In these terms, testing was anticipated in relation to the perception of infection risk within a relationship. Condom use was envisaged as a time limited activity, where cessation of usage was dependent upon evidence that demonstrated the removal of risk. In this context, testing for infection was envisaged as a ritualistic process marking a point of transition within the lifespan of the relationship. It was presented either as something that the respondents envisaged themselves going through or that they would require future partners to go through at a

significant point in the relationship. This approach is founded upon a personalised concept of risk. In some respects it appears to be a more rational and discriminating approach, however there are a number of fundamental difficulties associated with it. It requires that future partners are viewed as a potential source of infection and has resultant consequences for the partner and the relationship that are largely absent from the routinised approach. These include the requirement for a degree of intimate communication and an expectation of partner conformation that conflict with prevailing sociocultural constraints.

### **10.6 Retesting intentions**

There were two threads that ran through the descriptions of the infected state. One was the concept of contamination and a frequently expressed imperative was the need to feel clean. The test of cure conducted after the completion of treatment was instrumental in this process as discussed in section 8.5. A second concept was the element of risk and an expressed vulnerability to the possibility of re-infection. A movement from the position of 'it can't happen to me' to 'it has happened to me' opened up the theoretical possibility that 'it might happen again.' An infection that does not manifest itself in a clear and identifiable way and for which re-infection is a possibility, created anxieties as to how one might become aware of its presence in the future. This sense of vulnerability was reinforced if the infection experience was not associated with recognisable symptoms. The diagnostic test takes on special significance in this respect. Its central role in the detection process resulted in many of the respondents expressing an intention to be re-tested in the future, as a means by which to achieve security by the provision of ongoing protection of a vulnerable body.

*"Now I know that you can not have symptoms, it could be something more serious that isn't a symptom that could cause a problem later on in life, so I would say you're better off going for a swab, like coming here quite regular, like, just to make sure, it's better to be safe isn't it." (Robert)*

The experience of having already gone through the procedure of testing reduced concerns about the possibility of being tested again at some point in the future. Removal of fear of the unknown and having overcome the barriers associated with using a stigmatised service, reduced the reluctance to accessing the service on subsequent occasions. Consequently a number of the respondents felt able to consider the possibility of attending the clinic again with equanimity and in some instances almost with alacrity as Steve indicated.

*"I'd love to go through tests again, just to make sure, I'd feel, now that I know what's going off and I know what's happening and I know what to do and everything, it would stop me thinking about stuff, worrying, it's just pretty straightforward, just like going to the supermarket, buying some crisps and coming back out again."*

If one accepts that infection is an inevitable risk of sexual behaviour and requires some means by which to prevent the long-term consequences of infection, then regular testing provides a way in which to identify and then treat any infection on an ongoing basis. If there are no significant physical or psychological barriers to accessing the service and instigating such a course of action, then the natural conclusion is a behavioural pattern that includes regular attendance at the clinic for testing and if necessary treatment.

#### **10.6.1 Testing in the absence of infection**

A number of respondents expressed a willingness to be tested for infection on a routine basis. The explanations provided centred predominantly around use of the test as a means of making sure that there was no infection present, of 'being on the safe side.' It was founded upon an underlying expectation that the result of the test would be negative, its purpose being primarily to provide peace of mind. There was little indication in such a context that it was associated with an increased perception of infection source and transmission in behavioural terms, rather the test served a central function of providing ongoing reassurance and peace of mind. Indeed it was considered by some to have a function in the absence of any possible exposure to infection, as a means of making sure. This was clearly demonstrated by Steve whose infection was not associated with symptoms and who had consequently come to see testing and treatment as a good thing in itself, distinct from any perception of possible exposure to infection.

*"Of course I would [consider testing], just to be on the safe side, even if she hasn't been with anyone else behind my back or I haven't been with anyone behind her back, I could be 100% sure but I'd probably still come up just to make sure."* (Steve)

This reflects the public portrayal of screening as the responsible thing to do, unlinked to risk perception. Comparable activity is evident in relation to requests for HIV testing where the test is used as a way of protecting body boundaries, of re-establishing feelings of self-containment following sexual encounters, rather than in relation to perceived exposure to infection (Lupton et al., 1995b). In terms of chlamydial infection,

the body boundaries have not only been threatened but breached and to this extent the requirement for self-containment, realised through tests of cure and follow up testing may be greater.

### **10.6.2 Periodic testing and screening**

A number of the respondents identified routine testing as a realistic approach to take, with several of them drawing on the cervical cytology programme as a comparable activity. Periodic testing and screening activities throughout the lifespan are a modernist response to the threats posed by diseases, particularly those that are invisible (Lupton, 1995) to the extent that they have become institutionalised practices in specific groups and specific stages of life. This is exemplified by the cervical cytology programme which for most women has become an obligation, where the invitation to participate is perceived as expectation of compliance (Howson, 1999). Cervical cytology and other screening has become institutionalised to the extent that some viewed it as compulsory and as such an approach that should be extended to chlamydial screening.

*"I think they ought to make it compulsory as well, when you go for like an examination at the doctors, they should actually do a test, I think they should actually make it compulsory. Like your blood pressure, that's compulsory to do, I reckon they ought to do a test to everybody that way, like breast screening, that's compulsory, like the smear test, that's compulsory, they should do that." (Angela)*

Routine screening represented an attractive and desirable proposition on a number of counts. Pryce identified how the GUM clinic is primarily concerned with the policing of sexual roles and anxieties, realized through activities of the clinic itself and through the recruitment of active patients in practices of self-surveillance (Pryce, 2000). Routine testing for a sexually transmitted infection exemplifies this process by its effective detachment of the medical process of looking for infection from those activities that resulted in its acquisition. Whilst it may be considered as the product of the disciplinary mechanism of biomedicine (Armstrong, 1983), it represented an acceptable option to a number of respondents for precisely those reasons. Secondly it imposes a degree of regularity on the testing interval that standardises and normalizes. This enables it to be incorporated into a life timetable that is punctuated by a multitude of institutional, social and personal interval events which range from annual festivals to daily routines. In health terms this is characterized by three yearly cervical cytology, two yearly eye tests and six monthly dental checks.

An institutionally organized screening programme that produces letters of invitation and reminders could be considered to be a way of pressuring women into behaving in the 'correct' way by requiring that they opt out rather than opt in (Bush, 2000). This is an acknowledged aspect of any institutionalised practice that aims to increase uptake by removing personal responsibility for initiation of the process. For those who expressed a wish to comply but recognized personal limitations of reluctance and inertia, service initiated invitations for attendance presented an attractive means by which to facilitate their attendance for a process that they considered personally and morally desirable.

*"If somebody said to me, if I got a letter in 6 months to say that you're due to come back, I'd just come, because that's like when you get your letter for smears ...because I get a letter through that says right, you've got to have one, we've made you this appointment, if it's not right then change it, I just go and do it...but I think if the onus is left up to me to come I'm dreadful and I would think oh yes I will and then I wouldn't, I'm sure I wouldn't." (Jenny)*

The testing in this instance did not reflect considerations of the possibility of being infected. Its routinisation enabled it be constructed as a responsible activity in which one might participate even though no possibility of a positive result exists as Jenny went on to explain.

*"If someone told me that I had to go, yes then I would, even if I thought it was totally pointless, I'd still go if they said that I'd got to. But if they said come back in 6 months if you think you need to then I wouldn't, I'd never think, I wouldn't have thought that I needed to come now."*

Devolving the responsibility for determining the time interval to the health service medicalises it and assumes that there is some scientific basis on which it is founded, in much the same way as screening intervals are set for breast and cervical screening. Whilst the aetiological basis of these is fundamentally different, nevertheless routinised screening requires a time interval to be attached to it. One aspect of responding to a service initiated screening programme is that the testing interval is determined by someone else and this may be one of the contributory factors that underpinned such explanations.

### 10.6.3 Frequency of testing

A key question in relation to regular testing is the frequency with which it should be carried out. There does appear to be a high re-infection rate with this infection. Studies indicate incidences ranging from 6-13% at 4 months after the initial infection (Mardh and Persson, 2002) and an increasing incidence with increasing length of time in those under 20 years of age (Xu et al., 2000). However recommended re-screening intervals have not been established (Mardh and Persson, 2002, SIGN, 2000) and retesting is currently not recommended practice, even in those who have had the infection. There was some indication that it may occur in specific settings with two respondents citing regular six monthly testing as common practice in the army. However there is currently no significant professional or public discourse of retesting and retesting intervals although a retest study was undertaken subsequent to the Department of Health prevalence study and will inform future discussions.

The intervals that were identified by the respondents were arbitrary in respect of this infection, but derived from other comparable health experiences. Any standardised interval is fundamentally flawed in relation to an infection that may potentially be contracted immediately after treatment. The interval that is set bears no relationship to the behaviour of any individual. The attraction of regular surveillance lies in its ability to enable separation of sexual behaviour from its consequences. This separation affords a degree of safety to the test, thereby increasing its social acceptability. However the detachment that is afforded by such an approach, which effectively presents the infection as a separate and nebulous entity, may paradoxically also increase the danger to the individual because of potentially lengthy time intervals between infection and testing.

The dilemma of establishing a suitable time interval was recognised in the data.

*“But there again, what can you do about it [the asymptomatic nature of infection]. You can’t drag everyone into a clinic every week saying right, you’ve got to have a test for this, that and the other.” (Karen)*

A very frequent interval is clearly impractical even though for Jean, immediate feelings of anxiety about susceptibility to infection resulted in an expressed intention for this level of reassurance.

*"Once a week if it were up to me. I'll be coming more often, I can't see why because I won't be doing anything but....." (Jean)*

This degree of anxiety is likely to diminish with the passage of time and with it the imperative to be frequently tested. Even though Jean was initially very keen to be tested frequently, her intentions were not translated into practice as she explained when she returned several months later with a second episode of infection.

*"I did intend to go for regular checkups but I didn't really think about it."*

#### **10.6.4 Determining the screening interval**

Suggested screening intervals largely draw upon the recognised and well established processes of routine screening that are associated with other health considerations. Roth identifies the way in which health careers have an internal structure, being divided into periods of time by markers or signposts by which one can monitor progress. When a new career arises alongside an older and pre-existing one, it will be aligned such that the lack of clarity between events is reduced by making them equivalent to analogous points on the pre-existing line (Roth, 1963). Screening intervals and contraceptive consultations constitute signposts on the established careers of cervical health and contraceptive usage. Thus cervical health is monitored at three yearly intervals whilst ongoing hormonal contraceptive provision depends upon satisfactory assessment by health professionals at service determined intervals. When an additional career, that of freedom from chlamydia is added, these provide two alternative paths along which it may be aligned. In two cases cervical cytology was cited as an appropriate opportunity to be tested for infection, possibly as a reflection of both the established routine that it presents and the anatomical and procedural similarities of the two tests. However, when it was used in this way, it was in relation to a forthcoming smear test rather than as providing a realistic retest interval. The cytology screening interval of three years was not cited in this way, in all probability because it would be considered too great. The respondents were most likely to fix upon a 6 monthly interval in their stated intentions of retesting.

*"I might make an appointment every 6 months or so, I don't know, just do something like that." (Wayne)*

and

*"I'll probably do it every 6 months from now on even if I don't go out with anybody, just for safety really, peace of mind ...just to make sure even if I don't think I've got anything." (Tracy)*

and

*"I think I just do, probably every 6 months I just go and say can I have some swabs done, I don't think I give them a reason and they do them and they're clear." (Jane)*

This interval reflects experience of other comparable health consultations, for example dental checks which are drawn upon in the explanations. Most evident however was its linkage to contraceptive consultations both as an opportunity to use routine appointments for this secondary purpose and as a comparable career line against which to align chlamydia testing. In this context, it was the frequency of the primary consultation that determined the retesting interval.

*"I go there for my pills every 6 months and I do usually ask them if they will do a test to see if I'm alright." (Helen)*

and

*"I think before you go onto the depo, because its such a long term 12 week injection, I think that they should test you before you have that, because it is a long term injection and think of all the partners that you could be swapping in between them and not having condoms because some people think that they don't need them for anything apart from protecting yourself from pregnancy." (Sian)*

This opportunistic approach presents advantages in terms of economy of effort and as a means of overcoming the difficulties of initiating testing in its own right as was reflected in the accounts above. It has a historical legacy as the original approach to cervical screening prior to the introduction of the call recall programme and was more recently used as the primary method of approach in relation to chlamydia screening (Underhill et al., 2003). However if retesting is attached to contraceptive consultations, then the time interval is determined by the frequency of those appointments which is itself variable. Some appointments such as those for Depo Provera are determined by therapeutic considerations. The majority however, such as 6 monthly appointments for supply of oral contraception have no such basis. This interval is arbitrary, established by custom and practice and is not inevitable as supply intervals may range from a few weeks to twelve months depending upon individual requirements. To this extent therefore they constitute an unstable basis on which to found a testing interval.

These accounts suggest that many of the respondents saw regular chlamydial testing as the means by which to protect themselves from the danger and threat of undetected infection. In the majority of cases this located it within the construction of pre-existing health surveillance structures. In some cases this was represented as a fully routinised call and recall programme with a stand alone structure. In others it was constructed as a routinised process with time intervals imposed upon it by separate but related health activities.

This viewpoint largely reflects the professional perspective both as a means by which to normalise and destigmatise the infection (DH, 2001a) and as a realistic approach in efforts to reduce prevalence. Although the Expert Advisory Report (DH, 1998) stopped short of proposing routine testing at pre-determined intervals, it did recommend opportunistic testing of young women using other health attendances as the means of access. This was justified on two counts. Firstly biological considerations given that the sequelae of infection are greater in women than men. Secondly on the basis that young women are a more accessible population than young men, being more likely to attend health care facilities where screening is feasible. The report recommended assessing individual risk of infection but was focused exclusively on women and on family planning clinics and general practice as the means by which to access them. This incorporates chlamydial screening within those other routine aspects of female embodiment, notably cervical screening and contraception. This has been reflected in the opportunistic screening study and can be expected to become standard practice as it provides the basis of the chlamydia roll out programmes (LaMontagne et al., 2004). However the logistical difficulties and the high frequency of offering testing that occurred with this study has resulted in a call for a standardised call-recall chlamydia screening programme (Perkins et al., 2003).

In effect therefore the views of these respondents are in accordance with the professional perspective. However a consequence of this approach is that it serves to perpetuate the representation of women as transmitters and contractors of infection, the psychological and emotional consequences of which are considerable as was evident from the earlier section in this chapter.

The surveillance processes for women brings their sexual activity under intense and detailed scrutiny in a way that is almost unknown to men (McKie, 1996) however it simultaneously provides facility for them to access services in a way that is largely unavailable to men. In this sample, future testing intentions were less pronounced in

the men than the women, however they were identified as a reasonable course of action by a few of the men, most notably Steve. There is no comparable structure for men into which they can locate testing requests and they must therefore initiate the process without the facility that routine consultations provide. This focus on women and the use of pre-existing structures peripheralises men and as such it serves to reinforce existing inequalities by the tacit acknowledgement that they cannot take responsibility for their own sexual health (Duncan and Hart, 1999).

### **10. 7 The consideration of testing within relationships**

Testing strategies that are linked to sexual behaviours differ fundamentally from routine testing. They are founded upon an understanding that acknowledges the possibility that one's partner may represent a source of infection and therefore a danger to self. Testing is undertaken either by self or a partner in the context of the relationship. This approach raises a number of potential interpersonal difficulties and may therefore present a threat to the relationship itself. However it also has the potential to provide security within a relationship. A partner who represents danger as a potential source of infection prior to testing represents safety subsequent to testing when they can be demonstrated to be free of infection. Consequently decisions about the need for continued protection can be based upon the information that this approach provides.

#### **10.7.1 Safety within an ongoing relationship**

In an established relationship, diagnosis of infection in one partner leads to a medical assumption that both are infected and the approach is to treat both partners even if there are discordant results. For those respondents in this position, the primary concern was the confirmation of the elimination of infection. Where there was no expectation of partner change this enabled the couple to view themselves as a closed unit, safe from the possibility of re-infection. As such there was little intention to return for retesting.

*"My way would say that me and G are together and so I don't see that we should have any problems." (Alison)*

This position of physical safety also removed the necessity for continued personal protection in terms of continued condom use. As a result it provided opportunity for greater sexual freedom and enjoyment as Angela explained.

*“C and I have been tested for lots of things and we know that we’ve not got anything. I think as soon as this is cleared up, I don’t think we’ll be using condom. I know that everything is cleared up and we don’t like using them anyway.”*

Clearly this security is dependent upon both partners having been declared free of infection and therefore upon the willingness of both partners to be treated. When this was not the case, ongoing protection of self was the only possible means by which to prevent re-infection. For Margaret, whose partner had refused to attend the GUM clinic, the resultant constraints on sexual activity that she described contrast with the tantalising possibilities that she envisaged when he had also been treated.

*“We can never get carried away in the heat of the moment, we can never just be doing something and slip into sex and out again. We’re always going to use a condom no matter what .....when we’ve both been cleared, and we both know that we haven’t got anything, if I’m on the pill, we don’t necessarily have to use condoms all the time, if we both know that we’re clear of everything.”*

#### **10.7.2 Testing strategies within a relationship**

To envisage testing within the context of a relationship requires someone to view their partner as a potential source of infection from which they need to protect themselves. This approach is fundamentally problematic because of the location of STI's in otherness and the categorisation and undesirable attributions of those 'people who have STI's'. This may make it difficult to conceive of the possibility that a partner may have an infection. However the egocentric basis of partner assessment, together with the realisation that infections are not socially selective that comes from having been infected oneself, enables consideration that 'it happened to me' and therefore that 'it might also have happened to him.'

To raise the possibility of the existence of infection with a new partner requires these concerns to be verbalised and therefore become more concrete. It also exposes the individual to the responses of their partner. As identified previously, much of the concern about disclosure of an infection was founded upon the anticipation of negative responses from others. This concern is clearly evident in respect of raising the possibility of testing. The individual places herself in a highly vulnerable position by asking the question. She opens herself to the possibility of being charged on one of two counts. Firstly that she was making assumptions and accusations about her partner.

*"I don't know if I'd dare to say to a new partner, I don't know if it'd scare them off or something, but I don't know if I could ask them, but I feel if I had to ask them they would think that I thought that they were dirty." (Beccy)*

Alternatively that the request that a partner be tested must stem from her own experience and therefore indicate that she herself has or has had an infection.

*"I can hardly talk to him, go and get yourself checked out and he's like why, what's wrong with you, why are you so funny about it, have you had something?" (Isobel)*

Consequently, whilst this approach presented the means by which to protect oneself from infection and therefore offered physical safety, it represented a significant potential threat to the relationship and therefore simultaneously represented interpersonal danger. Notwithstanding this, it was identified as a realistic strategy by a number of the respondents. Within this overall strategy, a range of alternatives were apparent in terms of the specifics of the approach which offered a greater or lesser degree of interpersonal danger and physical safety.

### **10.7.3 Testing of self**

In someone who has been previously demonstrated clear of infection, undergoing testing oneself at the outset of a new relationship represents an indirect and somewhat imprecise way of ascertaining whether a partner is infected. Such an action may have consequences for that relationship, particularly if the result is positive. However it represents a relatively safe action in comparison with the more direct method of requiring that a partner attend for testing. This was the logical conclusion that a number of respondents arrived at in terms of the best way of protecting themselves.

