THE PSYCHOLOGICAL IMPLICATIONS OF SURVIVING TESTICULAR CANCER: IMPACT ON BODY IMAGE, SEXUALITY AND MASCULINITY

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Introduction: Men's health generally and testicular cancer in particular are neglected areas of research. This particular malignancy is the most common among young men in the western world (Champion, 1996), and its prevalence is on the increase, however, so too are cure rates. As a consequence, there are an increasing number of young male survivors. Impact on sexual function of survivors is well documented in the literature, yet little is mentioned about the impact on the sexuality and masculinity of the young man following treatment. The objective of the research therefore was to explore the impact on survivor's self-perceptions, in particular focusing on the areas of sexuality, masculinity and body image.

Method: The research followed a cross-sectional design, comparing men at four different stages post-illness. Repertory grid technique was utilised for data collection purposes, which combined qualitative and quantitative methods. Semi-structured interviews (n = 10) were analysed using content analysis, which formed the basis of a generic repertory grid. Quantitative data from subsequent grid completion (n = 37) were analysed using a beta version of SPSS to carry out 3-way 3-mode multidimensional unfolding.

Results: The results suggest that men's self-perceptions change as a consequence of testicular cancer, and that sexuality, masculinity and body image play a part in these changes for some, but not all men. The constructs rated in this study all contribute to the differences in patterns across groups. Results suggest the occurrence of an adjustment process, showing current perceptions of the self as more aligned with retrospective pre-illness perceptions by 24 months post-illness. The majority of men judged repertory grid technique to be a satisfactory means of evaluating self-perceptions relating to the illness experience.

Discussion: The results of the study have implications for the level of professional support received by men with testicular cancer, both generally and with specific reference to issues of sexuality, masculinity and body image. However the innovative style of this research and the absence of pre-existing evidence in support of the findings, mean that further research will be required to gain a thorough understanding of the psychological implications of surviving testicular cancer with regards to these issues. Specific recommendations are made for further research.

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ABBREVIATIONS

BEP	Bleomycin, Etoposide, Platinum Combination Chemotherapy
GCT	Germ Cell Tumour.
GU	Genitourinary
MDS	Multidimensional Scaling
NHS	National Health Service (U.K.)
NICE	National Institute for Clinical Excellence
NST	Nonseminomatous Tumours
PCA	Principal Components Analysis
PTSD	Post-Traumatic Stress Disorder
RPLND	Retroperitoneal Lymph Node Dissection
SIP	Self Image Profiles
SPSS	Statistical Package for the Social Sciences.
SRRTM	Secondary Resection of the Retroperitoneal Tumour Mass
ST	Seminomatous Tumours
TC	Testicular Cancer
TIP	Paclitaxel, Ifosfamide, Cisplatin Combination Chemotherapy
TSE	Testicular Self-Examination

CHAPTER 1: INTRODUCTION

> "...I questioned everything: my world, my profession, my self. I had left the house an indestructible 25-year-old, bulletproof. Cancer would change everything for me, I realized; it wouldn't just derail my career, it would deprive me of my entire definition of who I was."
>
> (Lance Armstrong, 2001. p 14)

Taken from his book about the journey back to life following his experience of testicular cancer, this quote from Lance Armstrong describes the impact of the diagnosis. This study aims to explore in detail the implications of surviving testicular cancer. It focuses on the specific impact on elements of the self-concept, particularly body image, sexuality and masculinity. With a view to explaining the importance and relevance of this area of research to the provision of supportive services for this group of men, the following literature review explores the concepts of masculinity, sexuality, body image and men's health before summarising the available literature on the psychological impact of cancer in general, and testicular cancer in particular. Initially, however, an attempt will be made to define the concepts of interest: masculinity, male sexuality and the concept of the self.

Preface

Each of the concepts of relevance to this particular research are complex, multi-dimensional, and subsequently difficult to define. They can each be viewed from a number of different perspectives, some of which are contradictory: however, in this study the social constructionist perspective will be adopted. This stance has been chosen largely because of its fit with personal construct theory and repertory grid technique, the chosen methodology in this investigation.