In common with routine testing, partner related testing appeared to emanate primarily from concerns about bodily pollution. For Beccy, who had experienced a profound sense of contamination as a result of the infection, the prospect of retesting subsequent to holiday relationships provided a means by which to regain and maintain bodily control even though it was considered in the context of a low perception of infection risk and may have necessitated a frequent retest interval.

*"I will do [return for testing] after I get back from holiday, even, I was talking to the nurse about it before and even with a condom on, there's still, the bacteria's that small, there's still a chance that you can easily catch it, there's less chance but the possibility*

*is there, so if you don't know who you're going with and their background I think you'd have to really, I think I'd want to know anyway because it makes me feel dirty and I want to feel clean, clean, its important."*

Whilst such an intention was clearly expressed, the extent to which it may be translated into action is likely to be influenced by a number of factors which several of the respondents acknowledged. In many cases, the passage of time might be expected to diminish the perception of risk and consequently the resolve as was previously identified in the case of Jean. Alternatively however, as Jill identified, the memory of previous experience may with the passage of time serve as sufficient motivation to initiate action.

*"[Testing at the beginning of the relationship] would definitely be something that I would contemplate 100%. I can't say obviously whether I would go through with it, but it would be there and I think it would fester on my conscience, and the more I was with him, I think it would be always niggling me, especially after the experiences that I've had, I wouldn't want to go through that again."*

Adopting this approach requires that the frequency of testing is determined by the frequency of partner change. For Isobel, this was sufficient deterrent to cause her to reject the prospect, at least during the time of greatest partner change.

*"You never know, in the next year I could sleep with another three blokes so I might as well wait after those blokes until I've found my man and when I've found my man then I'll be alright. So you think, what's the point of taking it now and going through all that awful rigmarole whatever they do to you, so it's like, so I've got that and then they do whatever and then the next week I see another bloke ..."*

#### **10.7.4 Requiring that one's partner be tested**

For those who did feel able to contemplate broaching the subject of testing with their partner, the timing of such a request was determined by the conflicting interests of protecting one's sexual health whilst also protecting the relationship from potential emotional conflict. Two alternatives were identified in terms of the stage of the relationship at which testing was to be required. For some the obvious point at which the issue needed to be dealt with was prior to commencement of a sexual relationship. This would provide the highest level of personal safety by ensuring that there was no possibility of exposure to any infection that may be there. This suggestion appeared to

be born out of the respondents' previous experience of having had the infection and a determination not to repeat the experience. However it was also envisaged to serve an ulterior motive as an indication of the partner's view of the relationship and degree of commitment to it.

*"In a sexual relationship, I'll be, I don't know, I think I'll be you get tested or that's it. They'll get tested or I'm not sleeping with them. I wouldn't risk getting it again because it were really painful. If they couldn't do that then it's a waste of time isn't it," (Michelle)*  
and

*"Before I went with anyone else I would actually expect them to go for a check. If they didn't they wouldn't be worth it, if I turned round to them and I said will you go for a check, on AIDS, chlamydia, anything, if they love me that much, they would do it." (Angela)*

In part, these opinions seem to stem from the individual's view on relationships. However they are likely also to have been influenced by previous experience. As discussed in section 10.3.2, Angela's perspective had been shaped by her interpretation of the means by which she had become infected. She felt angry and resentful that she had become infected and considered her infection to be due in part to her previous partner's lack of personal responsibility. It would appear that this influenced her opinions on screening which incorporated elements of both compulsory routine screening and relationship based screening.

The rapid decrease in the extent to which perception of infection risk is maintained within a developing relationship is further confounded in situations where physical intimacy precedes emotional intimacy. As the level of intimacy increases the risk perception decreases. From this perspective therefore it might be important to broach the topic at an early stage of the relationship. However it is a considerable leap from considering someone as a potential source of infection to actually broaching the topic with them. For some, it did not represent a realistic option because it was considered too sensitive a subject to consider broaching at the outset of a relationship. Whilst it may represent the position of greatest physical safety, the interpersonal cost was considered too great to justify this course of action.

An alternative option was to choose a compromise position by waiting until the relationship had become established before bringing up the subject, possibly in conjunction with the prospect of negating the subsequent requirement for condoms.

Although this represented a potential loss of personal safety, the greater degree of familiarity that came with establishment of a relationship served to diminish the level of interpersonal risk to an acceptable level.

*"You've got to have been in a relationship for long enough to say, hang on, why don't we both go to GU and get tested and then we don't need to use the condoms anymore then I suppose it depends, if you've been with someone 3 months you should be able to say that shouldn't you, I think." (Tracy)*

From some however the prospect of requiring a partner to undergo testing was rejected outright. Whilst the willingness to undergo testing was considered by some as proof of commitment to the relationship, for Marion, this was considered too great a requirement to ask of someone else.

*"I wouldn't [ask a partner to be tested]. I'd feel awful saying I want you to go there first, it sounds like I'm laying down some kind of like contract and I'd feel awful, no, I wouldn't bring that up at all."*

#### **10.7.5 Being tested together**

A compromise position was proposed by a few in terms of the option to both undergo testing at the same time. If an individual has been demonstrated to be clear of infection prior to the commencement of a new relationship, then it is theoretically not necessary that they undergo testing themselves at the outset of the next relationship. However, if the difficulty lies in asking a partner to undergo testing, an alternative approach may be to suggest that she and her partner attend for testing together. This may reduce the difficulty in raising the topic and largely overcomes the issues previously identified in relation to blame and labelling and may therefore decrease the possibility of implied attribution of blame both for herself and for her partner.

*"I think it would be a lot easier saying do you think we should go together just to double check than to say, I would even say, even if I knew that I was clear, but just from the point of that person, so, it's not so daunting." (Beccy)*

In this context the cost to self of undergoing further testing appears to be favourably offset by the reduced risk to the relationship whilst also enabling physical safety.

To some therefore the possibility of testing within the context of a relationship represented an appropriate and realistic approach to the problem of self protection. Safer sex in this context is that which takes place between those who have both been shown to be free of infection and as such represents resistance to the dominant discourse of risk that represents consistent condom use as the only reliable means by which to protect oneself (Metts and Fitzpatrick, 1992, Edgar, 1992, Hillier et al., 1998). Clearly it does have limitations in so far as it is founded upon an expectation of monogamy from that point onwards. However trust, a common euphemism for monogamy, is the premise upon which the majority of established relationships are founded. Even in relationships of short duration it is commonly the basis upon which cessation of condom usage is justified, an observation common to this study and many others (Thompson and Holland, 1994, Lear, 1995, Flood, 2003, Skidmore and Hayter, 2000).

#### **10.7.6 The challenge of communication**

How realistic it might be to introduce the subject of testing or to require a partner to be tested is a matter of some conjecture. It was recognised as being unrealistic by several of the respondents and it was largely on this basis that proposals of routine testing were developed. Communication concerning sexual activity is recognised as problematic. There is a dichotomy between the verbal and physical aspects of sexual behaviour where the verbal component is often considered more dangerous than the physical (Pliskin, 1997). Much of the debate around this has concentrated on communication in conjunction with protected intercourse and condoms, the use of which is deeply symbolic, associated with concepts of trust and commitment (Skidmore and Hayter, 2000, Flood, 2003, Thompson and Holland, 1994). Negotiation of condom use is influenced by considerations of power, control and autonomy within sexual situations and there is often considerable discrepancy between intentions and practice. In a study of sexually active adolescent girls, although the majority expressed a willingness to request condom use in future encounters, only a minority had done so previously in practice (Thompson and Holland, 1994). One of the particular problems in making such a request was the necessity of expressing a wish to have sex (Hillier et al., 1998).

Requests for testing may be considered less problematic than negotiation of condom usage because they are detached from the immediacy of sexual activity. However they are more likely to involve discussion around STI's and previous sexual history, which may be emotionally threatening in a new relationship. Commonly therefore such

discussion is not broached (Skidmore and Hayter, 2000) and when it is, it is often accomplished symbolically by the use of indirect discussion (Pliskin, 1997). Testing within a relationship would serve as a verbally indirect and physically direct method of determining infection. It therefore presents an attractive proposition to some although it is likely to be considered an option only within the context of what are considered established and ongoing relationships.

### **10.8 The case of Jean**

The opportunity to interview Jean twice occurred because she coincidentally attended the GUM clinic with two separate infection episodes during the interview phase of this study. The two episodes were approximately thirteen months apart. On both occasions she was generous with her time and agreed to be interviewed. This provided a unique insight into the extent to which one experience informed the other and the extent to which intentions were realised within complex social relations.

On the first occasion she described how she had recently finished a long term relationship with the father of her child. The infection had come to light as a result of abdominal pain and the GP had performed tests *“to see if you’ve got any infection.”* Not surprisingly the diagnosis delivered by telephone had been something of a surprise causing her upset and discomfort. Subsequent to treatment she described several protective intentions to ensure that she would not become infected again. She would require either that future partners would come for testing or that they would be required to use the *“stashes of condoms”* that she had collected. Additionally she intended to return herself for further testing *“once a week if it were up to me.”*

Her second episode of infection was diagnosed after she presented at the GP with abdominal pains. Although the GP attributed these to irritable bowel syndrome, Jean had requested chlamydia testing because she made an association between the two episodes. As she explained:

*“It’s the same pain as I had before and I didn’t really think about it until I got there and I started explaining it to her and I just asked for one [chlamydia test].”*

She related this episode of infection to her previous boyfriend, the father of her child with whom she had re-established a relationship. As she considered that he had been treated in conjunction with the previous episode, she assumed that he had contracted the infection from someone else and then passed it on to her. As on the previous

occasion she stated an intention to ensure that future partners "*go and get tested first.*" In relation to this current episode she had not felt it necessary to require that he be tested before they got together again because

*"I didn't think he would do it again. I trusted him I think. You think when they've done it once they won't do it again but they do."*

In terms of condom usage she considered that her usage had changed because she had "*a lot stashed away in case*" although she reflected that she hadn't used them when she restarted her relationship because "*I didn't think I'd get it again.*"

Since her last episode of infection she had not requested retesting until the symptoms had occurred even though she had attended the GP for a cervical smear in the meantime. As she explained

*"I did intend to go for regular check ups but I didn't really think about it".*

In both accounts, Jean described a long term relationship with her boyfriend, who was also the father of her child. However she described their relationship, which had spanned several years, as being punctuated by periods of separation. On both occasions she described him as a recent but no longer a current sexual partner. She also considered him to be responsible for her episodes of infection although there was some change in the details between the two accounts. In the first she identified the source of infection as a casual sexual encounter that she had had after separating from her boyfriend. By the second account she considered that she had been infected by her boyfriend on both occasions. She assumed that he had been treated after the first episode of infection because she had told him to do so and therefore that he had subsequently contracted the infection again.

A comparison of these accounts highlights a number of points, not least the precarious nature upon which the explanations of events and actions are founded. At a conceptual level they illustrate the point of departure between rationalistic and sociocultural constructions of risk. A rationalistic approach such as is advocated within the health discourse, would have required Jean to use condoms consistently and indefinitely on the basis that all partners represent a potential source of infection. A modified form of this would have required her to use condoms until such time as she and her partner were tested and it was established that neither of them was infected.

Both of these viewpoints are evident in both of Jean's accounts, clearly portrayed through the 'stashes of condoms' and the requirement that 'he go and get tested.' She therefore clearly knew how to protect herself from infection in a theoretical sense.

However, Jean's accounts illustrate the unsustainability of personal danger within the construction of social safety which derived from the characteristics of her relationship and her expectations of her partner. The social situation within which she was located provided her with a sense of social safety such that her theoretical considerations of personal protection became redundant. The stores of condoms remained untouched, confined to the realm of intention and having little personal relevance for her at this time.

Consistent condom usage is theoretically sustainable through two mechanisms. The first is that it become an established behaviour pattern. This does not require one person to consider anyone else as a potential source of infection. It simply requires them to incorporate and maintain condom use as part of their sexual behaviour. The second is that they consider any sexual partners as being a potential source of infection and maintain condom use by sustaining a level of distrust. Both of these are in reality far from simple, determined as they are by a complex interplay between personal, social and structural influences some of which were explored in chapter six and earlier in this chapter. Jean's situation demonstrates some of the reasons for their non viability.

This was a long term relationship, albeit punctuated by periods of separation. Patterns of sexual behaviour had been established long ago and there was therefore no role for condoms as part of routine behaviours. Equally there was no facility for considering her partner as a potential source of infection. On the contrary, her feelings of safety appear to have derived from having a detailed knowledge of her partner, believing that he had been previously treated for infection and that he would ensure that he did not become infected again. To have maintained a degree of distrust in such a situation, given that trust is a fundamental element of a meaningful relationship, is clearly problematic and highlights a fundamental flaw in the health discourse.

Jean's previous testing intentions had rapidly disappeared after her first episode of infection, presumably due in part to the feelings of safety that derived from the circumstances of her relationship. It was the appearance of symptoms and the link that she made between what was happening to her and what had happened before that

acted as a trigger. This brought the possibility of an infection to mind and caused her to request testing, although the body signs that she described may or may not have been directly attributable to the infection in either instance. Their significance lay in their triggering of an embodied memory. They brought to mind the physical experience that she had had before as a result of this infection and consequently raised the possibility that she may have a further episode of infection. It was the signalling of danger in a physical sense that caused her to request a chlamydia test from her GP even though he had already attributed her body signs to some other cause.

Given the high proportion of asymptomatic infections and the variability of presentation in those episodes of infection that do produce symptoms, that embodied memory is unlikely to be available in many situations. It is this aspect of the infection that produces one of the greatest challenges. Testing for infection that would otherwise be triggered by physical evidence is largely dependent upon social indicators that are commonly highly complex, dynamic and emotionally invested such that they fail to be apparent.

### **10.9 Conclusion**

Chlamydial infection represents a threat to self such that information control becomes a matter of consideration. Whilst it is not always possible, because of the effect of sign vehicles, it is a common response to be highly selective as to what information is divulged and to whom. This primarily arises from the moral connotations of a sexually transmitted infection and consequent concerns about the effect of such information upon one's reputation.

The sharing of this information with sexual contacts provides the means by which to re-establish self worth because it is the means by which one can enable others to rid themselves of the infection. However it is in this context that self is most vulnerable to challenge because of the facility it offers for moral positioning, providing the basis on which partners can make accusations of blame and intent and justify questions about past and future behaviours. In this respect testing of one partner in a relationship contributes to a significant imbalance of knowledge and power.

The experience of having had an infection increases the sense of personal vulnerability. One effect of this is a determination to protect oneself in the future which is expressed through a number of intentions. In theoretical terms these may equate to routine behaviours, either routine testing or routine condom usage, alternatively they

may be envisaged as being incorporated within a developing relationship. However the extent to which they are realised is dependent upon a number of factors that collectively comprise the complexity of personal considerations and interpersonal relationships.

## **Chapter 11: Using the service**

### **11.1 Introduction**

The availability of direct access to a specialist service provides the opportunity for the client to choose their service provider if they are aware of both the existence and function of the clinic and the availability of this method of approach. It also provides a referral service for Primary Care providers. It is common practice for many practitioners in Primary Care to diagnose infection in women and then require that they attend the GUM clinic for treatment. Alternatively they may treat and then recommend that the woman attend GUM for follow up. For males there is clear reluctance on the part of many practitioners to instigate any investigations and the majority approach therefore is to refer straight to GUM (Griffiths and Cuddigan, 2002). In both cases it is most likely that partners will be required to attend GUM.

A number of anxieties surrounding the whole process of GUM attendance may colour the experience, possibly to a considerable extent. Such anxieties will be reflected in behaviour patterns. A high degree of reluctance may result in significant delays and even preclude attendance at the clinic. As recruitment of the participants for this study was predominantly through the GUM clinic, this clearly eliminated the voice of those who were unwilling or unable to attend the clinic. The secondary recruitment strategy through the FPC attempted to address this concern. Despite these efforts, it transpired that only one of the participants recruited in this way had not attended GUM, consequently she represents a minority voice in this respect. The majority voice is of those who did attend but who nevertheless did express a number of anxieties which were a matter of considerable concern. Their concerns clustered round two specific issues. Firstly attendance at the clinic itself and secondly the processes that they anticipated went on there and to which they expected to subject themselves, particularly the necessity for physical examination.

### **11.2 Attending the GUM clinic**

Attendance at a GUM clinic serves to increase the visibility of the infection itself. If the clinic is defined in terms of such a purpose, then attendance equates to actual or suspected infection. As discussed in chapter two, whilst it was the lack of adequate treatment facilities that led to the development of these clinics, it was the recognition of this conundrum that resulted in them being hidden from sight and mind, located in hard-to-find corners of the hospital, often with a separate entrance and a title that disguised their function.

However, as previously identified, the geographical and linguistic cloak that has traditionally covered GUM services to ease entry through the clinic door, has paradoxically hidden it from view and confounded attempts to increase public awareness of structure and function. Those systems that are instigated to ensure the anonymity and confidentiality aspects of the service arise from concern for the personal experience of those that use the service. However insofar as they emphasise the public persona of GUM as a service separate and apart from others, they serve to perpetuate the social stereotyping of STI's.

In recent years there has been a move towards standardised usage of the term Genitourinary Medicine either alone or in conjunction with a pseudonym in order to improve accessibility of the service. Thus signposting may incorporate both terms, the function of the clinic, usually expressed as Genitourinary Medicine, and the pseudonym attributed to that clinic. To suggest however that this is a clarification that will prevent misunderstanding of function is to assume that the term Genitourinary Medicine clearly indicates the function of the clinic to the lay person. This may then be further complicated when the term is abbreviated to GUM, as it commonly is in lay and professional references, as this then requires an additional linguistic connection of the term and its abbreviation. The assumption that people will necessarily have sufficient knowledge to make these links is not supported in the data.

*"I'd never even heard of this clinic...so really I didn't know until I came, and then I didn't know where I was coming and I was asking people and they were GU clinic, they thought I was a bit strange really, that was me because I didn't know whether it was a clinic just for this sort of problem" (Michelle)*

In consequence therefore those structures that are designed to enable discrete attendance may paradoxically necessitate visible attendance in so far as it relies upon other's knowledge.

### **11.3 Increasing the visibility of the infection**

The extent to which attendance increased the visibility of the infection itself was a matter of considerable concern to many of the respondents in this study. There were a number of factors that collectively constituted the anxieties around this issue. In part these appear attributable to the anxieties around the physical procedures concomitant with attendance. The investigation and management of genital infections can reasonably be expected to necessitate examination procedures of an intimate and

possibly painful nature and attendance at a service whose function is defined in these terms represents the first stage of submitting oneself to such procedures. It is evident from the data that this factor comprised a significant proportion of the associated anxiety, particularly in relation to males. This will be considered in chapter twelve.

The second core component that was evident in the data as a source of anxiety associated with attendance was the psychosocial significance of attending a service that carries such symbolic meaning in relation to its historical role in the management of STI's.

#### **11.4 Crossing the threshold**

The first aspect of attendance, having ascertained the existence and location of the service, is the physical act of crossing the threshold. Thresholds have special significance as the point of transition from one place or state to another. The establishment and maintenance of specialist GUM services within the structure of the clinic separates it in a concrete way from other interrelated services. In this respect it is comparable to other specialist medical services, however it is the symbolic significance that is attributed to the service and therefore to the boundary that surrounds it that necessitates consideration.

van Gennep (1960) likens society to a house divided into rooms and corridors. Whilst the partitions may be thin and the doors of communication wide and open in a civilized society, as he goes on to suggest, the extent to which this has occurred is not universal and the partitions are still apparent. Equally, whilst those doors of communication may be wide and open, the necessity to pass through the threshold within which they are contained still remains. For some that process produced considerable difficulty and anxiety, a response that has been reported previously, particularly in relation to the first time of usage (Pryce, In press, Evans and Farquar, 1996).

The significance of the threshold in relation to the GUM clinic is interlinked with the social significance of both the infection and the service itself. The function of the GUM clinic is defined in terms of STI's. In the same way that someone with symptoms does not directly access the service because they do not conceive of the possibility of having an infection, the reality of crossing the threshold of the clinic is to bring oneself face to face with the possibility or the reality of having an STI in a concrete way. When a diagnosis had been made and attendance at the clinic was presented as the next step in the process, for several of the respondents there was a sense of urgency about

accessing the service. This is understandable as it represents a desire to be treated and be rid of an unwanted infection.

*"I wanted to go there and then and get it sorted and then forget about it." (Jill)*

For some, the idea of attending the clinic in order to be rid of the infection was not problematic. For others however, even though ridding themselves of the infection was a key concern that compelled attendance, the physical act of entering the clinic proved difficult. In the case of Jean who was having problems coming to terms with the shock of being diagnosed as having an STI, the very act of walking across the threshold was viewed as problematic because of the significance that such an act conveyed.

*"Yes [it was a problem] walking in there, walking into that place in the hospital, especially as it's a place just for things like that" (Jean)*

The threshold is symbolic because it forms the point of entry into the service, the line over which one has to pass. However it is also significant in that it marks the point at which one obtains access to those services that are contained within that facility. The separateness of the service is tightly bound up with its specialist function and the threshold marks the transition into the otherness of those who have STI's but also to the associated specialist care that enables one to deal with such a situation. There was acknowledgement that crossing the threshold was a necessary prerequisite to accessing that specialist care although potentially it may be too problematic for some.

*"But then again, if you're in need of what the place offers, then you've got to have the guts to walk in the door anyway haven't you. But I can imagine some people would avoid it for ever just because they don't want to come through that door" (Judy)*

and

*"I think most people would say to me, oh I don't want to go to GU because its embarrassing, but I say to them, get yourself to GU, you might have all sorts and they'll say no, I don't want to, it's embarrassing" (Tracy)*

### **11.5 Separating the experience**

If one does feel able to cross the threshold, as well as enabling access to a specialist service, it also provides opportunity to distance oneself from that experience once the episode has been resolved by containing it within the confines of the service. This is an opportunity that is not afforded to those who access general health services in

relation to this infection because of the necessity of revisiting those services again for all other health concerns. In this respect the separateness of the service may be considered valuable in enabling someone to distance the experience from other aspects of their life.

The episodic and treatable elements of chlamydial infection create the opportunity to close the episode of infection. Many of the respondents identified their future testing intentions in relation to possible future exposure to infection as discussed in section 10.6. However whilst re-attendance was entertained as a possibility, the value of closing this episode of infection was apparent and the ability to do so contributed to the definition of this infection as little as discussed in chapter nine. The episodic nature of the infection provided opportunity for it to be contained and compartmentalised. The purpose of the retest discussed in section 8.6 was for many the means by which to achieve this in a physical sense with a closure point that allowed the infection episode to be left behind and the person to move on. The structures and the geographical location of the clinic provided additional ways in which to compartmentalise this infection episode for those who crossed the threshold.

The structures and procedures around record keeping and the separate storage of records in the GUM clinic enable this chapter of one's life to be closed and fully compartmentalised if the information pertaining to it has been contained solely within the clinic. Information flow out of the clinic occurs only in response to information flow into the clinic. If a formal written referral has been received in relation to a patient, then there will be a formal written response to the referral service. However in the absence of this, there is no indication in any other health records that the visit to the clinic has occurred. Whilst several of those patients who elected to self refer identified a wish to keep this part of their life separate, not to consult the practitioner that deals with other aspects of their health, the separation of health records was not specifically identified as being a key consideration. However several of the patients who had accessed the service via a primary care provider expressed regret at the consequences of doing so in terms of the documentary information that had been recorded in their general health record. The key regret in this respect was the recurrent effect of being faced with such a record when consulting a practitioner on subsequent occasions either because it served as a reminder of this episode or because of the anticipated reaction from practitioners and a resultant impulse to justify oneself to those people.

*"I wish I'd come here straight away because now it says on my records, at the doctors and I don't like to see it on the screen every time I go to the doctors. If I'd come straight here that wouldn't have happened would it?" (Judy)*

and

*"Every time I come here [to the FPC] and they look at my files and you see a different person every time and they say, oh you've had this, and you shrink, I do anyway, I think oh, no, what are you thinking about me sort of thing, because you don't explain, every time you go in and don't explain what's happened, what your situation is ... so I'm thinking, oh, I bet they think I'm a right so and so if you know what I mean." (Sian)*

Such experiences serve to perpetuate the experience of an infection which it is possible under other circumstances to detach from the rest of one's health and to separate by containment within the confines of the GUM clinic. However such containment is contingent upon direct access to the clinic and therefore an opportunity not afforded to those who arrived there via other routes. It is dependent upon prior knowledge of the implications of consulting other health providers and also requires that those who sought medical care in respect of this infection were aware of the existence of the infection from the outset. However as was discussed in chapter eight, many indicated that they had little awareness of the possibility of infection when they sought medical care in relation to symptoms.

The facility of containing their infection episode within the GUM clinic in a documentary sense is more readily available to men than women and is becoming less and less available to women. The vast majority of diagnoses in Primary Care occur in women. Diagnosis in this setting means that this will be documented in the general health records for posterity creating an infection legacy. By contrast male diagnoses are predominantly confined to the GUM clinic even for those who seek advice from Primary Care as so little male testing occurs in that setting. Documentation that details the diagnosis will only occur in this situation if there is a formal referral to the GUM clinic. The number of women being diagnosed in Primary Care is increasing as a result of the increased amount of testing and screening activities in this setting. In this situation, males are accessed via their partners through partner notification. The current management of this process almost exclusively through the GUM service therefore affords a degree of documentary containment to a man that is not available to his female partner in whom the infection was first identified.

As well as containment of the documentary records pertaining to the infection, there is also opportunity to contain the experience of attending the clinic. The act of accessing a separate service provides one with the opportunity to leave the experience behind when it ceases to become necessary to attend that service. Such a distinction serves a symbolic function in enabling that episode to be closed at the completion of infection management. The location of the clinic in an out-of-the-way place further contributes to this in that it is not in a place that one is likely to pass by in the normal course of events.

*"I know when this is done I'll leave this .... and I won't have to see this and it's just a contained area that once you're not here its gone...I think about it like that because it's round the back of the hospital and you have to drive around to the back. I think I'll never have to drive past it or anything, it won't even occur in my life and I think that that's helped a bit." (Jenny)*

#### **11.6 Being seen**

When entering the clinic, it is possible that one may be observed passing over the threshold. This constitutes a highly visible gesture as there is unlikely to be any other probable explanation for entering the clinic. This is the basis on which discrete locations and separate entrances were instigated from the outset, however although they may be discretely located, the possibility of being seen entering the clinic remained a possibility and a cause of anxiety for some.

*"I kept thinking, what if someone, if I know someone and they see me coming into it, because it used to be called VD didn't it, so everyone says VD clinic and I think someone would, I think they'd look down on you if they see me coming in" (Andrea)*

The extent to which these factors prevent attendance can only be speculated upon. By definition, the vast majority of the respondents in this study had attended the clinic, albeit with some degree of anxiety and difficulty. The statistics indicate a steady increase in the number of people attending the GUM service year on year. It may be therefore that the level of reluctance, to the extent that it actually prevents attendance, is diminishing to some extent and may be a generational issue as Pryce (2004) has suggested. However the perspective of Julie, the single respondent who was interviewed in the Family Planning clinic and who did not attend GUM would appear to lend some credence to the suggestion that the act of crossing the threshold and the

visibility of the infection that results from doing so is an insurmountable problem for some.

*"I saw that as a big problem, getting up there. If you could treat it, I think, obviously I don't know, here, somewhere, at the GP, basically so you don't have to go to that place, it's like going in with a great big banner over your head."*

### **11.6.1 Others knowing why you are there**

A consequence of crossing the threshold is that one finds oneself in the clinic in the company of all those who are also attending at that time. The action of registering and then sitting in the waiting room confirms one's status as a patient. Attendance and being seen in such a place was associated with a high degree of anxiety and personal vulnerability.

On the basis that STI's are synonymous with socially vilified people and behaviours, by association those clinics whose primary purpose is to manage such infections are marked in the same way. If certain types of people have STI's then it follows that GUM clinics are frequented by such people. This results in a situation where people may be reluctant to access such a service because of its definitive association with these people. There are two components to this reluctance. The first is a reluctance to associate and be associated with such people by frequenting the same building. The second is the fear of being seen in this way by others. If you attend a GUM, then you must have an STI. If you have an STI, then you must be 'other'. If you attend the clinic then this easily and clearly marks you out as being other. In relation to the concept of stigma, this represents one of the most visible aspects of a largely invisible and undetectable condition. This was a significant consideration at the point of entry to the clinic as identified previously, however the placement of the entry route in a discrete location served to minimise the possibility of disclosure at that time. On entering the clinic however there is little opportunity for comparable concealment strategies.

STI's are discreditable rather than discrediting in so far as their presence is not immediately apparent to others. It is possible to be aware of the discrepancy between the virtual and actual social identity of someone who is discreditable either before becoming acquainted with them or upon meeting. A discreditable person however has nothing immediately apparent to mark out their spoiled identity. This discrediting factor is in effect invisible and the issue is one of managing information (Goffman, 1990). To some extent these decisions lay in the hands of the individual, deciding who to tell and

who not to tell, and if so how, why and when, an aspect that was discussed in chapter ten. However when it became necessary to attend a clinic designed for the express purpose of managing STI's, those decisions about information management were largely taken out of their control. All those other people who were also attending the clinic would know that they had an infection. They were therefore faced with the reality of being seen as someone with an infection. It created an expectation that others were privy to personal information about them, a feeling of high visibility that was apparent to all.

*"To be honest you think, you're sitting in the waiting room and think I wonder if they know what I'm in for" (Jean)*

and

*"It's just, I don't think you do it to other people, it's more paranoia on yourself, you're sitting there and you think, maybe I've got it written across my forehead" (Isobel)*

This produced a marked degree of self consciousness, a feeling that everyone was looking at them and judging them on the basis of the fact that they were in that particular place. Goffman (1990) describes this as 'defensive cowering', an anticipatory response to the reactions of others that is adopted upon entering a 'mixed'<sup>1</sup> social situation in those who have a discreditable condition. This was evident in the way that Jenny described her entry into the GUM clinic.

*"I came in and I'm like putting my head down and thinking oh God, I don't know, it's just a stigma I'm sure, it never occurs to me to feel like that if I go to the doctors or the hospital normally."*

### **11.6.2 Seeing others that you know**

The visibility of purpose that accompanies clinic attendance and the resultant self conscious response is of significance even if the people that one meets are unknown. However the discredibility stakes are raised if one unexpectedly meets an acquaintance in this situation. Social information about a person is both embodied and reflexive. It is information that is conveyed by a person in the presence of those who receive such information (Goffman, 1990). It is the means by which we categorise others and it forms the basis upon which we relate to one another. The way that we

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<sup>1</sup> I use the term 'mixed' advisedly here. Whilst the shared experiences of those using the clinic preclude this term as will be discussed later in this section, the data indicates that this is how the respondents initially viewed this setting.

present ourselves is our social identity. The imputation of character that one associates with the necessity of attending the clinic challenges that social identity. It creates the possibility that you will be seen in a different way by that person, forcing a re-categorisation and thereby altering social relationships with that person. It also carries the threat of uncontrollable information leakage and the wider implications of being talked about as someone who needs to attend such a place. Consequently the possibility of meeting someone that they knew was a matter of considerable concern for some

*"I kept thinking, what if I see someone that I know, that was the worst thing." (Michelle)*

### **11.6.3 Anonymisation strategies**

The value of anonymity in those attending the service has been long recognised. The provision of discrete waiting areas to reduce the possibility of inadvertent encounters is a recommended feature of all GUM clinics (BASHH, 2001a). However, for those who already know one another, there is little opportunity to avoid recognition if chance produces a situation where they are in the same place at the same time. It is possible and acceptable to attend a GUM clinic under a pseudonym although this option is realistically only available to those who self refer. The extent to which this practice occurs is unknown and a matter of speculation.

An alternative strategy by which anonymity is maintained is by using the unique identifier code as the sole means of referring to people in the open areas of the clinic, for example in calling them from the waiting area. Some clinics adopt this practice whilst others use a first name only, as a compromise between familiarity and anonymity. These strategies can do nothing to anonymise a meeting between acquaintances. Equally, when neither name nor appearance are known to another person, stating the name in a public place is likely to have little significance because it has no relevance to that other person. Avoidable information leakage and discredibility may however occur when a person is known about rather than known, for example a friend of a friend. In this situation, it is possible a name may be known to someone without them recognising it as belonging to the person sitting next to them in the waiting room. Using a name in this situation creates the possibility of linking the person and the name and thereby information leakage into the social network. In this respect therefore some degree of anonymisation may be useful.

The threat however of being seen in the GUM clinic by someone who knows you is balanced by the fact that they are by definition also there themselves. As the purpose of the clinic is seen in terms of STI's, it follows that if you are attending with an STI, then they are also. The extent to which this is considered a mixed social situation becomes modified in the light of experience and reflection. This consideration provided a degree of security to those that found themselves in this situation. On the basis that they were unlikely to tell others of their clinic attendance, logic would suggest that others might be equally as reluctant. To tell of someone else's attendance brings into question how one came to be in possession of such information. The contact within the clinic has not occurred between, in Goffmanian terms, a normal and a stigmatized individual but between two stigmatised individuals and the security therefore comes in the shared stigmatization and a resultant unspoken but shared instinct to keep all knowledge of clinic attendance private.

*"When you come here and you see people that you know, they know why you're here, but I just think well, they're here because of why I'm here so what have I got to worry about. They could say guess who I saw in the so and so clinic but they'll not because they were here as well." (Sue).*

### **11.7 Associating with others that need to attend**

A strong disinclination to meet friends and acquaintances in the clinic was matched by an equally strong aversion to having to associate with those stereotypical categories of people that are considered to frequent such places. STI's are located in certain types of people and behaviours. As the most visible demonstration of the existence of the infection is being seen in the clinic, it follows that those types of people that get STI's will be found there. There is a persistent social view that these types of people exist on the marginalised periphery of society and this results in a disinclination to associate with them because they are 'other.' There is also a fundamental assumption that one is able to identify such people by appearance alone.

Stigma symbols are those signs that draw attention to a debasing identity characteristic (Goffman, 1990). They include a variety of features and aspects of appearance, however their common feature is their ability to determine that individual as stigmatised. Although there are no specific stigma symbols that serve this function in terms of STI's, it is the social categorisation and the physical appearances associated with such categories of people that are used as the visible evidence in this respect. It is self evident that STI's are not confined to specific groups of people. Equally that any

group of people such as prostitutes do not possess characteristics that make them identifiable as such. Prostitutes are a widely diverse group of individuals in dress and appearance (McKeganey and Barnard, 1996). Although there may be specific indicators such as behaviour and appearance in specific geographical locations that may lead someone to categorise another person in this way, these socially bound stigma symbols are context specific and have little transferability. Despite this, these perceptions persist and colour the expectations of who one might expect to meet in such a place as the GUM clinic both in general terms of physical appearance and in more specific terms of social categorisation.

*“ I've got to admit it, I did before I came, I just thought it was people that had got infections and I just thought it would be like loads of rough people in here” (Jane)*

and

*“I think I just expected something full of old prostitutes or something, do you know what I mean, something really bizarre” (Jenny)*

and

*“It just feels as though, like prostitutes come to these kind of places, I know that's wrong, but that's the way people make you feel about it.” (Zoe)*

### **11.8 Conclusion**

A number of aspects of the service effectively serve as considerable deterrents to attendance. They are largely anticipatory and founded upon assumptions relating to the consequences of attendance. The primary problem associated with attendance at the clinic is the way in which it makes the infection more visible and the concerns associated with being categorised in a certain way as a consequence of this visibility. These associations derive from the historical legacy of the GUM clinic that has suffused through the fabric of society. Such a legacy is so tenacious that it precedes attendance. The result is a level of anxiety about attendance that becomes a considerable barrier to access, greater than many of the more commonly identified logistical considerations and sufficient in some instances to prevent attendance.

However the structures that produce this degree of visibility also provide the means by which to separate and compartmentalise the infection episode. By contrast infection management in primary care provides a means by which to avoid visibility in a public sense in so far as attendance at such a service is not associated with STI's. However in primary care the loss of visibility comes at the cost of containment as infections managed in this arena become indelibly written into the health record, serving as a

permanent reminder to self and staff of an episode that one might have wished to have left in the past.

## **Chapter 12: Being done to**

### **12.1 Introduction**

The point of interface between the health professional and the patient has considerable impact upon the patient's understanding of the infection and thereby contributes significantly to the way in which the infection is managed and viewed by the patient. The number of professionals involved in this process varies depending upon the route that the individual takes through the health service. For some who self-referred, their experience was limited to consultation with those working in the GUM clinic. For others who had been tested and diagnosed in another health setting, their experiences were shaped and formed through their contact with both non specialist and specialist GUM service providers.

### **12.2 The involvement of primary care**

The involvement of Primary Care was a much more likely occurrence for the females than the males. This produced significant differences between the male and female experience. For a number of the females, the initial examination and diagnosis had occurred in Primary Care whereas only one of the males had been diagnosed in General Practice, on the basis of a urine test performed in response to symptomatic presentation. Any aspect of infection management that related to Primary Care was therefore an issue that was largely confined to females.

The Primary Care setting, where non specific presentations are managed by generic practitioners represents a significantly different experience to that of attendance at a specialist service for a suspected or established sexually transmitted infection. In the first instance there are considerations around the way that non-specific symptoms are managed in a generic health care setting. Secondly there are communication issues both in terms of the patient's understanding of what has been done to them and why, and also of the way that potentially emotionally traumatising information is conveyed in a non specialist setting.

#### **12.2.1 Prior experience of the physical examination**

One particular aspect of the difference is the experience of the physical examination. It is highly significant in so far as it is inextricably linked with the process of infection management. In the majority of cases it is the means by which the infection is detected and even when it is detected by other less invasive means, for example a urine test, genital examination remains a component of the GUM clinic experience. However the

intimate and sensitive nature of the examination extends its significance to incorporate personal and emotional considerations and it therefore has implications that embrace the wider considerations of the infection experience.

Experience of a genital examination prior to attendance at the GUM clinic was very different for males and females. Most of the females had been examined previously, either specifically in relation to this infection episode or on previous occasions in conjunction with other health considerations. They were therefore much more likely to be familiar with the examination than the males who had little previous experience of genital examination. None of the men had been examined previously in other health care settings in relation to this episode and only one reported previous attendance at the GUM clinic. For the majority of the men in this sample therefore genital examination was a novel experience, a situation that is likely to largely reflect the wider picture. This situation produced gender specific considerations that related specifically to Primary Care; the extent to which the purpose of testing was understood and the way that this impacted upon the infection experience. It also produced gendered differences in relation to genital examination which merit comparison and consideration in relation to their implications for both males and females.