Social constructionism is an epistemological position that focuses on meaning and aims to provide explanations for the ways in which certain phenomena are constructed in society through language (Gergen, 1985). In this approach there is no such thing as an accessible objective reality, therefore internal constructions and perceptions of reality are of primary interest. It is assumed that there are numerous different ways of constructing everything, and the meaning of these individual constructions will vary accordingly. As a result of the fact that everyone is born into a social structure, it is thought that the socialisation of individuals plays a large part in the construction of the meaning of events, characteristics, behaviours and possessions. Ultimately the influence of others within the social network will shape the way we see the world.

In this particular investigation men's personal constructions of cancer and masculine identity will be examined, allowing for comparisons and commonalities. The social constructionist stance will be adopted throughout consideration of the following concepts in this research.

Defining Masculinity

Masculinity is a complicated concept to define, and one that is commonly misunderstood. The literature does not converge on one specific definition. Often the terms sex and gender are used interchangeably, as are male gender and masculinity, yet the three concepts are not identical. Whilst it does not seem possible to create a simple definition of masculinity, an attempt will be made to summarise the theoretical descriptions in the literature, and make links to the notion of masculinity employed in the context of this study.

Masculinity has been described in many ways by different authors, but briefly, it is seen as the behaviours, languages and practices, existing in specific cultural and organisational locations, which are commonly associated with males (Kimmel & Messner, 2000; Whitehead & Barrett, 2001). These provide resources for the creation of identity, in a way that sets men apart from women (Whitehead & Barrett, 2001; Whitehead, 2002). That said, this is something that occurs over and above the genetic, biological and anatomical sex differences, which have been termed sexual destiny by Moynihan (1998, 2002). In other words masculinity is what a man feels, says and does in order to demonstrate his 'manliness'. However, it is not immediately evident what process results in all men acquiring a uniform masculine sense of self. Indeed it is doubtful that all men perceive this concept in the same way.

Physically speaking, the biological sex of a man is set apart from that of a woman by the presence of a Y chromosome. It is this genetic component that results in a man being physically male. However, this alone does not determine an individual's sense of masculinity, as is evident when looking at groups in society, for instance gay or transsexual men, who may be genetically and physically male, but who differentiate themselves from the cultural norms of masculinity (Whitehead, 2002).

If men are not born with an innate sense of what it means to be masculine, determined solely by the presence of a Y chromosome, they must formulate this meaning by actively construing their environment and building a sense of masculinity within the framework of social and historical context (Fausto-Sterling, 2000; Kimmel & Messner, 2000). The presence of this process is evident when looking at differing behaviours of men throughout different cultures, and across various historical periods. The meaning of masculinity can be constructed using different tools dependent on the contexts within the man's life, for example through sport, crime or sex (Courtenay, 2000). Biddulph (2004) argues that boys are taught, from a very early age, to put on an act and play one of a small selection of roles, such as 'tough guy', 'hard-nosed businessman' or 'cool dude'. In other words, from a social constructionist perspective, men learn what it means to be a man from others around them, within the context of their surroundings, from childhood into adult life. However, there is an element of agency in men's construction of masculinity (Messner, 2000). They are not merely passive beings in the process, rather they choose to embrace some or all of the lessons in their everyday lives, which dictates their language, behaviour, beliefs and attitudes (Pleck, Sonenstein, & Ku, 1994).

The existence of traditional male roles in society provides a framework on which men can base their construction of masculinity, or indeed as a basis for the construction of an alternative representation of masculinity. In a sense, when men adopt the traditional roles they are conforming to gender role stereotypes, or culturally defined norms (Chapple & Ziebland, 2002; Moynihan, 2002) either at a conscious or subconscious level. Subsequently, beliefs about 'who men are', and what is expected of them, form a collective societal definition of gender, which they are encouraged to espouse. What is more, research evidence shows that relatively speaking men are exposed to more social pressure to conform to gender related stereotypes than women (Golombok & Fivush, 1994; Laws, 1998; Lloyd, 1998) to appear independent, strong and tough. However, this issue is likely to be contested by feminist writers, who may argue that women are subjected to more pressure to provide on an equal footing and simultaneously be good wives and mothers.