### **12.2.2 Testing for chlamydia**

The majority of testing occurs in the Primary Care setting and consequently the majority of infection is detected in this setting (Underhill et al., 2003). This situation will clearly increase as the chlamydia screening programme is rolled out into Primary Care. As has been identified previously this places a clear emphasis on the testing of women (DH, 2001a, LaMontagne et al., 2004) which reflects the current position. Indeed, consideration of testing is so firmly located in women that the existence of men is not acknowledged in many studies that have considered aspects of current and proposed management of chlamydial infection in Primary Care (Pimenta et al., 2003, Joshi and Dixon, 2000, Tobin et al., 2001, Armstrong et al., 2003). In those that do there is marked reluctance by either GPs or Practice Nurses to carry out any testing on males whether or not it involves genital examination. Little testing of males occurs overall in Primary Care. The majority of those who attend with symptoms are referred to GUM without prior testing (Ross and Champion, 1998, Griffiths and Cuddigan, 2002, Shefras et al., 2002). Similarly whilst there is a body of literature that considers the female genital examination in psychological and sociological terms, a comprehensive literature search of medical, nursing and social science literature revealed no comparable literature that related specifically to the male genital examination.

### **12.3 The process of looking for infection**

Genital examinations are performed on women for a variety of reasons. Some of these may be considered regular surveillance practices whilst in other circumstances they are conducted when women present with symptoms, in conjunction with the diagnostic process. Alternatively it is possible and indeed increasingly common that swabs for infection are taken at the same time as a cervical smear. Whilst this may seem reasonable in terms of economy of effort, in the absence of clear communication it results in a situation where women subject themselves to a procedure but have a limited or hazy concept of its purpose. Commonly the terms smear and swab are used interchangeably by women suggesting a lack of understanding of the difference between the two. However, even if testing for infection is the only procedure conducted at one time its specific purpose may still be unclear, hinging as it does upon clear and accurate communication by the health professional. The result of this confusion has considerable impact upon the infection experience for those women who undergo testing in General Practice both in terms of understanding what they have been tested for and what the results of those tests mean.

#### **12.3.1 Medical looking**

Medical looking in relation to establishing a diagnosis is a specific type of looking. Atkinson (1995) outlines the way in which the clinical gaze has become dispersed, where data is gathered on the body by sampling and collection techniques. This enables the body to then be scrutinised and interrogated in a dissociated way at sites other than the bedside. As such, the looking and the seeing is a fragmented process with other professionals, each with their own specialism and expertise, involved in determining how those samples are prepared and what is looked for (Atkinson, 1995). This is broadly the case in microbiological testing that includes looking for chlamydial infection. When testing for infection involves different sampling sites and different swabs it becomes a selective process at the sampling stage whereby someone is tested for some infections and not for others. Detection of chlamydia by vaginal examination requires the use of a specific swab and appropriate sampling from a specific site; the endocervix. In this situation the decision whether or not to look for this infection lies with the person who is taking the swabs. When a urine sample is used, the decisions may be less well defined as there is facility for the process to be less selective at the sampling stage. However, as for swabs, urine testing for chlamydia imposes specific requirements both on the type of sample (first void urine) and the utensil within which it is collected. The decision should therefore also lie with the person who instigates its collection.

When special swabs have to be used for chlamydial testing, it is by no means inevitable that they will be used when infection is looked for and so it may be that looking for infection does not include looking for chlamydia. In Primary Care, there is considerable variability in the swabs taken in response to a vaginal discharge with a forty-fold variation between General Practices in the extent to which diagnostic testing for genital chlamydial occurs (McNulty et al., 2004) and marked failure of the investigations initiated in Primary Care to achieve diagnosis (Champion and Ross, 1999). When women attend the GP as a result of an altered vaginal discharge it is most likely that a high vaginal swab will be taken, however it is much less likely that they will also be tested for chlamydia (Noble et al., 2004). Less than half of those women under 25 years who have a high vaginal swab taken for genitourinary symptoms will also have a chlamydial swab taken (McNulty et al., 2004). The result is considerable variability in the way that genital symptoms are investigated in General Practice.

### **12.3.2 The meaning of 'all clear.'**

You cannot obtain a negative diagnosis in relation to an infection for which you have not tested. These limitations in interpretation will be self-evident to the practitioner who has made the clinical decision about which tests should be performed and has subsequently received laboratory reports stating the results of the tests, both negative and positive. However, unless the client is specifically told at the time of testing what swabs have been taken and for what purpose, she is unlikely to be able to elicit that information by any other means. In the absence of a clear explanation from the health professional of the purpose of the tests performed in conjunction with any vaginal examination, a woman may be very unclear as to what she has and has not been tested for. Vague statements such as 'we will check you for infection' can reasonably be taken to mean just that and the resulting assumption is that any infection present will therefore be detected. Unless all the information relating to her results is conveyed to her when those results become available, there is ample facility for misunderstanding and misinterpretation of the information that she receives. This may therefore lead to the assumption by the woman that she does not have a specific infection when in fact she may not have been tested for it in the first place. However, a negative result is important in both physical and social terms and merits specific communication.

Acceptance of a negative result also relies upon concordance between the information conveyed by the health professional and the bodily experience. When there was

conflict between the two, it resulted in considerable difficulty in terms of making sense of the diagnostic information. This arose as a result of discrepancy between the individual's perception of physical signs, indications that all was not right, and negative test results. The vague statement of 'all clear' which was presumably intended to provide reassurance clearly did not achieve this purpose. The underlying assumption when someone presents with symptoms is that the investigations that the health professional instigates will identify the source of the problem and therefore that the phrase 'all clear' means exactly that. In reality however, the phrase only relates to those infections for which one has been tested. To understand the meaning of the terminology requires one to understand which tests have and which have not been carried out. When this information was not provided, the consequence was a sense of frustration and dissatisfaction firstly that the situation presented no opportunity for treatment and potential elimination of symptoms and secondly because of the possibility that problems had been allowed to persist for longer than necessary.

*"I knew there was something wrong and I'd been to my doctors and they did tests and they kept saying that everything was clear, but I knew that something was wrong.....I feel a bit annoyed that it had gone on for so long and that there was something wrong but I mean, but perhaps it didn't show up." (Sarah)*

This data relates specifically to the patients' perception and recall of the information that was conveyed. It is therefore their interpretation of that information that forms the basis of this discussion. Whilst this may not accurately reflect the content of what was said in the consultation, it is the most accurate reflection of what was understood and therefore arguably most closely reflects the client perspective. However the readiness with which the respondents recounted specific infection names suggests that this piece of information was highly significant and emotive and is therefore likely to be an accurate representation of the extent to which it was included in the explanations of procedure.

### **12.3.3 Understanding the purpose of testing**

The amount of information which appears to have accompanied testing that took place in a Primary Care setting seems to have been highly variable. For some such as Jean and Michelle who had presented in General Practice with symptoms, the discussion appears to have been confined to the procedure. Jean initially presented herself to the GP and had to see the Practice Nurse in order to have the swabs taken. She acted as

messenger in the process whilst receiving no indication of their purpose from either practitioner.

*"I just said [to the Practice Nurse] doctor says I've got to have a couple of swabs as well, she says do you know what they're for, I said no, she just did them."*

Similarly Michelle was able to recall the number of swabs taken but appears not to have been privy to their purpose.

*"She should have said we're testing for this and we're testing for that but she didn't, she just did these 3 swabs I think they were and then [said] phone up for the results."*

It would appear that in these circumstances explanation of their purpose was considered to be sufficiently contained within their function as the means by which to ascertain the cause of symptoms. This was evident in a number of other accounts, where the tests were justified as the means by which *"to find out what was it that was causing my bleeding"* (Anne) or *"just to see if there was anything wrong"* (Sarah).

#### **12.4 The issue of consent**

It is difficult to conceive of a situation whereby someone is tested for an STI without prior discussion, however this was undoubtedly the case for some of the individuals who contributed to this study. In some instances there seemed to be little prior understanding of the purpose of testing. Explanations and justification of the investigations appear to have been couched in very general terms; either in terms of the procedure or in terms of identifying a cause of the symptoms. It reflects the willingness of individuals to undergo tests without understanding their purpose. However, it raises the question of consent. What is it that a patient consents to in such a situation? Is it the procedure by which the samples are obtained or is it the test for which the sample has been obtained? In the main it appears to have been the procedure, however to perform the procedure without any explanation as to the purpose of it seems to deny an individual the right to give informed consent.

There is an expectation in the health system that in approaching the doctor for medical assistance one places implicit trust in their ability to use specialist knowledge without needing to be privy to the stages of the process. When investigations and tests are performed for the majority of medical conditions, their purpose is understood in terms of finding out what is wrong rather in terms of any specific condition. There is also a

tendency on the part of professionals to act as gatekeepers of information, arising from a desire to protect patients from emotional harm (Levy, 2004) which in this situation may equate to withholding the purpose of the test in order not to cause undue anxiety.

#### **12.4.1 The case of HIV**

There are specific examples where testing would not be conducted without some explanation of the purpose. One obvious example of this is HIV testing. Specific consent, such that the individual is aware of the purpose of testing and has the opportunity to accept or decline the test, is considered a pre-requisite of HIV testing and identified as best practice at a National level (DH, 1997). Largely as a response to the increased volume of testing, there has been a considerable reduction in the amount and detail of information that is considered appropriate to accompany testing and the time required within which to obtain informed consent. The introduction of antenatal testing for HIV for example, produced considerable debate around the skills and training of the practitioner and the extra time within the consultation that was required in order to gain informed consent (Ades et al., 1999, Low et al., 2001). This has produced considerable concerns as to the extent to which informed consent remains a reality (Hewson, 2004). Similarly in the GUM clinic, a move from an opt-in to an opt-out process which serves to routinise testing has been advocated as an effective means by which to achieve required targets (Stanley et al., 2003) and the use of leaflets to replace pre-test discussion has been presented as an acceptable and effective approach to HIV testing in GUM (Rogstad et al., 2003). The legal basis of such an approach is questionable, as legal precedent has established that adequate pre-test counselling cannot be provided simply by the provision of an information leaflet. This may result in failure to obtain informed consent and lead therefore to a charge of negligence if harm results (Hewson, 2004). Notwithstanding these worrying developments, informed consent has remained a core consideration in relation to HIV testing and consequently one could not conceive of a situation where HIV testing in the absence of informed consent would be considered socially acceptable.<sup>1</sup>

#### **12.4.2 Testing without explicit consent**

Whilst the ramifications of a positive diagnosis are considerably greater than they are for other STI's, their similarity in relation to mode of transmission and social context

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<sup>1</sup> A case came to light recently whereby non consensual forensic testing had identified a man as being HIV positive. This information was disclosed to him and the rest of the court during a legal cross examination. It produced a national outrage and was widely reported in the national newspapers.

challenges the apparent acceptability of testing people for other STI's without their knowledge. However this is undoubtedly the situation in some circumstances. Screening for syphilis has been a part of routine antenatal testing for approximately 40 years, however my own personal and clinical experience indicates that this commonly occurred with little or no discussion and by implication therefore without the explicit consent of the woman. Related work in midwifery similarly suggests that much decision making occurs with little informed choice and is heavily influenced by health professionals who drive decisions towards technological interventions, many of which have become routinised, these being largely portrayed as the 'right' choices (Stapleton et al., 2002). Consent has also been identified as an issue in relation to diagnosed and treated infections. In a study of 1404 women in the USA, a considerable proportion of those reporting previous treatment for an STI did not appear to know that the infection that they had had was sexually transmitted. The likelihood of this happening varied between infections and ranged from 6.8% of those who had had gonorrhoea to 42.9% in those with genital warts (Fleisher et al., 1994).

Any consideration of the issue of consent is markedly absent from the literature surrounding chlamydial infection, particularly in relation to testing rather than screening. A literature search of the medical and nursing literature of the past 10 years using the key words '*Chlamydia trachomatis*', 'chlamydial infection' and 'genital chlamydial infection' in conjunction with the term 'informed consent' produced no articles that considered the issue of gaining consent prior to female testing. This lack of dialogue suggests a lack of acknowledgement and engagement with the issues, however it is intrinsically problematic to determine the extent to which consent to testing is either discussed or established prior to investigation, not least because the majority of literature relates to research studies where additional considerations of consent create a somewhat artificial situation.

Consent has been addressed as a specific aspect of the chlamydia screening programme. In the Department of Health funded opportunistic screening study (DH, 2001b), the consent process was founded upon an information leaflet that receptionists were required to hand out to those patients who were of an eligible age and this approach has similarly been taken in the chlamydia screening roll out programme. The concerns surrounding this which have been identified in the literature are those of the receptionists who felt ill-equipped to deal with the inevitable questions that arose and considered the information too sensitive and embarrassing for distribution in an open reception area (Perkins et al., 2003).

In relation to other studies, I identified one single report in the literature whereby opportunistic testing of urine samples for chlamydia was criticised as unethical because explicit consent had not been secured. This incident was notable on two counts. Firstly it concerned testing of males and not females and secondly because the point of debate was around where the testing decisions were made. The authors (microbiologists) justified their approach on the basis that supply of a sample implied consent for screening for all relevant pathogens (Basarab et al., 2002) however it provoked challenge because the decision to look for this infection was made by the microbiologist rather than the clinician thus denying the social implications of an STI (Valentine, 2002).

For some who present at the doctors with symptoms and require investigation, it may be acceptable to be tested for infection without specific prior discussion. Isobel for example, had sufficient trust in the system and her doctor that she considered it enough to know that he appeared to know what he was doing. She therefore did not feel that she required detailed information at the stage of investigation.

*"I know he had a suspicion what it was but he didn't want to say in case it was wrong, which was fair enough, but from the patient's point of view, the doctor's got a pretty good idea of what it is so hey, I'll be alright." (Isobel)*

Others however clearly felt that they should have been made aware of the fact that they were being tested for an STI. There are two possible explanations for why a health professional may undertake testing for an STI without adequate discussion; either that they consider the possibility of an STI an emotionally charged topic that is difficult to broach or alternatively that they may consider chlamydia a 'small infection' that does not merit specific pre-test discussion and explicit consent.

#### **12.4.3 Considerations in broaching the topic**

Difficulty and reluctance in broaching the topic may have been a contributory factor in the lack of discussion that accompanied so much of the testing, either because of concerns about the possible reactions or because the health professional felt ill equipped to broach the subject. Reluctance to take sexual histories in General Practice is well recognised and attributed to a number of factors ranging from a lack of training and lack of knowledge, to practitioner embarrassment and concerns around patient embarrassment (Temple-Smith et al., 1999, Verhoeven et al., 2003, Temple-Smith et al., 1996). The gulf between policy and practice is considerable. For

example, the Sexual Health Strategy identifies HIV testing as a first level service and therefore expects that it will be widely conducted in Primary Care (DH, 2001a). However the inclusion of this topic within the Primary Care training package, the Sexually Transmitted Infection Foundation (STIF) programme which was previously discussed in section 2.11, bears witness to the discrepancy between this policy objective and the current reluctance of practitioners to undertake such testing in General Practice because they feel ill equipped to deal with the associated issues.

Similar concerns in relation to chlamydia may produce some reluctance on the part of practitioners to test for this infection and this was evident to some extent within the opportunistic screening programme (Perkins et al., 2003). However it is unlikely that the level of reluctance to test or screen for chlamydia would exist to the extent of that associated with HIV. The curability and commonality of chlamydia positions it as a significantly smaller infection on the part of both practitioner and patient alike. However to view it as small in relation to HIV is not the same as considering it a small and inconsequential infection. Also this is often not the patient's perspective from the outset. If she comes to view it as a small infection, she does so in comparison with other infections and subsequent to diagnosis as part of the personal resolution process. Therefore there may be discrepancy between the perspectives of the health professional who has had considerable dealings with this infection and the patient for whom it is commonly a novel experience. If practitioners view chlamydia as a 'small' infection they may be willing to test for it without considering it necessary to discuss it adequately with the patient.

To be informed of the diagnosis of chlamydial infection without having been aware that you have been tested for this infection not surprisingly produced powerful emotions. For Yvonne who had experienced severe abdominal pains and undergone tests for what she thought was a urine infection without opportunity for adequate discussion, the shock of diagnosis extended beyond the feelings of contamination described in chapter eight to encompass feelings of astonishment and outrage at the absolute unexpectedness of this information and the way that it was conveyed. These clearly related to the fact that she had had no idea that she was being tested for an STI in the first place.

*"I looked at him [the doctor] as if he had two heads ...I weren't impressed, he just came out with the words ..... because they tell you that they think it's a water infection, you just believe what they tell you and you don't realise they're testing you for other things,*

*without them explaining what they're testing for ... I would rather that people would tell me before, rather than just fob me off really, saying that I've got a water infection, they should say we're testing you for this and that." (Yvonne)*

If a practitioner perceives this as a 'small' infection, they may alternatively consider it acceptable to suggest the probable diagnosis to the patient at the point of testing without considering the possible impact of what they are saying. However, their perception of the infection is unlikely to be shared by the patient who is entirely unprepared for this information. The emotionally devastating impact of insensitively suggesting the presence of infection at the point of testing was discussed in chapter eight. Testing requires one to wait several days for results to either confirm or refute the provisional diagnosis. This data indicates that those whose diagnosis was confirmed experienced considerable anxiety waiting for their results and although it is not possible to confirm this, it is probable that similar anxieties would have been experienced by those who subsequently found that they did not have the infection.

#### **12.4.4 Strategies for minimising distress**

Sufficient information and discussion is therefore required in order to establish informed consent, however it is essential that information is provided in a sensitive and contextualised way in order to minimise the degree of anxiety and distress. Personal characteristics will greatly influence the extent of the patient response with the same information being received in widely differing ways by different people. In relation to the diagnosis, contextualisation of the infection appeared to be important, particularly in terms of treatability, commonality and transiency as discussed in chapter eight. At the time of investigation, alternative strategies were evident which appeared to moderate the impact of proposing testing for an STI. These were to either ground it within routine procedures or to diminish the expectation of a positive diagnosis by presenting it as a possibility but not a probability.

*"She said she was going to test for STD's and that and do some routine tests and that's all she said she was going to do." (Karen)*

and

*"He says you might have a water infection, but the sex, the bleeding bit, you might have chlamydia, he said it's highly unlikely, it's probably just a water infection and its just because of the pill." (Angela)*

These strategies may create a false sense of security at the time of testing such that the diagnosis is unexpected. However they do appear to overcome the dilemma between providing sufficient information to gain informed consent and to prepare the patient for possible outcomes of testing whilst simultaneously not causing unacceptable levels of anxiety whilst awaiting results. For those whose results are subsequently found to be negative, this approach justifies testing and grounds their experience in the context of routine procedures, whilst for those whose results are positive, some degree of preparation appears to have reduced the unexpectedness of the diagnosis.

### **12.5 The intimate examination**

The examination is an instrument in the exercise of surveillance representing the means by which to create and exercise control over a docile body. It is the process through which power and knowledge relations are superimposed upon and through the body, establishing a visibility over individuals through the techniques of an 'observing hierarchy' and 'normalizing judgements' (Foucault, 1977 p. 184). It is central to the construction of the medicalised body and has been widely considered in this respect in relation to a range of disciplines (Armstrong, 1983, Nettleton, 1992, Pryce, 2000), however in relation to genital examinations, the exercise of that power and the process of medical surveillance falls predominantly upon women.