In most instances the physical destiny, or biological sex, of the individual determines the set of gender roles to which a person conforms. Ultimately this can also determine the way in which a man expresses his sexual feelings. Moreover, because men and women are distinct in their biological make-up it is assumed that their corresponding gender roles will have no common characteristics (Liss-Levinson, 1982). Once assembled, the male identity is open to change throughout life. Hence rather than being a core, fixed construct, it incorporates multiple elements to realise a complete sense of self (Rajchman, 1995). In order to achieve a complete self-concept, a man must work towards its attainment, and in doing so he must attempt to obtain a feeling that he 'belongs' in his social world (Bell, 1999).

True masculinity is almost always thought to stem from the male body (Connell, 1995). Historically, and currently, the male sex drive is associated with masculinity and the phallus is often taken as a symbol of power. One author noted that for proper male identity to develop, a male child must have sufficiently sized genitalia for there to be no doubt in anyone's mind of the legitimacy of his male identification (Fausto-Sterling, 2000). Evidence supporting the significance of the male genitalia in gender identity comes from studies of intersex children, whereby gender assignment surgery is frequently carried out where children are born with ambiguous genitalia (Bradley, Oliver, Chernick, & Zucker, 1998), under the premise that without intact, normal-looking external genitalia a child cannot develop a stable gender identity (Domurat Dreger, 1998; Money, Hampson & Hampson, 1955). This issue is somewhat contentious and policies regarding gender assignment of these individuals are now under scrutiny (Thyen, Richter-Appelt, Wiesemann, Holterhus & Hiort, 2005). Furthermore, there is evidence to suggest that the role of the testes in male fertility is significant in identity and a masculine sense of self, in addition to the importance placed on the ability to obtain an erection and demonstrate an adequate sexual performance (Gurevich, Bishop, Bower, Malka & Nyhof-Young, 2004). It has been said that a deficiency in these characteristics and abilities, which are held in such high esteem in the male culture, can result in a threat to the individual's masculine identity (Ofman, 1995), thus placing further emphasis on the importance of the sexual organ in the development of a masculine sense of self. With particular reference to testicular cancer, Van Basten, Jonker-Pool, Van Driel, Sleijfer, Van de Wiel et al (1996) reviewed the significance of the testicles in the contexts of cultural fantasies, and concluded that the symbolism of the testes is linked to sexual morbidity in testicular cancer. Additionally, brief examination of cultural colloquialisms supports this emphasis, given that the ultimate statement of bravery between men is to be told, 'you've got balls' (Chapple & McPherson, 2004). In sum, the symbolism surrounding male genitalia and masculine identity may be of particular significance for men who, for one reason or another, require surgery to this part of their anatomy, for example in testicular cancer.

Masculine stereotypes, often painted by the media, portray the male to be assertive, athletic, independent, powerful (Donald, 2001) and dominating, yet protective over women, the 'weaker sex' (Whitehead & Barrett, 2001). Men are also portrayed as emotionally inexpressive, or 'emotionally constipated' as one author so aptly describes (Farrell, 1974). Characteristically, the stereotypical male is also a breadwinner; motivated by sexual conquests and lacking in the sensitive, caring characteristics associated with femininity (Kimmel, 2001). Whilst stereotypes by their very nature are extreme representations, the above description does not markedly deviate from the masculine gender roles represented in the literature on men's health and masculinity (Alt, 2001; Courtenay, 2000; Farrell, 1974; O'Neil, 1981). Furthermore there is a significant level of consensus in western societies about the nature of traditional male and female roles (Golombok & Fivush, 1994) and typically masculine and feminine characteristics (Connell, 1995). What is more, the socially constructed nature of the masculine role requires that men should not deviate a great deal from the norms. Hence, men who do not fulfil this stereotype tend to be seen as inferior, and in some way not 'real men' (Brittan, 2001). This has tended to apply to gay men especially, or men who do not adopt the gender role stereotype because of some other inhibiting factor (Kimmel, 2001; O'Neill & Hird, 2001). Consequently, it appears that, to men, being a man is defined by ones' ability to 'belong', and fit within the roles constructed by society, including the ability to perform as a heterosexual male (Segal, 2001).

However, many authors argue that masculinity cannot be understood as a single, unified concept in the manner portrayed above, rather it should be referred to as a plurality, given that these concepts vary so greatly over time and between different cultures and societies (Barrett, 2001; Connell, 1995; Kimmel, 1986; Peate, 2003; Sabo & Gordon, 1995). Indeed, the changes in male roles become apparent when examining historical patterns. For instance, the contrast between the role of the husband / father in the early twentieth century, and current western society whereby it is not unheard of for the man to fulfil the role of 'house person', which would have been an anathema prior to recent social advances. Moreover, Courtenay (2000) in reviewing ideas in this area, highlights the existence of a number of different masculinities such as subordinated, marginalized, complicit and resistant, all of which contrast with the traditional hegemonic masculine ideal (Connell, 2001), this latter concept originating from Connell (1995). The term refers to the idealised form of masculinity in any society, hence the most dominant construction of masculinity in existence at a given time, which has the power to influence men's social relationships of all kinds. Courtenay (2000) described the current hegemonic ideal in U.S. society as being located in heterosexual, highly educated, upper class, European American men. In circumstances where men have neither the power or the resources to adopt this hegemonic ideal they are likely to forge an alternative construction using whatever resources they have available (e.g. violence), to validate their masculinity (Courtenay, 2000). It is proposed that the alternative masculinities, when compared to the socially constructed ideal, can better account for the existence of varied personal contexts such as economic status, ethnicity, and sexuality, each of which might result in the construction of different male roles (Connell, 1995; Courtenay, 2000). Thus with increased societal changes, the cultural norms and boundaries to which men must adhere in order to fulfil the masculine role have shifted considerably. Indeed some suggest that confusion rules for today's men with regards to what it means to be a 'real man', as a consequence of this revolution in the male role (Gough, 2001; Kimmel & Messner, 2000).

In summary then, it appears that masculinity is a complex concept and it is almost impossible to identify a definitive description. It is multi-faceted, ever changing (Kimmel, 1995) and means something different to every individual. Furthermore, the concept of masculinity is interwoven with male sexuality.

Male Sexuality

Little seems to be written in the literature to define male sexuality as a distinct concept. It frequently appears to be documented in a manner suggesting that sexuality is in fact synonymous with masculinity (Frosh, 1993; Kimmel, 2001). Alternatively, male sexuality is described in terms of physical sexual functioning, and the act of sexual intercourse as a means of expressing sexuality, a definition criticised by Gurevich et al (2004). It is this definition that is widely used in medical literature, especially when describing the impact of illness on sexuality (Jonker-Pool, Hoekstra, Van Imhoff, Sonneveld, Sleijfer et al, 2004; Schover, 1987). For this reason, sexuality will not be discussed in great detail here, other than to briefly outline the relevance of sexuality in the context of the current work.

Carr (1991) states that: "sexuality refers to far more than a mere sexual act" (p.52). In his description of sexuality, the concept incorporates biological, social, as well as psychosocial elements. He goes on to describe the psychosocial aspects as including self-concept, self-esteem, body image, gender, sexual identity as a man (or woman), sexual preference and gender roles (Carr, 1991). Correspondingly, Mantell (1982) defines sexuality as a multidimensional concept, encompassing biological and socio-cultural aspects, such as self-concept, satisfaction, libido, body image, sex roles and interpersonal communication. Both these views suggest that to define sexuality in terms of sexual behaviour alone is too simplistic.