#### **12.5.1 The female experience**

For women, the genital examination is an experience that is inextricably associated with the biomedical construction of fertility and reproduction. From late adolescence until old age, women are expected to submit their genitalia to medical scrutiny (Martin, 1987). Genital examination is considered a normal part of being a woman. For women this normalisation of intimate examination is associated with specific activities, in particular childbearing, however in conjunction with cervical cytology it epitomises routine surveillance to which women subject themselves at fixed and predetermined intervals. Vaginal examination is the majority experience for women over the age of 20 years and an imminent expectation in those under 20, largely as a result of cervical screening. The organizational elements of the programme which include standardized invitation and reminder letters and established failsafe mechanisms contribute to the construction of this institutionalised practice. These processes together with incentive target payments to General Practitioners create a culture within which women are pressured to participate (Bush, 2000) and contribute to uptake rates in excess of 80% (DH, 2001f). The smear programme has come increasingly to be viewed as part of

being a woman, a normal aspect of female embodiment (Howson, 1999) and by extension, the vaginal examination, the means by which the smear is obtained, is understood in the same terms. This is not to say that women find the process easy. Fear, embarrassment and discomfort comprise a dominant part of the experience (Howson, 1999, McKie, 1995), nevertheless its construction as a moral obligation results in women describing the requirement to overcome such feelings (Howson, 1999).

### **12.5.2 The male experience**

Genital examination is a much less likely experience for men. Men's participation in reproductive health care is marginal and largely detached. Their bodies are not the primary focus of contraceptive control and their direct role in unassisted reproduction is minimal. Even in situations where failure to conceive occurs as a result of male subfertility or infertility, the medical solution invariably lies in assisted conception techniques where the female body is the site of intervention (Shildrik, 1997, Strickler, 1992). There is no male screening procedure comparable with the cervical screening programme and therefore genital examination of a male is an unusual occurrence, associated exclusively with pathological considerations. There is also a similar lack of theoretical exploration of the male genital examination.

These oppositional constructions of female and male genital examination where one is viewed as normal and routine and the other as abnormal and pathologised are apparent in the literature, policies and approaches of health staff. This is illustrated by the proposed structure of sexual health services outlined in the National Strategy for Sexual Health and HIV. STI testing for women is identified as a level one service to be provided in every general practice setting. By comparison, the level of care to men within level one services is in terms of assessment and referral of those with symptoms. STI testing for men is identified as a second level service (DH, 2001a). Identified as invasive, a description that is not afforded to the comparable female investigation, the implicit assumption in these proposals, reinforced by the lack of explanation, is that male testing is a more difficult and complex task requiring the degree of expertise that would be available in level two but not level one service provision.

### **12.5.3 Invasive procedures**

The dictionary defines invasion as 'an encroachment or intrusion' (Collins, 1994). On this basis let us consider the extent to which this term is justified in relation to male and

not female examinations. A female genital examination that includes inspection of the cervix necessitates the insertion of a metal instrument. This speculum is then opened and secured in an open position by means of a screw device in order to separate the vaginal walls and enable visualisation of the cervix at the end of the vagina. The conduct of such a procedure is fraught with potential danger as the required supine position with legs parted is a position of such extreme vulnerability and potential sexualisation that it necessitates careful dramaturgical management (Emerson, 1971, Henslin and Biggs, 1971). In comparison, whilst a male genital examination is also charged with sexualised potentiality, the positioning is such that he is not required to subjugate himself to the same extent. Equally there is no requirement for metal instruments, simply the passing of a small cotton bud into the proximal 2cm of the urethral meatus and then a double rotation prior to removal. It is difficult, on the basis of these procedures to conceive of a classification that describes the male examination as invasive whilst suggesting by inference that the female examination is not.

#### **12.5.4 Attitudes to the examination of males**

The reasons for reluctance to test males are not clearly apparent. There is increased reluctance of practitioners to broach sexual health issues with males as compared to females (Stokes and Mears, 2000) which is likely to contribute to this situation. Indeed the lack of male testing for chlamydial infection by means of a urine sample supports the assumption that there is an underlying reluctance to initiate sexual health care even when a physical examination is not essential. Similar concerns have also been expressed by staff, both male and female in relation to discussing testicular cancer and testicular self examination (TSE) (Hamilton, 2001). In relation to physical examination there are also concerns about technical expertise. Many practitioners have never swabbed a male and do not know how to do so (Griffiths and Cuddigan, 2002). A recent survey of Practice Nurses confirms this finding. Only one of the thirty one respondents in this small study reported that they ever examined male genitalia, the primary reason given being lack of expertise or training (Robertson and Williams, 2005).

Personal communication with medical colleagues supports the premise that there is little male testing, however the explanation provided was not the need for greater expertise but the assumption that it is a more painful procedure for men to undergo than women based upon the observed reaction of men to swab taking. The possibility of inflicting pain is an unusual explanation for not performing a medical investigation as it is the medical definition of circumstances that justifies the infliction of pain that in other contexts would be considered cruelty (Emerson, 1971).

In a comparable situation, the official publication of the national cervical screening programme states specifically that “there is no pain” associated with smear taking, whilst any discomfort that may occur does so as a result of the woman herself being tense (HEA, 1996). Thus any physical considerations in relation to smears are the fault of the woman and therefore something that should be either tolerated or rectified by her and are certainly not a justification for non screening. Pain in conjunction with smears and therefore in conjunction with vaginal examinations apparently does not exist, a perspective that is also affirmed by staff within the context of labour despite clear indications from the women that the process is in fact a source of pain (Bergstrom et al., 1992). Indeed this perception has even been extended to operative procedures of the cervix, based on the accepted wisdom, handed down from one generation to the next, that the cervix has few nerve endings (Posner, 1996).

The perception and assessment of pain is not gender neutral. Women are considered to be better able to cope with pain because they are culturally conditioned to do so and therefore their pain is not taken seriously whereas for men it is seen as being outside their experience and associated with a state of abnormality (Bendelow and Williams, 1998). It has been suggested that in certain circumstances pain may result in men resisting intrusive investigations (Cameron and Bernandes, 1998), however it seems equally probable in this situation that any pain related considerations in testing lie as much with the health professional as with the patient. Women's pain in relation to genital examination is institutionally and professionally denied thus negating the experience of the woman themselves, whilst the possibility of inflicting pain on men as a consequence of examination forms a central consideration.

#### **12.5.5 The comparable situation of TSE**

There is similar reluctance to subject males to examination in other comparable situations. TSE is a simple technique which is advocated as a method of self surveillance for the early detection of testicular cancer. However men appear to have a very limited knowledge of the procedure and few seem to carry out TSE with any degree of regularity (Wardle et al., 1994, Moore and Topping, 1999). For best effect the procedure relies upon a systematic examination of the testes which enables the male to be familiar with the normal structures and thereby to distinguish between normal and abnormal (Rosella, 1994). It therefore necessitates some degree of tuition in the process. Although physical examinations have been identified as the most suitable way in which to teach such a process (Rosella, 1994) the evidence indicates

that this is not happening. The limited literature on this subject suggests that neither Practice Nurses nor GPs are involved to any extent in teaching patients (Webb and Holmes, 2000) or even in discussing the topic (Moore and Topping, 1999).

TSE education occurs in a fully detached and non contact method with the majority of health promotional activity being conducted in groups settings, commonly within school educational programmes or in community settings (Hamilton, 2001, Peate, 2003). In this context and other settings, information is shared by means of leaflets, models and audio visual aids (Rosella, 1994) with concerns about the verisimilitude of such methods producing recommendations for photographic images (Peate, 2003) and no consideration of the possibility of instruction that uses the anatomical structures themselves.

However males express a preference to learn about it in a more personalised way with the inclusion of TSE within general physical assessments (Moore and Topping, 1999). The debate around teaching of TSE is more complex than simply considerations of physical examination. Issues of efficacy, cost benefit and coverage of a healthy population who are unlikely to require physical examinations within which TSE could be performed all contribute to the debate. However it does seem to support the indication that there is marked reluctance on the part of Primary Health Care professionals to engage in any activity that involves examination of male genitalia.

### **12.6 The sexualised arena**

The individualisation and containment of the body that occurred as part of the civilising process produced an imperative for the naked body to be covered and hidden from sight, as it became shameful to expose one's body to others and a matter of embarrassment to view the naked body of another. These changes were also reflected in changing social standards of shame towards sexual life, with increasing levels of concealment and secrecy developing over time. The increasing restraint of behaviour that the civilising process imposed, served to systematically remove sexuality behind the scenes of social life and enclose it within the enclave of the family, whilst simultaneously surrounding it with an aura of embarrassment (Elias, 1994).

Any body work is replete with potential for producing embarrassment because it requires the transgression of social boundaries and the breaking of social rules. Any physical examination therefore presents a challenging situation for both the patient and the professional. It creates positions of power and vulnerability and requires the

subjection of one body to the direct bodily action of another (Lawler, 1991). The genital examination arguably presents the greatest challenge of all to both patient and professional. It requires the exposure of those areas of the body that are normally hidden from view and the touching of those body parts considered most private. The cultural baggage that accompanies any body is greatest in this situation because of the connotations associated with sexuality and sexual function. As such, it requires careful management within the medical context, in order to contain the sexualised elements that represent a continual potential threat to the process. The genital examination exists within multiple contradictory definitions of reality; within the co-existent requirements to construct the patient as an object upon which medical procedural techniques are conducted, whilst simultaneously maintaining the counter themes of the patient as a person and the genital region as a special private area that is intimately associated with intimate and sexual activity (Emerson, 1971). Structures and rituals are utilised to symbolically strip the body of its eroticism (Pryce, 2001) thereby enabling procedures to be undertaken. However this containment is under continual threat by a body which retains its potentiality (Pryce, 2001) and a social dialogue that constructs the female genital examination in sexualised terms (McKie, 1996).

#### **12.6.1 Desexualisation of the examination**

Genital examination occurs as a structured interaction which is carefully managed in order to effect its purpose, whilst minimising the degree of embarrassment and self consciousness in order to preserve the identity of those involved. In these terms it is constructed from a series of acts and framed by a prologue and epilogue whereby transition is effected, initially from person to patient and subsequently from patient to person (Henslin and Biggs, 1971). Within the scene, doctors and nurses perform ritualised roles and props such as blankets are used. Collectively these further reduce the patient to a pelvis in order to depersonalise and desexualise the encounter, thereby legitimating the conduct of the examination. Whilst this may be construed as a ritual of respect in so far as it confines medical attention to that specific area thereby preserving the dignity of the woman (Emerson, 1971), it constitutes a fragmentation process which effectively separates the woman from what is being done to her (Martin, 1987). This, together with the required supine lithotomy position, serves to create feelings of vulnerability and a sense of exposure (Posner, 1996), although it simultaneously provides facility for the avoidance of eye contact, a strategy commonly used to reduce the level of embarrassment.

The ease with which the process is effected will largely depend upon the experience of the health professional but will also be influenced by the patient. If the patient has experienced the procedure before, she will 'know the ropes', what to do and when to do it. By contrast a novice patient will be dependent upon the practitioner to guide her through the process, assisting her in the avoidance of embarrassing moments. In this way, the patient and professional collectively manoeuvre their way through the process according to the set of rules that construct a context within which to govern the management of the body for this particular type of body work (Lawler, 1991).

The male genital examination is arguably more problematic than that of the female. Male sexuality is less easy to medicalise because it is closely linked to performance (Meerabeau, 1999) and retains its sexualised potential in a way that is not comparable in females. The female genital examination is a well rehearsed activity for most health practitioners. They have a ready script and a toolkit of strategies that are utilised to manage the process, many of which are not afforded to the male examination. For a male, it is more likely to be a novel experience and he will therefore be reliant upon the experience of the practitioner to guide him through the process. If the practitioner lacks experience and expertise, there will be greater propensity for non adherence to the set of rules thereby increasing the facility for embarrassment on the part of both players. Those props and strategies that are readily apparent in female examinations are not readily transferable. Whilst male positioning for examination is variable, anatomical positioning makes it a more front to front process and provides the option for the man to stand or sit. He is therefore able to adopt a position that is less vulnerable than that required of women which effectively provides the male with greater control. However drapes and similar strategies are not readily usable in this situation and therefore there is less facility for fragmentation and separation. This requires the process to be managed in a much less detached way, which may further contribute to the embarrassment level of both players, whilst the face to face positioning does not easily afford the possibility of avoiding eye contact.

### **12.6.2 The wider sexuality of male sexual health**

Whilst the reluctance to engage with men in sexual health related matters appears to be due to a considerable extent to the problems of physical examination, it extends to include a general reluctance and reticence that is reflected in the wider male sexual health arena. Meerabeau (1999) describes the role of 'amused jollity' that is used to manage the embarrassment of male genital examination but is significantly absent from the comparable female circumstance. As she identifies, this is not confined to the

examination, but is evident in the general approach to male sexual health. There is a marked contrast in the way that health activities are promoted to women as compared to men. The health promotional literature is replete with suggestions for engaging men the majority of which involve social and leisure activities and commonly have a strong sense of 'amused jollity' (Peate, 2003, Hamilton, 2001). In the promotional literature TSE is presented as 'A whole New ball game' or men are required to 'keep your eye on the ball' (Cancer Research UK, 2003) whilst the Prostate cancer charity launched 'peeball', a urinal based game and website, as a strategy through which to draw attention to prostatic problems (Peeball, 2002). If humour is used as a strategy to manage embarrassment, the implication of these approaches is that male sexual health is a source of collective embarrassment that requires social management.

### **12.6.3 Embarrassment associated with the examination**

Given that genital examination represents such a sensitive procedure, closely associated with negative responses which include embarrassment and fear, it is perhaps surprising that specific references to embarrassment in this context were relatively uncommon in the female accounts. Only two women spontaneously discussed the physical components of the procedure in a direct way however it is evident from both of them that the requirement to expose their genitalia, to make public that which is considered private, was a matter of considerable distress and embarrassment.

*"I mean, it's very degrading in a way showing other people what you've got, I mean, I know they've seen plenty of funny things but for me it's very degrading, it's very embarrassing." (Kelly)*

and

*"I'm sick and tired of people messing around up there, I wish they would leave it alone. I think that's what it is, it's because it's so undignified, it's not like you go and someone looks at your throat and gives you some antibiotics. You come in and you get your legs up and it's just dreadful and I think that's what it is, I'm sure a lot of it is because of where it is, it's just your private area, I think it's such a private area and all of a sudden you've got it out for everyone" (Jenny)*

However although the number of direct references were few, there were several indirect references that are suggestive of the fact that a number of the women found the physical examination difficult to contemplate. The thought of attending the clinic

was problematic for many. Some described how they had been extremely anxious prior to attendance or extremely reluctant to attend and those who had intended to request screening for infection some time previously had commonly rationalised the situation away. Whilst these anxieties will have been due to a variety of factors, concerns around the procedure itself are likely to have figured significantly among them.

There were a proportionally greater number of references to embarrassment in relation to males although this was not a universal male response. In some cases the embarrassment appears to have been wrapped up in the whole procedure of clinic attendance rather than specifically the physical procedure itself and expressed in terms of nervousness and reluctance to attend. For Tom however it was the physical process that clearly caused the greatest degree of concern both for himself and on behalf of his partner.

*"It must be as dreadful for a woman as it is for a man to have a test and everything, complete strangers looking at your private parts."*

Some men however adopted a much more pragmatic approach to the process. They viewed it as a situation that required resolution and a process that needed to be gone through, either rejecting the concept of embarrassment or viewing it as something to be overcome.

*"There's nothing to be embarrassed about. There's nothing to be embarrassed about, if you've got it you've got it, get it sorted." (Luke)*

*and*

*"I didn't want to come here, it's not one of the nicest experiences in the world is it, but it's one of those things that's got to be done, it's got to be done, you can't go on like that." (Phil)*

Although women are often embarrassed by the experience of genital examination (Sandelowski, 2000, Williams et al., 1992, Emerson, 1971, Larsen et al., 1997), its construction as a moral obligation, a necessary consequence of taking personal responsibility for their own health is likely to decrease the acceptability of them expressing such feelings. Women feel embarrassed to admit that they are

embarrassed. However they did appear to provide this as an explanation for their male partners' behaviour in those situations where they demonstrated extreme reluctance and delay in attending for treatment. Male sexual health appears to be associated in the public consciousness with embarrassment in a way that is not paralleled in the female literature. This may result in men feeling more able to express such views or, as was the case for several of the women, the presentation of this as an acceptable explanation for male non attendance. Although the lack of familiarity with the process would increase the propensity for embarrassment in the males, this would have also been the case for the younger females for whom it would also have been an absolute or relatively novel experience. Whilst embarrassment is a feature of the experience for both males and females, the extent to which it represents a justifiable explanation for non subjugation appears to be confined to men.

#### **12.6.4 Horror stories**

The limited amount of male examination creates a cultural context where examination is not the norm. There is little socially shared experience between men in the way that there is between women who have common experiences of examination in association with non pathologised conditions such as cytology and childbirth. The result of this is an information vacuum which creates a climate in which anecdotes and sensationalised stories abound largely unchecked and unmodified.

The extent to which horror stories appear in the male accounts but are absent from the female accounts is striking. For those men who expressed concerns about attendance, their primary concern was of the examination process fuelled by those stories that persist in the social dialogue in relation to the service. The lack of personal experience produces a situation where a male attending the clinic has little idea and no experience of the types of procedures to which he will be required to submit. The lack of examination in other health settings means that there will also be little transferable experience that he can bring to the situation. In all probability he will only have previous experience if he has attended the clinic before. The lack of social knowledge creates a climate within which anecdotes can proliferate and flourish. These will largely pass unchallenged and unquestioned, because to challenge the stories would reveal oneself as the possessor of privileged knowledge and expose oneself to the risk of scrutiny as to the means by which one came to be in possession of such information. It therefore represents a potential source of information leakage. The preponderance of these rumours is apparent in the men's descriptions of the examination procedures where the image of the metal umbrella looms large.

*"They put fear of God into you like, they tell you that the swabs are all different to what they use and say umbrella and that, and they say it's metal, and they put it down and open it up and then scrape it all out, so, and it were nothing like that." (Robert)*

and

*"The worse thing for the man is the swab test, I don't know if you know about it, it's terrible, it used to be a lot worse because I've had it done before, but men do talk about that but they completely lie about it, the umbrella test and things." (Tom)*

It is apparent therefore that there is a considerable amount of mythology around what happens to a man when he attends the GUM clinic which centres round the procedures that he will be required to submit himself to. The origins of these can be traced back to the treatments that existed in relation to gonorrhoea and were commonly used prior to the discovery and subsequent availability of antibiotics. In the treatment of chronic gonococcal lesions the two stated aims of treatment were the destruction of the gonococci and the restoration of the integrity of the urethral canal which had become scarred and occluded as a result of infection. A variety of treatments were used of which the most common were antiseptic irrigation and lavage of the urethra and urethral dilatation. Irrigation used a variety of substances including permanganate of potash, nitrate of silver and oxycyanide of mercury, all of which were considered to be effective in eliminating the causative organism (Watson, 1914). Urethral dilatation was considered the most useful means by which to 'incite the retrogressive histological changes which tend towards restitution' (Watson, 1914, p129). Watson identified three forms of instrument that were used for this purpose namely flexible bougies, metal sounds made of steel or copper, and metal dilators which were capable of mechanical expansion and reclosure within the urethra as illustrated below. The third of these were considered of particular value because they were designed to pass through an ordinary meatus without difficulty, thereafter they could be expanded to break down the scar tissue in the distal section and subsequently collapsed prior to withdrawal.

It is not difficult to see how these devices came to be described as metal umbrellas or how they have passed and remained in the collective male memory given that they were used without analgesia and the procedure was repeated up to twice per week although the onset of bleeding was taken as an indication for at least a fortnight's rest (Watson, 1914). Such devices belong to the history of venereal diseases and have

been long since assigned to the museums, however their legacy appears as persistent as the social connotations of these infections.