With regards to male sexuality specifically, the male body is seen as the most significant factor. The majority of discussions around this topic stem from older psychoanalytic writings regarding the importance of the phallus (for example Freud, 1933). Here the phallus is seen as the main identifier of male sexuality in that it signifies difference between the two sexes. The presence of the penis is taken as the norm and women are defined by its absence, "a vacancy where it is taken to matter" (Frosh, 1993, pp 44). Some have highlighted the association with dominance that this notion brings with it (Connell, 1995; Frosh, 1993). Frosh (1993) particularly links male sexuality in a historical network of domination and abusiveness, where men have difficulties with the dependence associated with the sexual act of intercourse. Ultimately Frosh sees the foundations of male sexuality as being rooted in relationships, through domination, fear and ambivalence towards intimacy. However, according to others, this dominance is more likely related to a natural hunting tendency among men, which links to the emphasis on power, competition, hierarchy, and sexual conquest in male sexuality (Connell, 1995).

So it seems, much like masculinity, sexuality is not a distinct clearly defined notion. Rather a number of concepts seem to combine together to form the male sexual identity, and thus define what it means to be a man. However, one factor remains consistent throughout, and that is the emphasis on the male body as critically important in building and maintaining a masculine sense of a self (Connell, 1995; 2000), and it seems to me that this is almost inextricably linked with male sexuality. Sexuality and masculinity appear engaged in a 'chicken and egg' scenario, sexuality being assumed to be a central aspect of the 'self', and the means by which a man defines himself (Carr, 1991; Caplan, 1987). Likewise masculinity is an important factor in the way a man forms his self-concept, as we have seen. The two concepts, although separate, are linked and interdependent, such that each in turn influences the expression of the other, but which arrives first in the development of the self is arguable. In any case, the body of the male is seen as crucial to the development of both, hence it seems essential at this juncture to examine the concept of body image.

Body Image In Men

Also connected to the concepts of masculinity and sexuality is the idea of body image, and a general sense of self. In broad terms body image has been defined as,

> "the picture of our body which we form in our mind; the way in which our body appears to ourselves" (Schilder, 1935 p.15).

Schilder was the first to discuss the concept of body image in a manner close to how it is referred in psychiatry today, even though awareness of some form of body image dates back to the sixteenth century when surgeons were discovering the notion of phantom limbs (Kolb, 1975). Despite Schilder's pioneering of the idea, some have disputed the subjective element of this definition, and argue that it should be defined as a more dynamic concept, especially given that one's feelings towards their body are usually complex, and, like other self-representations, change over time (Kolb, 1975). In his writings Kolb chose to talk about body image as,

> "the perceptions, attitudes, emotions and personality reactions of the individual in relation to his own body" (Kolb, 1975. p.813).

Kolb argues that the term body image is too broad and ought to be more narrowly defined by separating the notion into several separate elements, which include:

- Body-percept – the sensory experiencing of the body.
- Body-concept – thoughts, emotions and attitudes about the body.
- Body-ego – the element of personality that views the body image.
- Body ideal – the dream version of the body with which comparisons are made with the other elements.

Major changes in the way someone views their own body tend to coincide with physical alterations to the body, such as illness, injury or ageing (Monga, 1995; Price, 1990). The natural occurrence of changes in body image which come about with time, and age, are often difficult enough to deal with, but the impact of unexpected and imposed changes is far greater in magnitude (Schain, 1980). Such alterations to a person's body have been known to result in reactions likened to a grief response (Kubler-Ross, 1969 cited in: Price, 1990; Smith, Livisnie, Nelson & McNemar, 1977), which require a progression through stages to incorporate the physical changes into a new sense of self. Concomitantly, a number of radical surgical procedures, necessitated by disease, are regarded as severe assaults on an individual's body integrity (Schain, 1980).

Price's (1990) model is particularly useful in understanding the formation and maintenance of a healthy body image, which is viewed as crucial for optimal psychological well being and effective sexual functioning (Gritz, Wellisch, Wang, Siau, Landsverk & Cosgrove, 1989; Monga, 1995). Ultimately, Price (1990) viewed the body as responsible for self-understanding and an individual's feelings about their own self worth. The model separates body image into three distinct components, namely body reality, body ideal and body presentation. Body reality is the label given to the body as it actually exists, warts and all, although this might not be the way in which the individual would like to see it. Body ideal is the picture in our minds of how we would wish the body to be, the individual's representation of perfection. This image is enormously influenced by society and culture, in that people's ideals change along with norms. Body presentation is the way in which we present our physical appearance to the outside world, the use of clothes and accessories as a way of making a statement, and the behaviour one exhibits, for instance as an expression of sexuality. Body image is adjusted regularly over time, and tends to be prompted by life events, such as puberty, illness and ageing (Price, 1990). Stemming from this need to account for adjustment, in Price's model all elements are seen to impact on each other with equal force. It is this tension and balance that is required to sustain the stability of a healthy body image. A change in one factor (e.g. body reality) will ultimately impact on the others (body ideal and body presentation), and whilst on occasions they may work jointly to compensate for changes: if this were not possible the result will be an individual with a negative sense of self. So, for example, if an individual were to have high expectations in terms of body ideal, and their body reality was close to that ideal, they would have a healthy, positive perception of their body. However, if they were to unexpectedly experience disfigurement as a consequence of an accident, this person might be more vulnerable to disturbances of body image, as a result of their placing so much emphasis on achieving security through body beauty. Such disturbances can have potentially pathological effects on a person's psychological well-being (Kolb, 1975).

Indeed, with respect to male body image specifically, the male body is viewed as being central to masculinity (Connell, 2000), perhaps because it is the vehicle for the enactment of the traditional male role (Messner, 2000). As such the male body is viewed as complete, strong and invulnerable (Petersen, 1998), in keeping with masculine character. Indeed the male body, and the penis are often depicted as machine-like in their social reputation (Bordo, 2001). Thus, the male body and its connection with masculinity further serve to define men's place within society. Consequently, because a large component of male identity is grounded in the physical self, when illness or disability occurs a man's sense of masculinity is placed under threat. Such difficulties serve as a constant reminder that the individual falls short of the dominant male portrayal (Gerschick & Miller, 2001), which can cause their sense of masculinity to crumble.

To sum up, a person's body image is the thoughts feelings and attitudes that the individual holds about their body, which develops from the prenatal stage through to adulthood, via physical and social interactions with the environment. Evidently the development of a positive view of the body is important in the development of an integrated sense of self. Perhaps more important is the ability to be adaptive when changes in body reality occur. However, as body image is only one part of the self-concept it seems logical to move the discussion in this direction.

The concept of the self

Self-concept is a further notion that is arguably interwoven with masculinity, sexuality and body image. A simple definition originates from Schain (1980), and is quoted widely in the literature, stating that self-concept is: "the sum of all that a person feels about himself / herself" (p.16). It has also been described as a group of feelings and cognitive processes originating from observations of behaviour. In other words, a self-concept is a person's appraisal of their appearance, background, attitudes and abilities that direct the individual's behaviour (Labenne & Greene, 1969: Cited in Morris, 1985).

Schain (1980, 1981) proposed a useful model of self-concept, sub-divided into four components:

- Body self - relates to physical functioning and body image.
- Interpersonal self - focuses more on psychosocial interactions, including relationships and sexuality.
- Achievement self - relates to the domain of work and the function of employment roles.
- Identification self - incorporates the more philosophical elements in connection with religion and ethical beliefs (Schain, 1980).

Kelly (1955) draws upon personal construct psychology in thinking about the way we define ourselves as individuals. This theory is characterised by the notion that we have a pre-existing and adaptable system of beliefs with which we understand our experiences. Kelly suggests that humans are scientists, such that individuals aim to predict and control their environment by carrying out experiments, within the context of their current surroundings and historical events. In doing this, we base our subjective reality on the meanings we attach to experiences. In attributing meaning to our environment, we form constructs that will allow us to make sense of ourselves, situations we find ourselves in, and even the entire universe (Fransella, Bell &

Bannister, 2004). Consequently, in this theory, the meanings are of significant importance rather than the events themselves. The very nature of this thinking places Kelly's approach in the constructionist school of thought.