## Male urethral dilators



FIG. 33.  
Torpedo sound for penile infiltrations.

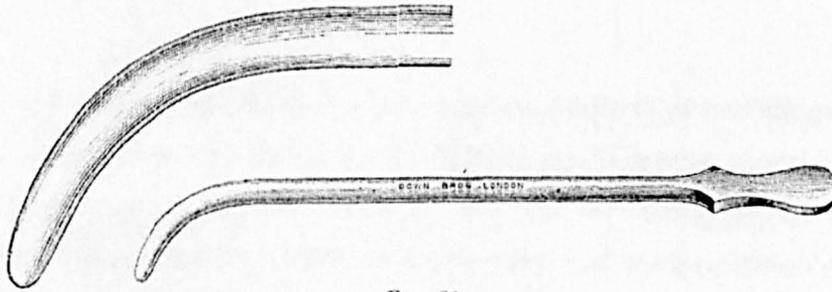


FIG. 30.  
Clutton's steel sounds.



FIG. 31.  
Acorn and olivary tip bougies.

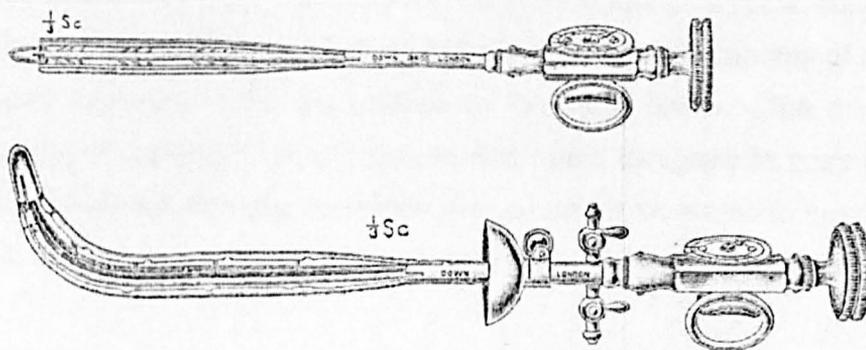


FIG. 35.  
Kollmann's dilators.

Watson (1914)

Attendance at the clinic served to dispel the myths for the individual. The reality of examination is a small cotton bud that bears no resemblance to metal contraptions of torture and although some of the men appeared to find it a source of discomfort, for most of them it did not appear to cause undue difficulties and did not resemble prior expectations and anxieties.

*“Now I’ve been up and had all the tests and everything, I’d recommend anybody to come up here, it’s not scary at all, people might make it out to be scary but it isn’t.”*  
(Steve)

It was recognised by some of the men that part of the reason for the persistence of such stories was the propensity of men to exaggerate the whole experience, largely as social ritual as Robert explained.

*“Loads of people told me that [about the metal umbrella], but my friends like, they’re just winding me up and that... they do exist, I’ve heard them many a time, all the lads at work definitely when I said I’ve got to go to GUMed clinic, one of the blokes, he’s more experienced than me so he knew what I were on about, so that I took a bit of stick for a week I think it were while I was waiting, but when I went back and I said it weren’t that bad, he said I know, I were just winding you up.”*

This male approach also appears to extend to other related aspects of health care. In a study of men’s experiences of vasectomy, Amor & Rogstad (2001) similarly reported the way that discussions with colleagues were characterised with horror stories, particularly after they had decided to proceed with vasectomy and made their decision public. In much the same way as the GUM fears centred on the procedure, these stories were also concerned with the physical aspects of the experience with stories which related primarily to the surgery and included reports of burst stitches and bloodbaths whilst avoiding more sensitive topics such as emotional and sexual concerns (Amor and Rogstad, 2001).

In the equivalent situation of women attending for genital examination there is no evidence of a similar tendency to invoke fear in the person contemplating the

procedure. Indeed the opposite culture exists whereby women actively encourage and recruit friends and family to participate in such activities (Howson, 1999). This tendency may further extend to investigation for STI's. Several of the women described how they had encouraged close friends to attend for testing as a direct result of their own experience, in some instances this being the basis on which decisions to share the diagnosis with friends were made. This tendency to exaggerate and mythologise does therefore appear to be peculiar to male culture.

### **12.7 Impact upon attendance**

Given that genital examinations are a significant cause of embarrassment they may well be expected to serve as a deterrent to those considering accessing the service and consequently result in either delay or deferral of attendance. For men, social rumours may further contribute to this situation. It is intrinsically difficult to ascertain any specific linkage because of the multitude of factors that may contribute to delays in health seeking behaviour. However, the mode of transmission of chlamydial infection and the potential impact of delay or non attendance upon onward transmission has produced considerable interest in this issue and is the reason for the investment of considerable effort by health advisors.

There are two ways in which fear of attendance or fear of examination may affect the attendance pattern of those who access GUM. In the first instance it may delay attendance or it may result in non-attendance at the clinic. The extent to which fear acts as a barrier to the extent that it causes one or other of these is difficult to assess. Those who do not attend are a largely invisible and inaccessible population whilst delay in health seeking behaviour is a complex and multifactorial situation. Similarly, the interrelatedness of the two concepts makes it difficult at times to distinguish between them. Thus non attendance could be considered to be indefinite delay which only becomes non attendance by the establishment of an arbitrary cut off point determined by service providers or researchers.

#### **12.7.1 Delayed attendance at GUM**

There is evidence in the literature that delay in accessing GUM does occur among a significant proportion of attenders and more particularly among older attenders, namely those over 50 years (Hook et al., 1997, Gott et al., 1999). The primary reasons given for this were hoping that their symptoms would go away (Hook et al., 1997) and embarrassment or being afraid to attend the clinic (Gott et al., 1999). The proportion of

those who delayed and the length of delay were considerable. The Gott study reported that 43.8% of the respondents had delayed more than two weeks between symptom recognition and clinic attendance and 9.9% reported delays of more than two months.

In a study by Pitts et al that examined delay among first time attenders for whom attendance was a novel and therefore an unknown experience, three aspects of delay in treatment seeking were examined. The first two, appraisal delay and illness behaviour delay relate to the time that it takes to identify that something is wrong that requires medical treatment. The third component of the process is utilization delay in which decisions about seeking treatment are weighed up against the associated costs and barriers. In these terms, fear of examination would be expected to contribute to this third component. Utilization delay was identified in the Pitts study with considerable variability in the length of delay. Although a median value of nine days was reported, 29% waited more than 4 weeks before contacting the clinic and delay was increased among those at the older and younger ends of the sample age range in agreement with the Gott study (Pitts et al., 2000). All three of these studies failed to identify significant differences in the delay behaviour for males and females. However, a fourth small scale qualitative study of males and females with chlamydial infection did report a greater tendency to delay among males as compared to females although no details were provided in the report (Darroch et al., 2003).

The presence or absence of symptoms is recognised to be important in treatment seeking behaviour (Pitts et al., 2000) and appears to also be important in the uptake of opportunistic testing with those who have symptoms more likely to accept offers of testing (Pimenta et al., 2003). This is unsurprising in so far as the presence of symptoms is acknowledged to be a key factor in defining illness. Whilst the presence of symptoms does not inevitably result in seeking treatment (Scambler, 1997) it does appear that they influence behaviour in relation to this infection which is largely asymptomatic, demonstrably in terms of testing and conceivably in terms of treatment. The extent to which an asymptomatic state, in conjunction with both known and suspected infection, impacts upon seeking treatment is a matter of speculation which will affect both delay and failure to attend.

Delay in attendance is determined retrospectively in those who subsequently do attend. However, given the lengthy periods of delay reported in the previous studies, the distinction between delay and non attendance can only be a subjective judgment determined by an arbitrary cut off point applied in relation to those who are

recommended to attend the clinic and fail to do so. Data pertaining to non attendance derives from audit of contact tracing activity. There is considerable variation in the data collected from GUM clinics in England with reported rates of non attendance of sexual contacts ranging from 16-62% (Priestley, 1998, Lewis et al., 1999, Monteiro et al., 1997) whilst a comparable study conducted in the Netherlands reported rates of 40% (van der Laar et al., 1997) and a study that focused specifically on those under 20 years reported a rate of 50% (Baird et al., 2002). The considerable variability in practice between clinics has been demonstrated to impact upon attendance rates (Matthews et al., 2003) and further contributes to difficulties in the collation and interpretation of data (Stokes and Schober, 1999). Differences in the attendance rates between males and females are not known. No gender comparison was provided in the previous studies and although a national audit of contact tracing for gonorrhoea demonstrated no difference between the contact rates for heterosexual males and females, there were significant methodological difficulties in this retrospective study and findings should therefore be interpreted with caution (FitzGerald et al., 1998).

#### **12.7.2 Non attendance at GUM**

An alternative source of data is the proportion of those who are diagnosed with infection and recommended to attend for treatment and fail to do so. Research studies report high rates of attendance for treatment (Baird et al., 2002, Haddon et al., 1998, Moens et al., 2003). However research studies may utilise processes and levels of effort that do not necessarily translate into real life and are likely to have contributed significantly to the reported treatment rate of 90% in a study that dealt with under 20's (Baird et al., 2002) and the rate of 95% in the Department of Health funded chlamydia opportunistic testing study (DH, 2001b). By contrast, a review of females diagnosed in the FPC as having chlamydial infection demonstrated that almost half failed to attend GUM for treatment (Wilkinson et al., 2000).

The extent to which fear of examination increases anxiety around attendance to the extent that it either delays or prevents attendance is a matter of speculation which is intrinsically difficult to determine, largely because such people are effectively absent from studies. For women, there is a small amount of data relating to the comparable situations of cervical cytology and vaginal thrush. Whilst it was identified as a concern by women in relation to cervical cytology (Howson, 1999, McKie, 1995) by definition it did not prevent the women in these studies from undergoing the procedure. In relation to vaginal thrush where alternative care pathways are available, fear of consultation and examination may influence a woman's decision to self diagnosis and treat. A study

that interviewed a sample of women who chose to self manage vaginal thrush by means of purchasing over the counter medication overcomes the problems that are inherent in the cytology studies. Although a number of reasons were presented by the women to explain their decision to bypass the GP and self medicate, these largely centred round convenience and the time required to wait for an appointment. Only one woman in this study sample of thirty based her decision upon embarrassment or fear of internal examination (Chapple et al., 2000).

### **12.7.3 The impact of fear of examination**

It has been suggested that fear of submitting oneself to examination and testing serves as a deterrent in relation to STI testing. However the evidence to support such claims appears to be exclusively drawn from hypothetical situations. When young people (18-23 years) completed questionnaires relating to hypothetical scenarios, perceived negative consequences and specifically embarrassment were given as the most common reasons for rejecting STI testing (Barth et al., 2002). Although some of the respondents in the Barth study had a previous history of an STI (39%), the majority of them did not. Unfortunately the study did not report whether the remaining 61% of the sample had ever undergone a vaginal examination and for whom this was therefore a wholly theoretical situation. In relation to chlamydial infection, developments in the non-invasive testing procedures for chlamydia enable the use of urine samples and therefore negate the need for vaginal examination. This has been portrayed as a significant breakthrough in the acceptability and therefore the uptake of testing and screening. The National opportunistic chlamydia screening study of 16-24 year olds used urine samples and reported that they were acceptable because they were quick and easy to perform. This study went on to report that many of the respondents would not have accepted screening if it had involved having a swab taken (Pimenta et al., 2003). The implication therefore is that vaginal examination serves as a significant deterrent to testing, however the circumstances of the situation negate the responses to some extent. They asked the respondents for an opinion on an alternative testing technique that was both unavailable and less attractive. This viewpoint should therefore be considered with caution. Although it may indicate the preference of urine testing over and above vaginal examination, it cannot be taken to reflect the willingness of women to submit to vaginal examination in circumstances where there is no alternative available.

#### **12.7.4 The impact of fear upon attendance**

Whilst delay was clearly identified as part of the infection experience in this study, it was largely in terms of the nature of the infection. It was the vague and non specific appearance of symptoms that was considered to be primarily responsible for any time lapse that occurred between their appearance and the decision to seek medical advice. The respondents did not specifically identify fear and embarrassment as factors that had contributed to any delays in their attendance. However they did offer it as the explanation for non attendance in others as discussed below.

Those attitudes described by women in the Howson (1999) study relating to cervical cytology, who described the vaginal examination as an unpleasant but necessary procedure to be gone through, were largely reflected in the women's attitudes towards examination in relation to STI's in this study. However unpleasant they may have considered it to be, there was no indication in the data that anticipation of examination was a factor in deterring women from attending either primary care or GUM. Their attitude rather was one of reluctant acceptance.

*"I suppose in a way it's embarrassing, the thought of going in and having a test like that, it is very undignified, obviously it's going to be even more so, but it isn't a nice thought of going and having it done." (Margaret)*

Similarly there is no indication that it played a significant role in deterring the male respondents from attending. Although concerns were expressed, they were not linked to explanations of delay. Only one of the males specifically described a significant time lag between recognition of symptoms and self referral to the clinic which he explained in terms of prioritisation of other activities. By definition those who had decided to attend the clinic were those who had managed to overcome any anxieties they may have had. It is perhaps not surprising therefore that although they spoke of such feelings, they did not represent them as impacting upon their own behaviour.

#### **12.7.5 Non attendance of partners**

Of greater significance in this respect are the reports pertaining to those who had been required to attend but to date had failed to do so, the contacts of the respondents. It is recognised that a proportion of partners and contacts do not attend for investigation and treatment. However the likelihood of attendance is increased if the patient returns themselves for a test of cure visit (Jarvis et al., 1999), the normal practice in the clinic

when this study was conducted. It is possible therefore that partner attendance rates among participants was higher than would be expected if this was not the case. Notwithstanding this, a small number of respondents did report reluctance or refusal of their partners to attend the clinic. This provided the opportunity to identify and discuss their non attendance from the perspective of their partner. All episodes of non attendance related to the male partners of female attendants although this may have been influenced by the preponderance of females in the study sample.

Unless partners attend the clinic together it can be difficult to ascertain with any degree of certainty whether or not they have attended and this is particularly uncertain when relationships have ended, a fact that was reflected in the accounts provided by one male and several of the females. Over and above these accounts, a total of three women reported that their male partners had declined to attend the clinic whilst a further one strongly suspected non attendance on the basis of her proven re-infection. One of these was in a relationship that was perceived to be stable and ongoing whilst the other two considered their relationships to have ended and in one instance to have no possibility for re-establishment as a consequence of their partner's non-attendance. Whilst these were represented as non attendance by the women, in two of the three cases the women described how they would pursue the matter until such time as he did attend and they may therefore more accurately reflect delayers who had not yet attended the clinic.

Non attendance for treatment on the part of one individual clearly has implications for current and future sexual partners. The extent to which this is accepted by that individual will be dependent upon their willingness to consider the possibility that they are themselves infected which is not in itself a forgone conclusion. However the perspective of the partner who has herself already attended the clinic and been treated for infection is likely to be very different. She will have been exposed to the medical viewpoint that emphasises the necessity of ensuring that partners are also treated for infection and has been recruited into the surveillance activity of the clinic, a role that many appeared to undertake with considerable tenacity as discussed in section 10.3.

Explanations of non attendance are of necessity those described by the women and therefore the extent to which their perception reflects someone else's action is a matter of speculation and should be treated with a degree of caution. It is difficult to explain the actions of someone else and to understand why it is that they have not sought treatment when this does not concur with one's own attitude and activity. As identified

in chapter eight, for many of the respondents, a realisation of the implications of untreated infection resulted in a sense of personal relief that treatment was both available and effective. It is perhaps not surprising therefore that one response to non attendance by a partner was primarily concern for his own health.

*"I don't want him to come down for me, I want him to come down for himself."  
(Margaret)*

The decision of a partner not to attend the clinic clearly has potential implications that extend beyond those of his own health. In a current relationship the failure of one person to attend for treatment effectively serves as a source of re-infection to the person who has previously been treated for infection. In a wider context they also serve as a potential source of infection to other women. Understanding those actions is likely to be more difficult if they have a direct impact upon self and have implications for one's own future health. In this situation they may lead to a questioning of the whole basis on which the relationship was founded.

*"Well, he can't think that much of me if he can't get it treated really, because there would be no chance that we could get back together or else I'm going to suffer again aren't I?" (Kate)*

For Margaret who was in the third trimester of pregnancy, the ramifications of possible re-infection from an untreated partner extended beyond considerations for her partner's health and her own health to those of their unborn infant. In this situation she was required to resort to the use of condoms for the indefinite future as the means by which to keep herself and her baby safe.

*"We can't, we're always going to have to use condoms no matter what, and he's like I know." (Margaret)*

#### **12.7.6 Explaining partner's non attendance**

How then did these women explain their partners' seemingly unreasonable and irrational decisions not to attend for treatment? The sole explanation provided by these women was fear and embarrassment.

*"I don't know, I think a bit of it were he was a little bit embarrassed but I told him, they're not here to look at him like that." (Kate)*

and

*“He’s just very embarrassed about coming down – he doesn’t know what they’re going to do to him, how he’s going to be tested, that’s all it is, he’s just very, he’s so shy, he’s a very shy person, he’s very embarrassed about coming down.” (Margaret)*

and

*“He is a little bit more shy about getting his bits out for doctors and things, and so he’s the one who is more likely to put off going to the doctors.” (Tess)*

These explanations focus on the physical aspects of the experience, namely the necessity of exposing his genitalia to health professionals and subjecting himself to genital examination. It is the prospect of making public that which is private that was considered the primary deterrent for these men rather than any specific consideration of what may have been done to them. This aspect did figure in a single account, however it was not the physical process itself but the social representation of that process, encapsulated within the metal umbrella, which was presented as the basis of his reluctance to attend the clinic.

*“Because they’ve got to take a swab haven’t they, from the man as well, and he’s heard all these things about umbrellas and stuff like that and one of his mates told him it was O.K. but it’s just what everyone says.” (Andrea)*

In terms of these respondents it does appear that fear and embarrassment relating to the physical examination was a consideration for several of the respondents. Indeed it may be that it was a greater concern than is readily apparent given that some people may have been reluctant to admit embarrassment because they felt embarrassed to do so, particularly in an interview conducted in a clinic setting by a researcher who was known to be a health professional. However, in the accounts pertaining to themselves, neither the males nor females identified these feelings as justification for delays in their own health seeking behaviour. Such an explanation was reserved solely as a means by which to explain the behaviour of someone else. Given that non attendance was confined to male partners, these explanations were similarly confined to males. However, this should not be taken to indicate that this is an explanation reserved for the application of women to men, only that there were no corresponding circumstances in which the male respondents were called upon to explain the non attendance of their female partners.

## **12.8 Conclusion**

The social construction of genital examination as a normal phenomenon for women and an abnormal one for men contributes to a situation where those in non specialist services are much more ready to perform examinations on women than on men. The result is that women's sexual health and therefore women's sexual practices are exposed to far greater scrutiny than those of men. Women's reproductive roles have resulted in this position and to some extent it is understandable within this context. However its extension to the screening for a sexually transmitted infection that occurs in equal proportions in males and females is considerably less justifiable.

Practitioners involved in the diagnosis and management of STI's need to be aware that to contemplate or discover that one has an STI has potential social and psychological consequences because it carries such negative connotations. A lack of awareness or recognition of this issue, in conjunction with swab taking that is incorporated within the routine structures of Primary Care, appears to result in a situation whereby practitioners view this infection screen within the concept of normalcy, in much the same way as cervical smears.