When summarising the basic theory behind his approach Kelly highlighted a fundamental statement (or postulate, as he referred to it), and numerous corollaries. Of particular relevance here, in light of the social-constructionist standpoint of the research, are the commonality and sociality corollaries. These focus on the involvement of other people in the formation of constructs, in that individuals are able to construe things in similar ways to others, and that we are also able to appreciate each other's construction of events.

As is emphasised by the label 'personal construct', Kelly assumes that each individual has a unique means of construing and attributing meaning, which results in an entirely idiographic approach to perceiving the world and the self. It is conjectured that constructs are dichotomous, suggesting that people make sense of things by viewing everything in the context of contrast. In other words, by identifying similarities with some things and dissimilarities with others, an individual can make sense of people, events, and even themselves. Thus, a finite number of these dichotomous constructs form our personal construct system. Ultimately, the system is fluid through time, allowing for altered experience. It follows then, that in Kelly's terms, a sense of self is a dynamic and complex concept, constructed in the context of societal influences, and is unique to each individual.

In a further description of self-concept Rosenberg (1986) proposed that the self-concept is made up of two dimensions, namely an ideal self and an actual self. Individuals strive to maintain proximity between the two elements, because any discrepancy between the two would result in psychological tension. Likewise, in Kelly's approach, the ideal self is often used as a point of reference with which to compare other perceptions.

Often the notion of self-esteem is discussed alongside the idea of self-concept. This term and others, such as self-image, self-worth, and self-perception tend to be used interchangeably, and with little explanation, but collectively they refer to the overall way we evaluate ourselves, and how much value we attach to ourselves as individuals (Fennel, 1999). If a person feels good about himself / herself, and is able to appreciate the value of their contribution to the world, it would be said that they have a high or positive self-esteem. Whereas low self esteem would be indicated by a person's inability to recognise their worth as an individual and to others.

In a similar manner to the concepts previously discussed, self-concept and self-esteem are seen to develop throughout life during interactions with the individual's environment, and are continually adapting and evolving with new experiences and interpretations of events. Negative changes are seen to occur as a consequence of personal crises, and these in turn are thought to have an impact on quality of life. Hence it can be assumed that positive attributions in each of the above areas; work, social life and physical well being, will result in a positive self-concept and a good quality of life.

Clearly, what makes up the complete entity of a man's sense of self is complex. It incorporates sexuality, masculinity and body image: however, each of these concepts in turn are complex and multidimensional and have some common characteristics. The picture of the relationship between these factors is somewhat confusing. All three concepts are fluid over time and are vulnerable to influence from the environment. Men do not have an innate perception of these factors: rather a sense of sexuality, masculinity and body image develops gradually, and involves learning and adjustment, meaning that social and cultural norms must also be integrated into the male sense of self. For example, employment, breadwinning, and perhaps sporting ability are historically central to a masculine sense of self.

Taking this into account, it is easy to see how changes to the body, employment, and social environment could all potentially impact on masculinity, sexuality, body image, and a person's overall sense of self. Furthermore, it is possible to see the relevance this holds for the field of men's health; illness can be one of the most significant changes one might experience in life and one that has tangible links to the body. What follows is a brief discussion of how these concepts relate to literature on men's health, and research around chronic illness and cancer.

Men's Health

When the health statistics for men and women are compared, the picture for men looks decidedly bleak, as it seems that they suffer more illness and die younger than their female counterparts (Lee & Owens, 2002). Yet despite the gloomy outlook, it appears that such poor health in men is largely preventable (Barton, 2000). This has led some authors to suggest that men's health is in crisis (Alt, 2001; Courtenay, 1998). The evidence pointing to this originates from a number of recent review articles about the state of men's health in America (Alt, 2001; Courtenay, 1998, 2000; Courtenay & Keeling, 2000) and across Western Europe (White, 2001; White and Cash, 2003, 2004). Specifically men are said to be more likely to die prematurely than women, in fact approximately 7 years earlier, and also have increased mortality rates for all 15 leading causes of death in comparison to their female counterparts (Department of Health and Human Services, 1996, cited in Courtenay, 1998, 2000). Even when these statistics are age adjusted, men exceed the number of women in all causes of death (Alt, 2001). Furthermore, rates for terminal illnesses such as cancer in men have increased more than 20 per cent over the last 35 years, whilst the same rates for women have remained stable (American Cancer Society, 1994). A number of theories for this apparent gender inequality have been proposed, including the biological fragility of men as a group (Kraemer, 2000). Whatever the reason may be, there is certainly a consensus that men's health is ill considered by scientists, researchers, medical professionals and politicians alike (Sabo & Gordon, 1995).