The data indicates that testing for infection can and does occur in the absence of adequate discussion. As well as the concerns surrounding consent, this means that they are ill-prepared for a positive diagnosis because it is totally unexpected, a situation that further contributes to their level of distress at the time of diagnosis.

Practitioners may fail to adequately discuss the purpose of screening for a number of reasons. Perhaps they do not consider that it merits discussion either because it is 'normal' or because the result is likely to be negative and they do not wish to cause unnecessary anxiety. Alternatively, they may wish to avoid such a discussion because they feel ill-prepared to broach the topic or they may consider the condition so commonplace that it does not require careful discussion. Both the blatant and the secretive approaches appear to be discrepant with the attitude and consequent needs of the patient and therefore a source of potential confusion and possible distress. A more sensitive insight into the inevitable issues for the patient has the propensity to prepare them for a positive diagnosis whilst not causing unnecessary distress in the interim between testing and diagnosis. The inequality in the male and female testing in Primary Care, which is sanctioned by health policy, means that the burden of this effect falls almost solely on women and can be expected to continue to do so for the foreseeable future.

Whilst the normality of examination makes a woman vulnerable to the insensitivities that occur as a result of being the target of surveillance processes, the abnormality of testing and treating for males creates an information vacuum within which myths and horror stories of ancient instruments flourish. These appear to be remarkably resistant to the passage of time and the replacement of metal instruments with simple and relatively innocuous testing procedures. The male culture of exaggeration appears to perpetuate these, although the extent to which they influence service usage is a matter of speculation. It was acknowledged in those who did attend but did not detract from attendance, whilst its attribution as the purpose of non attendance in recalcitrant partners is unsubstantiated and may simply be a more acceptable explanation than anything else.

## **Chapter 13: Discussion and conclusion**

### **13.1 Introduction**

In this study I set out to examine the impact of chlamydial infection from the perspective of the individual. Whilst this infection may in some terms be considered relatively innocuous because it is so amenable to treatment, it is clearly not considered in these terms by the majority of those who find themselves to be infected, or who subsequently discover that they have sustained physical damage as a consequence of this infection. For many, the effect of finding themselves infected with this organism constituted not only an invasion of their physical body but an assault upon their sense of self and a spoiling of their sense of identity. The effect of this does appear to be a relatively transient and time limited experience as one might expect with a curable infection. However, residual effects which include an increased sense of vulnerability and susceptibility to infection do appear to have been an issue for some. One consequence of these concerns may be more frequent requests for infection screening either in the absence of any symptoms or because bodily changes bring the possibility of infection to mind and therefore serve as a cue to action. Alternatively, they may result in more consistent use of barrier contraception. Both these courses of action figured in the resolutions for behaviour change. However, although some people may change their behaviour as a result of their infection episode, intentions to change behaviour do not necessarily translate into action because of the complexity of the personal and social situation within which sexual behaviours are located. Health discourse which presents self protection as simple and easily achievable, fails to acknowledge the personal, social and structural constraints on sexual behaviours.

### **13.2 Stigma and dirt**

The concept of stigma is commonly used to describe social reactions to chlamydia. Felt and enacted stigma which represent actual or anticipated social sanctioning were a matter of concern to many of those who contracted this infection. The threat that it posed to moral character was evident in a number of ways. The detailing of tight information control and careful disclosure indicate that it was considered sufficiently important to merit careful management and justified a range of tactics to ensure that this information was kept secret. This term stigma is also evident in health policy documents that characterise chlamydia as a stigmatising condition and present health strategies as a means by which to reduce the stigma effect. However, there is a remarkable failure to recognise and acknowledge the central aspect of this and the basis upon which the concept of stigma is founded, namely the pollution effect and the

sense of contamination that it produces. The dialogue is absent on this subject because talk of dirt is socially unacceptable largely because it is too dirty to talk about dirt.

However it is the dirtiness of this condition that is the basis of many of the issues that occur. It makes it difficult for individuals to consider that either they or their partner may carry this infection which is located in otherness and thereby increases their potential for becoming exposed to the infection. It is largely responsible for the emotional distress that diagnosis can produce and underpins the information management decisions that are attributed to stigma. It also contributes to the evident reluctance of some generalist health care practitioners to adequately discuss infection. This not only reinforces the implication that their infection is 'too dirty to contemplate' prior to diagnosis, but has a number of other effects including non consensual investigation and insensitive conveyance of diagnosis, both of which can magnify the degree of distress experienced by those with this infection.

The current health interest in this infection derives from the epidemiological situation and the development of testing technology. The primary effect of this is the rapid increase in the amount of testing activity, much of it as a result of the screening programme that is rapidly spreading across the country and is expected to achieve National coverage by 2007. This changing situation will necessarily impact upon the influences that determine the way people experience this infection. A number of paradoxes emerge which render this a complex and in some ways contradictory situation.

### **13.2.1 The effect of increased chlamydial diagnoses**

In the first instance, the increasing prevalence of this infection means that it is becoming a greater health threat to the population, and indeed this is the primary justification for the current focus of attention. This is one of the key messages of health information campaigns that make a point of describing chlamydia as a common infection that is indiscriminate and affects many people. As the number of diagnoses increase, more people will know someone who has had this infection and more people will be exposed to the possibility of becoming infected themselves. For those who found themselves infected, the realisation that it was a common infection was important in diminishing the impact of diagnosis and the sense of contamination. Consequently whilst a high prevalence rate adversely affects the physical health of the population and

the individuals within that population, it simultaneously reduces the emotional impact associated with each episode of infection.

This contributes to chlamydia's position at the bottom of the hierarchical scale of STI's which derives from a number of factors. As a relative new comer it does not have the history and social recrimination of the original venereal diseases of syphilis and gonorrhoea, whilst the absence of physical lesions places it below more visible conditions. The ability to eliminate it effectively by a simple course of treatment also serves to undermine the stigmatising effect, as feelings of dirtiness subside with the elimination of the infection and it is therefore not considered in the same league as the chronic conditions, most notably HIV infection. These factors collectively provide the means by which to view chlamydia as simply an infection and to detach it from the incapacitating social labelling that resonated through many of the accounts discussed in this study.

### **13.2.2 The transitional position of chlamydia**

Chlamydia can be removed from the category of otherness by producing a non threatening representation in terms of its commonality and removing the associated threat it conveys by easy testing and treatment. It might be expected that the screening process and the high detection rate that results will further contribute to the diminution of this infection, at least among the target population. However, chlamydia remains over and above everything else an STI and is therefore categorised in that group. It therefore occupies a position between the safety of being a common and treatable infection and the danger of being an STI. That territory is transitional land, recognised as being a potentially dangerous place in its own right because it marks the point of entry into other STI's.

Within the current infection management recommendations, referral to GUM for treatment is considered best practice. Referral to GUM will result in the offer of screening for other infections including HIV on the basis of a recognised probability of concurrent infections (Handsfield, 1999). The increased volume of screening for chlamydia is likely to result in an increased number of patients treated in Primary Care. Infection management in this setting is less likely to include a full STI screen. However co-infection is a common occurrence and the incidence of co-existing infection in those who participated in the Department of Health chlamydia screening pilot study resulted in the recommendation that all patients found to have chlamydial infection be screened for all STI's (Harindra et al., 2002).

Consequently the process of undertaking testing for chlamydia, a small infection which is further diminished by the volume of testing activity and a public portrayal that emphasises those characteristics that justify its diminutive status, may unwittingly lead people into a territory of testing for infections that are considerably greater in magnitude. Diminishing chlamydia in the public consciousness will affect its relative relationship to other STI's. There are two possible effects of this process. Either all other STI's will be diminished by virtue of an increased public understanding of chlamydia and a consequent recategorisation of all other STI's which locates them as less socially marginalised and dangerous. Alternatively, if all other STI's retain their original social positioning, the gulf between them and chlamydia will widen. Whilst the transition into otherness may be lessened for those who have a positive chlamydial diagnosis, there is no reduction of impact in those who are diagnosed with co-existing infections. A positive chlamydial result in this case represents the first step of a journey into STI testing for which people may have little prior warning and for which the psychosocial consequences may be considerable, particularly if it occurs in a less specialist setting where there is less recognition and acknowledgement of the emotional impact of these infections.

### **13.3 The female experience**

The findings of this study clearly indicate that the experience of infection was commonly very different for men and women. This is due in part to the gendered differences in the sociocultural construction of this infection. Whilst the embodied experience of males and females alike was one of contamination and bodily pollution, the moral agency of such a diagnosis was considerably greater for the women. The existence of female specific labels and categories, the slags and slappers who form the historical reservoirs of these infections, served to magnify the effect upon the women. They increased the impact of diagnosis because of the difficulty in conceiving oneself as having such an infection and intensified the sense of personal discomfort because of the threat that it represented to moral identity. They also led to a disproportionate expectation among the women of recrimination by others, by family and friends, as well as the wider damaging effect that it presented to moral reputation.

#### **13.3.1 Staff attitudes and service provision**

The women were much more likely than the men to have been treated and managed partially or wholly in a non specialist setting. Primary Care affords an easy means by which to access women and offer them testing and screening. Equally, increased testing and screening in Primary Care provides women with an easy means by which

to be 'checked out.' Although it was by no means a universal finding, the personal accounts of several of the women indicated that they had been subject to the insensitive and judgmental attitudes and actions of non specialist practitioners who appeared to have little insight into the personal and emotional impact of this infection. This magnified their level of distress and the emotional aftermath of infection, at least in the short term. This experience was absent from the male accounts because of the apparent reluctance in Primary Care to engage in testing and screening males for this infection.

For those people who had had negative experiences in Primary Care, the GUM clinic provided a forum within which responses were modified, pre-conceptions challenged, and levels of knowledge about the infection increased. Whilst many did not find it an easy experience to attend the GUM clinic, the benefit of sensitive and appropriate management that it afforded was evident in the accounts. Much of the testing intention revolved around re-attendance at a later date whilst resolutions not to darken the doors of the clinic again related to the infection not the service.

As the level of testing increases, the more likely staff are to view this infection as commonplace. Whilst this may diminish their reluctance to adequately discuss testing to the level required to gain informed consent, it may diminish it to the point where they view it as a trivial infection with little emotional effect and reflect this position in their dealings with the patients. As the data clearly indicated, a lack of discussion or a lack of contextualisation impacts considerably upon the emotional response to this infection. Additionally the increasing number of diagnoses and the greater involvement of primary care will result in more people being treated without referral to GUM. Whilst this seems a logical development, this study clearly indicates that infection management involves considerably more than medication. It therefore places an imperative upon all those offering this service to ensure that they do not limit their care to physical considerations but that they adequately address the social and emotional aspects of the infection.

### **13.3.2 The question of infertility**

Professional and lay representations of chlamydia represent the danger of this infection primarily in terms of its potential effect upon female fertility. Although this has been redressed to some extent in more recent health publications, women are much more likely to be offered screening and testing by health professionals and the verbal representation in this context will focus primarily upon the impact that the infection will have upon them. Additionally there is a preponderance of lay representations that

focus on women. These collectively serve to reinforce a public perception that continues to portray this infection as problematic primarily for women. It is perhaps not surprising therefore that concerns about infertility figured prominently in the female accounts and were largely non-existent in the male accounts. This created an additional female dimension to the infection experience with indications of residual anxieties that were almost non-existent in the male experience.

The implications of this infection are considered to reside solely with the females. In health promotional terms, the possibility of female infertility is a motivational factor and the hope and expectation is that young women will use the necessary means to prevent infection and thereby protect their fertility. Whilst this may be effective for some it is clearly problematic for many, the primary reason being the lack of perception of the possibility of infection. The female accounts were replete with uncertainty management strategies, however the extent to which infertility remains an ongoing concern for women when the memory of the infection has receded is a matter of conjecture. From the data, it appears that the infection episode and its consequences were conceived as separate concepts, overlapping only in so far as one was a potential product of the other. In relation to this episode, treatment eliminated feelings of contamination. In relation to future behaviours, the strategies described to prevent or detect infection focused only on the infection itself. Whilst it may be that some of the women viewed this as the means by which to protect their future fertility and this formed the basis of their explanations, this aspect did not figure in their accounts.

#### **13.4 The consequences of focusing screening strategies upon women**

The current policies which concentrate screening efforts primarily on women are justified by the two factors that are discussed above, namely their accessibility as regular users of Primary Health Care facilities and the impact of infection upon female reproductive capabilities. This seems a reasonable approach to take from a pragmatic perspective in so far as women represent the means and the end of the process. It will undoubtedly result in large numbers of women being diagnosed with this infection as a result of the huge amount of testing activity. However, as the data indicated, the personal and social consequences of such an approach appear to be considerable for women. Furthermore, a policy that fails to address the amount of infection in men to any significant extent other than through women is problematic on a number of counts.

#### **13.4.1 Needing to be tested / screened**

A screening and testing strategy that focuses on women requires to some extent that they consider themselves susceptible to the possibility of infection. This may occur through physical means, the identification of physical changes which serve as cues to action. However the ability to identify body changes can be extremely difficult when they are superimposed upon a dynamic and fluctuating background of secretions and menstruation or when they can be explained in terms of the artificially imposed body changes that characterise contraceptive usage. This situation contrasts with that of men where the background is unchanging and any penile discharge therefore constitutes abnormality. As the data indicated, many of the body changes that the women experienced had passed unchecked and disregarded for a considerable period of time because of the facility to absorb them within other rational explanations.

Screening in the absence of symptoms rests upon a woman considering herself as being susceptible to infection and therefore viewing her partner as a potential source of that infection. However, as was evident from the data and the literature, this is intrinsically problematic within the context of an established relationship, however short the duration of that relationship because it challenges notions of trust and fidelity. Given that the degree of emotional investment in a relationship appears to be greater for women than men, it is counter-intuitive to expect women to consider their partner as a potential source of infection. This problem can and will be addressed to some extent by health professionals offering screening and therefore putting infection on the personal agenda. However it is by no means assured that this approach will result in the uptake of screening by those who reject the possibility that they have the infection. Previous studies have indicated that requests for HIV screening are commonly not associated with perception of risk and it seems probable that requests for chlamydia screening will follow broadly similar lines.

#### **13.4.2 Guardians of health**

In so far as men's infection is identified indirectly through women, this approach constructs women as guardians of men's sexual health. It places the onus of responsibility upon women not only to ensure that they are treated but also that their partners are tested. This approach indicates little recognition of the emotional cost of this to women although it is evident from the data that many of the women found this difficult and in some cases impossible. Even though a partner may be informed of the advisability of being treated, it is by no means assured that he will do so. Though considerable steps may be taken on their behalf, making appointments, collecting

information, encouraging and cajoling, the final decision and action can only lie with that partner. When they do not receive treatment, they present the person who has been treated with a stark choice between measures that ensure self protection or the probability of re-infection and the concomitant health consequences.

#### **13.4.3 Adopting the moral high ground**

A system of infection diagnosis through one partner creates an unbalanced situation which enables one member of a partnership to adopt the higher moral ground providing them with the means by which to attribute blame and intent and to relate this to past and future sexual behaviours. It is by no means inevitable that partners will respond in this way and many do not do so, rather adopting a more sexually shared approach to the situation. However, it is the unbalanced facility that occurs as a consequence of this unbalanced approach to detection which is problematic. An unbalanced approach is inevitable if symptoms are the means by which infection is detected but in this situation both genders will be affected because the symptoms may occur in males or females. When this situation is the result of screening one member of a partnership, the imbalance is medically imposed. It is the product of a disproportionate focus of attention upon women and its effect is the perpetuation of social sanctioning of women's sexual behaviour.

#### **13.4.4 Staggered management**

This approach also presents considerable difficulties in terms of the delay that it creates between the treatment of one partner and the other. In the study, this contributed to a situation where a significant proportion of the respondents required re-treatment because of the possibility of re-infection. Within a couple who have 'sexually shared' this infection, this approach constitutes staggered management. It increases the necessity for prolonged periods of protected intercourse or preferably sexual abstinence. The data indicated how unrealistic this was for many. Health practices that rely upon lengthy periods of abstinence in a young and sexually active population are as conceptually flawed as those that rely upon consistent condom use because they fail to acknowledge the social complexities of human behaviour and the power of sexual attraction upon which those health messages are situated.

#### **14.4.5 Shared in name but not in deed**

At the outset of the opportunistic screening study, a decision was made to rename sexually transmitted infections (STI's) as sexually shared infections (SSI's) in order to remove the implications of culpability that are implicit in the term 'transmitted' (DH,

2001c). The dictionary defines the verb 'to share' as 'to divide or apportion'. Implicit in the term therefore is an assumption of knowing donation and acceptance. Although this is conceptually problematic in terms of the asymptomatic nature of infection and the consequent notion of joint ownership, this renaming represents a laudable effort to address the social effect of this infection. It seems ironic therefore that health services which have linguistically acknowledged the shared nature of these infections have singularly failed to acknowledge this element in practice. The policies that have been established to tackle this infection within the population persistently access men through women. They disproportionately lay the burden of responsibility at the feet of women and by their structure they create ample facility and opportunity for moral positioning and the perpetuation of blame and guilt.

### **13.5 Re-testing and re-infection**

The test of cure represents a particularly striking form of health surveillance as the means by which to ensure adherence to regime and instruction in relation to completion of medication, sexual abstinence and notification of sexual partners. Within a health climate, where pressures of work and target setting has resulted in a rationalisation of the service and paring of any 'added extras', the return visit and the retest has become increasingly redundant, reserved only for those deemed to merit extra surveillance. However there is a clear indication from this data that for many it served a valuable ritualistic function marking the transition from liminality. For those that needed to feel clean, it provided the means by which they could do so.

The extent to which a TOC creates and justifies its own existence is a matter of speculation. It may be that the provision of this facility and its promotion by health staff causes people to believe that it is a necessary part of management, that one cannot rely upon the drugs to eliminate the infection. Certainly much of the explanation by the respondents did centre round ensuring that the drugs had worked. It is possible therefore that health messages that affirm the effectiveness of the medication might be sufficient to assure people that their infection has been adequately dealt with. However, the primary need that was expressed so strongly by many of the respondents was an imperative to feel clean and the importance of receiving a negative test result before they could leave the infection episode behind and move on.

Retesting is theoretically available on request either at GUM or in Primary Care and it is possible that those who need this ritual will present themselves at a health facility with such requests. In this respect elimination of the TOC may be a false economy

simply moving the retest from GUM to Primary Care, whilst effectively removing the facility for identifying those who have been re-exposed to infection by their partner as a result of staggered couple management. However it is unlikely to be this simple. Many people would not feel able to justify a doctor's appointment simply to request an infection screen. The open access philosophy that characterises specialist contraceptive services make it a more realistic possibility in this setting, whilst contraceptive consultations and cervical cytology also provide opportunities for some to be able to request re-testing. An alternative that is expected to become available in the foreseeable future is the provision of chlamydial testing in pharmacies (DH, 2005). However this government initiative is part of the chlamydia screening programme and will therefore only be available to those aged 16-25 years. This facility would certainly overcome the difficulty in accessing health services for the purpose of testing. It may also therefore provide a means by which those who want and feel the need for a re-test in order to feel clean will be afforded such an opportunity. However the extent to which they might feel able to use such a service for this purpose and whether the structure of provision will enable them to do so is a matter of speculation.

The ritualistic use of testing was identified as a realistic option in relation to the beginning or end of relationships by many of the respondents. The concerns that chlamydia creates around reproductive capability may also lead to testing requests. Collectively these concerns, together with any that follow treatment, are likely to result in large numbers of testing requests. It will be difficult to deny these, however frequently they occur, because of the fluid nature of sexual relationships, the onward transmission rate and the possible long term effects. Indeed this is the basis of the opportunistic approach that is currently being adopted in relation to chlamydial screening and the basis on which testing facilities are extending further and further into the social spaces. However if this causes costs to spiral without impacting upon prevalence rates, then re-assessment of the situation may be necessary.

### **13.6 The future**

As a treatable bacterial infection, chlamydia occupies an identifiable niche in the spectrum of STI's, a position that has parallels with that previously occupied by gonorrhoea. Gonorrhoea has a similar effect to chlamydia upon women's reproductive capabilities and is also commonly asymptomatic in women. It represented a considerable Public Health threat largely as a result of its high prevalence until the emergence of antibiotics. Effective drug therapy together with socio-demographic

changes led to a sharp decline in prevalence and a consequent diminution of public and personal concerns associated with this infection.

Developments in testing as the process by which to detect and treat infection similarly promise the means by which to diminish the threat that chlamydia holds for the population. If prevalence is reduced as a result, it is probable that chlamydia will recede in the public consciousness in the way that gonorrhoea has, as something that people know about but do not get. However it is also likely that this space will be occupied by another organism. Conceivably the successor to chlamydia is waiting in the wings. The medical literature is beginning to pay increasing attention to *Mycoplasma genitalium* (Falk et al., 2005) and medical conferences are already dubbing this infection as 'the new chlamydia.'

### **13.7 Conclusion**

This piece of work has presented a detailed analysis of the individualised experience of having chlamydial infection. It identified the complexity of such an experience which is largely determined by the fact that sexually transmitted infections have a long and complex social history which has shaped their social and cultural definition. The effect of this is realised at a bodily level through the concepts of dirt and pollution and impacts upon personal responses and interpersonal relationships. It produced fears of stigmatisation and social sanctioning and necessitated the construction of narratives which reflected a moral self both in accounts of partner notification and intentions to modify sexual behaviours and safeguard sexual health through re-testing.

Those responses are further defined and modified by the specific characteristics of this particular infection. In particular the high proportion of asymptomatic infection was problematic and represented a challenge to the active self because there was commonly no way in which to detect infection through bodily surveillance. In situations where the absence of symptoms created a vulnerable self, the occurrence of symptoms afforded a degree of safety as they constituted the means by which to rid oneself of infection.

The analysis incorporated a detailed consideration of the current development of health policies and the consequent changes in service delivery. I identified the lack of recognition in current literature of the significant psychosocial impact that this infection has upon the individual and the extent to which the identified fears and anxieties of the individual are largely being ignored by efforts to drive infection management into

primary care to be managed by non specialists. The reluctance of individuals to attend the GUM clinic are well recognised, however this study has demonstrated the importance of specialist and sensitive care in caring for those who are rendered physically and socially vulnerable as a consequence of this infection.

There are limitations to this study. A single medium sized GUM clinic attached to a District General Hospital formed the focus for much of the study and the respondents were drawn from a specific semi-rural geographical location. It should not be assumed therefore that the findings readily translate to other GUM clinics or to other populations, particularly large clinics and urban populations.

The inclusion of a male perspective was an important part of this study and represents one of the few attempts to include men in the chlamydial picture. However as they were relatively few in number and comprised only 20% of the total study sample, this needs to be borne in mind when considering the gendered observations and conclusions.

The structure of this study inevitably resulted in a situation where the majority experience was attendance at GUM. This provided valuable insights into the way that this service was considered by those who attended and the role of the clinic in the management of chlamydial infection. A recruitment strategy that attempted to incorporate the voice of those who had not attended this service was only partially successful resulting in a single respondent. This is therefore a largely missing element and will require addressing at some later date especially as it is a common, although largely unquantifiable, experience which is set to increase.

### **13.8 Recommendations**

- It is essential that the implementation and ongoing management of the National chlamydia screening programme incorporates consideration of the impact that diagnosis of this infection commonly has upon the individual. This needs to be reflected in the structures that are put in place and the training of staff involved in the management of the programme.
- Increased use of non invasive testing techniques is making screening for this infection more straightforward and easier to perform. However the ease with which samples are offered and accepted should not be assumed to equate to the ease with which positive diagnoses will be received.
- Agreeing to be tested for an STI may arise from an increased sense of vulnerability to infection but does not necessarily do so because testing serves a symbolic purpose within the context of a relationship. Therefore diagnoses are largely unanticipated and require sensitive communication that reflects this fact.
- The movement of chlamydial management into primary care requires adequate staff training that incorporates consideration and discussion of the psychosocial aspects of this infection. The STIF (Sexually transmitted infection foundation) course which is being run at venues across the country is attended by medical and nursing staff and represents a commendable effort to increase STI training in Primary Care. However it pays little regard to the personal and emotional consequences of STI's. This needs to be acknowledged and addressed within the STIF courses and other similar courses.
- The movement of large-scale screening into Primary Care and increased infection management outside of the GUM clinic appears likely to impact upon the individual experience because of the lack of access to specialist practitioners. Studies that monitor the effectiveness of this programme need to fully address the psychosocial impact of the infection and particularly the extent to which the embodied and emotional aspects of the infection are acknowledged and addressed.

- There is a need to monitor the re-testing activity of those who have been treated for chlamydial infection. Their reasons for re-testing should be examined within the context of bodily dirt and contamination and a structure of liminality and re-integration in order to identify the extent to which the loss of formalised structures have resulted in patient initiated rituals of testing.
- There is an indication, derived from the patient perspective and supporting literature, that staff in Primary Care have difficulties in adequately and sensitively discussing STI's with those requiring screening, testing or treatment. Research is needed that explores the difficulties that non sexual health specialists have in providing STI related sexual health care.
- Infection management strategies that focus solely on individuals are problematic in respect of relationships because they rely upon periods of sexual abstinence and condom usage to prevent re-infection. This apparently simplistic solution which is the mainstay of sexual health education belies the complexity of sexual activity and sexual relationships.
- Screening initiatives should establish mechanisms that incorporate couple testing for those in relationships. This approach would enable both partners to be tested at the same time and then to be treated at the same time if one or both tests positive for chlamydial infection. This would reduce culpability and minimise the period of abstention which is required as part of management. It would reduce the possibility of re-infection rates within a relationship and would also enable males and females to take full responsibility for their sexual health.
- The effectiveness of dealing with this infection in terms of relationships rather than individuals should be monitored and evaluated in terms of its impact on re-infection and upon its acceptance and psychosocial impact upon those managed in this way.
- The emphasis in this study has been primarily but not exclusively on women. Work that specifically examines the male perspective would enable a more detailed examination of male responses to sexual health and infection and the extent to which male stereotypes are confirmed or challenged.

- The association between chlamydia and infertility is established and well recognised. However it is not known how this impacts upon conception and contraception activities. Research is required to understand the association between them, particularly in those attempting to conceive and the extent to which previous chlamydial infection influences requests for investigation and assistance with conception.

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## **Appendix I**

### **Biographical details of the study participants**

## Participant details

Name <sup>1</sup>	Gender	Age	Site of interview	1 <sup>st</sup> or subsequent infection episode <sup>2</sup>	Co-existing infections <sup>3</sup>	Symptoms attributable to chlamydia? <sup>4</sup>	Parental status <sup>5</sup>	Site of diagnosis
Jill	Female	24	GUM	1 <sup>st</sup>	Warts	No	No children	GUM
Alison	Female	26	GUM	1 <sup>st</sup>	No	Bleeding	No children	GP
Jane	Female	26	GUM	2nd	No	Abdo pain & discharge	One child	GP
Gail	Female	21	GUM	1 <sup>st</sup>	No	Vaginal discharge	No children	GP
Shirley	Female	16	GUM	1 <sup>st</sup>	No	Bleeding	No children	GP
Liz	Female	20	GUM	1 <sup>st</sup>	? Thrush	Vaginal discharge	No children	GP
Helen	Female	17	GUM	1 <sup>st</sup>	? Thrush	Bleeding, discharge, Dyspareunia	No children	FPC
Jean <sup>6</sup>	Female	20	GUM	1 <sup>st</sup>	No	Abdo pain	One child	GP
Carol	Female	19	GUM	1 <sup>st</sup>	No	Discharge	No children	GUM
Isobel	Female	22	GUM	1 <sup>st</sup>	? Bacterial vaginosis	Discharge	No children	GP
Jacky	Female	20	GUM	1 <sup>st</sup>	No	No	No children	GUM
Andrea	Female	17	GUM	1 <sup>st</sup>	? Thrush	Abdo pain	No children	FPC

<sup>1</sup> All names are pseudonyms

<sup>2</sup> The distinction between infection episodes is difficult and at times ill defined. If re-infection is suspected re-treatment may well occur without diagnostic confirmation. The categorisation in this chart reflects the perspective of the participant and the extent to which they identified discrete and separate infection episodes and therefore does not reflect possible or probable re-infection. For example, Gemma had required three sets of treatment but she described the circumstances as one single infection episode.

<sup>3</sup> The data here reflects the participants' understanding of the situation. Some co-existing infections were clearly reported in the accounts whilst others, specifically BV and thrush were often implied through symptomatic treatment rather than definitive diagnoses.

<sup>4</sup> This reflects the participants' perspective of cause and effect. Bleeding is vaginal unless otherwise stated and includes intermenstrual, post coital and atypical menstrual bleeding.

<sup>5</sup> Participants were not specifically asked whether they had children however the topic invariably arose in the course of discussion. Their status reflects the information volunteered.

<sup>6</sup> Jean was interviewed twice, subsequent to her first and second episode of infection

Name	Gender	Age	Site of interview	1 <sup>st</sup> or subsequent infection episode	Co-existing infections	Symptoms attributable to chlamydia	Parental status	Site of diagnosis
Angela	Female	17	GUM	1 <sup>st</sup>	No	Bleeding, pain, discharge	No children	GUM
Tess	Female	24	GUM	1 <sup>st</sup>	No	Dysuria	No children	GP
Jodie	Female	19	GUM	1 <sup>st</sup>	No	Only on reflection	No children	GUM
Michelle	Female	29	GUM	1 <sup>st</sup>	No	Bleeding	No children	GP
Karen	Female	18	GUM	1 <sup>st</sup>	No	Bleeding/pain	No children	GP
Julie	Female	21	FPC	1 <sup>st</sup>	No	Abdo pain	No children	GP
Robert	Male	19	GUM	1 <sup>st</sup>	No	Dry foreskin	No children	GUM
Paula	Female	19	FPC	1 <sup>st</sup>	No	Abdo pain, discharge	No children	GUM
Judy	Female	28	GUM	2 <sup>nd</sup>	No	No	No children	GUM
Sarah	Female	26	GUM	1 <sup>st</sup>	No	Abdo pains, dyspareunia	No children	FPC
Margaret	Female	18	GUM	1 <sup>st</sup>	No	Abdo pain	Pregnant	ANC
Andrew	Male	21	GUM	1 <sup>st</sup>	No	In partner	No children	GUM
Sheila	Female	29	GUM	1 <sup>st</sup>	No	Vaginal discharge	One child	GUM
Steve	Male	18	GUM	1 <sup>st</sup>	No	No	One child	GUM
Dave	Male	30	GUM	1 <sup>st</sup>	No	Dysuria	No children	GP
Sian	Female	20	FPC	1 <sup>st</sup>	No	No	No children	FPC
Marion	Female	21	FPC	1 <sup>st</sup>	No	No	No children	FPC
Gemma	Female	17	FPC	1 <sup>st</sup>	Gonorrhoea	Vaginal discharge	No children	FPC
Kelly	Female	19	GUM	1 <sup>st</sup>	No	No	One child	GUM
Yvonne	Female	25	GUM	1 <sup>st</sup>	No	Abdo pain	Two children	Gynae
Mike	Male	33	GUM	1 <sup>st</sup>	No	In partner	No children	GUM
Tracy	Female	21	GUM	1 <sup>st</sup>	Warts	Pain, vaginal discharge	No children	GUM
Phil	Male	19	GUM	1 <sup>st</sup>	Scabies	Pain itching	No children	GP
Amy	Female	18	GUM	1 <sup>st</sup>	No	No	No children	GUM
Jenny	Female	27	GUM	1 <sup>st</sup>	No	No	No children	GUM
Zoe	Female	19	GUM	1 <sup>st</sup>	No	No	No children	GUM
Mandy	Female	16	GUM	1 <sup>st</sup>	No	No	No children	GUM
Wayne	Male	20	GUM	1 <sup>st</sup>	No	In partner	No children	GUM

<b>Name</b>	<b>Gender</b>	<b>Age</b>	<b>Site of interview</b>	<b>1<sup>st</sup> or subsequent infection episode</b>	<b>Co-existing infections</b>	<b>Symptoms attributable to chlamydia</b>	<b>Parental status</b>	<b>Site of diagnosis</b>
Tom	Male	23	GUM	1 <sup>st</sup>	No	Joint pain	No children	GUM
Kate	Female	22	GUM	1 <sup>st</sup>	No	Vaginal discharge	No children	GP
Sarah	Female	22	FPC	1 <sup>st</sup>	No	Bleeding, pain	No children	FPC
Jean	Female	21	GUM	2nd	No	Abdo pain	One child	GP
Peter	Male	18	GUM	1 <sup>st</sup>	No	Penile discharge	No children	GUM
Luke	Male	23	GUM	1 <sup>st</sup>	No	Penile bleeding	No children	GP
Beccy	Female	17	GUM	1 <sup>st</sup>	No	No	No children	GUM
Anne	Female	25	GUM	1 <sup>st</sup>	No	Bleeding	Three children	GUM
Laura	Female	17	GUM	1 <sup>st</sup>	Warts	No	No children	GUM
Sue	Female	17	GUM	1st	Thrush & Warts	No	Pregnant	GUM

## **Appendix II**

### **Consent form and information sheet for GUM**

## **Patient information leaflet for Chlamydia study**

You will have heard of this chlamydia study from the nurse or doctor in the clinic. The purpose of this leaflet is to explain more about the study so that you can decide whether to take part.

### **What is it for?**

The aim of the study is to find out more about how people respond when they are diagnosed as having a chlamydial infection and what things worry them about having the infection. We hope that by increasing our knowledge of these things we can understand better what causes greatest concerns about the infection. We can then use this information to improve the care that we provide, for example by developing patient information leaflets that deal with these issues.

### **Who is doing the study?**

I am a nurse who works in sexual health and family planning services.

### **What is involved if I decide to take part?**

A private interview using a room in the genitourinary clinic when you attend the clinic or at some other time if you wish. The interview will be taped so that I do not have to write and listen at the same time. After the interview I will copy out the interview and the tape will be destroyed.

### **How long will the interview last?**

The length of time depends on you but will be approximately half an hour.

### **Will the interview be anonymous?**

Only first names will be used during the interview. When the written copy is made all names will be removed and replaced by a number so that the information cannot be traced back to you. Neither the people nor the clinic will be identifiable when the study is written up.

### **Do I have to take part in the study?**

It is up to you whether you want to take part in the study and your decision will not affect your care.

**Consent form for the study titled**

**“Chlamydia infection – a patient’s perspective.”**

I agree to participate in this study.

The purpose of the study has been explained to me and I understand that;

- Participation will be by means of an interview which will take place at the time of my visit to the genitourinary clinic.
- The interview will be carried out by the researcher and will take place within the genitourinary clinic.
- The interview will be taped.
- Only the interviewer will listen to the tape which will be destroyed as soon as a written copy of the interview has been made.
- First names only will be used on the tape and these will be replaced by a number in the written copy so that I cannot be identified.
- This form will be stored in my notes which are kept in the genitourinary clinic.
- I have the right to withdraw from the study if I wish without it affecting my medical care in any way.

Signed ..... (Participant)

Signed .....(Health Advisor)

## **Appendix III**

### **Consent form and information sheet for FPC**

## **Patient information leaflet for Chlamydia study**

You will have heard of this Chlamydia study from the nurse or doctor in the clinic. The purpose of this leaflet is to explain more about the study so that you can decide whether to take part.

### **What is it for?**

The aim of the study is to find out more about how people respond when they are diagnosed as having a chlamydial infection and what things worry them about having the infection. We hope that by increasing our knowledge of these things we can understand better what causes greatest concerns about the infection. We can then use this information to improve the care that we provide, for example by developing patient information leaflets that deal with these issues.

### **Who is doing the study?**

I am a nurse who works in sexual health and family planning services.

### **What is involved if I decide to take part?**

A private interview using a room in the family planning clinic when you attend the clinic or at some other time if you wish. The interview will be taped so that I do not have to write and listen at the same time. After the interview I will copy out the interview and the tape will be destroyed.

### **How long will the interview last?**

The length of time depends on you but will be approximately  $\frac{1}{2}$  -  $\frac{3}{4}$  hour.

### **Will the interview be anonymous?**

Only first names will be used during the interview. When the written copy is made all names will be removed and replaced by a number so that the information cannot be traced back to you. Neither the people nor the clinic will be identifiable when the study is written up.

### **Do I have to take part in the study?**

It is up to you whether you want to take part in the study and your decision will not affect your care.

**Consent form for the study titled**

**“Chlamydia infection – a patient’s perspective.”**

I agree to participate in this study.

The purpose of the study has been explained to me and I understand that;

- Participation will be by means of an interview which will take at an agreed time on a return visit to the family planning clinic.
- The interview will be carried out by the researcher and will take place within the family planning clinic.
- The interview will be taped.
- Only the interviewer will listen to the tape which will be destroyed as soon as a written copy of the interview has been made.
- First names only will be used on the tape and these will be replaced by a number in the written copy so that I cannot be identified.
- I have the right to withdraw from the study if I wish without it affecting my medical care in any way.

Signed ..... (Participant)

Signed ..... (Family Planning nurse)

## **Appendix IV**

### **Topic areas covered in the interviews**

## **Interview checklist**

Prior to interview - brief resume of the purpose of the study/ consent / questions/ taping and transcribing

### **Opening question**

What has been happening to you today / how did you come to be here today / what led you to attend the clinic today?

## **Key topics to cover**

### **Factors leading to diagnosis of infection**

- Symptoms
- Routine testing
- What triggered the testing
- Site of testing
- Means of receiving diagnosis
- Response to diagnosis
- Previous episodes of infection

### **Infection within the relationship**

- Relationship status
- Where did she consider the infection came from?
- Situation with regard to informing partner
- Partner's response
- Impact of infection upon the relationship

### **Awareness of this infection**

- Amount of knowledge
- Sources of knowledge
- Amount of social discussion of the infection
- Long term effects and feelings about these

### **Protecting self from infection**

- Previous sexual behaviours
- Future intended sexual behaviours
- Considering the possibility of infection within a relationship

### **Attendance at GUM**

- How they came to be at the GUM
- Concerns/considerations prior to attendance
- The GUM experience

**Any further comments / thoughts.**

## **Appendix V**

### **Example of codes and categories**

## Hierarchy of infections

### Open codes

Acceptability of thrush – not an STI  
Being an STI  
Sounding horrible

Visibility  
Physical discomfort  
Treatability  
Degrees of badness  
The magnitude of chlamydia  
Being glad  
Being little  
Commonality  
Selective disclosure

Public awareness – portrayal of HIV  
Educational coverage - HIV  
Naming HIV  
HIV the big one  
HIV - Acknowledging the link  
The bigness of HIV  
The rareness of HIV  
HIV – not wanting to know

### Axial codes

The legacy of STI's

Relative magnitude of STI's

HIV – above other STI's