There is insufficient evidence to support the fact that men are more vulnerable to illness based on biological determinants alone (Laws, 1998; Schofield, Connell, Walker, Wood & Butland, 2000). So it seems that the presence of the Y chromosome in determining male physiology cannot single-handedly be held responsible for the poor state of men's health. One other explanation commonly cited in the literature emphasises the importance of health related beliefs and masculine behaviour (Alt, 2001; Barton, 2000; Courtenay, 2000; White & Cash, 2003; Woolf, Jonas & Lawrence, 1996). This theory claims that men's poor health status stems from attempts to live up to a macho, stereotyped, lifestyle that is harmful to health (Watson, 2000). Generally speaking, men engage in more risk taking behaviours than women (Alt, 2001; Laws, 1998), and are encouraged to adopt attitudes that lead to increased likelihood of certain illnesses, such as internalisation of daily problems and stressors (Helgeson, 1995), by not talking about their problems (Good, Dell & Mintz, 1989), and denying pain and illness (Courtenay, 1998). In other words, the male role requires men to cover up all signs of vulnerability, in order to be viewed as masculine. Such behaviours are seen as a consequence of men's socialisation, in order to act out a male script, thereby consciously choosing to engage in destructive behaviours (Biddulph, 2004; Courtenay, 1998). In this sense at least, men have been labelled as the weaker sex, given that masculine attitudes and healthy lifestyles are thought to be incompatible. However, it should be noted that masculinity does not guarantee an unhealthy lifestyle, given that where some men are concerned, sport is central to their sense of masculinity.

Of importance here is the ability to evaluate physical symptoms effectively, and take appropriate action, for which men are renowned for their failings (Sabo & Gordon, 1995). As a rule, responsibility for male health is delegated to the female of the household, in that the mother or partner of the individual will be involved in persuasion regarding the need for medical consultation and time off work (Courtenay, 2000; White, 2001). Hence, it appears that the masculine role not only results in men taking more risks in their day-to-day lives, but neglecting their health in terms of concealing their suffering, and delaying or refusing to seek help in times of illness.

Likewise the masculine façade has been held responsible for men's coping strategies during times of illness, forcing men to 'take illness like a man'; be brave and hide from the true impact no matter how bad things are (Moynihan, 1998). Evidence from one study suggests that adherence to such a traditional male gender role is significantly likely to lead to procrastination in males seeking professional assistance (Good, Dell & Mintz, 1989). Similarly men have been found to avoid reporting illness, or under report the symptoms for such reasons (Good, Dell & Mintz, 1989; Hearn, 1994). Literature from the area of testicular cancer confirms this tendency, as men tend not to carry out testicular self-examinations (TSE), and delay seeking medical attention if symptoms are detected. Whilst some of this neglect can be attributed to lack of awareness about testicular cancer, this does not sufficiently explain this behaviour (Gascoigne, Mason & Roberts, 1999). Even when health problems have been detected, young men are reluctant to make health related lifestyle changes immediately, and older men see it as 'too late' for change to be worthwhile (Lee & Owens, 2002). Having said that, the effects of the social and cultural pressures on these men, cannot be underestimated. As was mentioned earlier, when discussing masculinity, men are seen to be under more pressure to conform to the masculine stereotype than women (Golombok & Fivush, 1994; Laws, 1998; Lloyd, 1998). With reference to health behaviour this involves rejecting all that is assumed to be female (talking about problems and seeking regular medical checks), in order not to undermine their masculine status (Sharpe, 1999). Consequently, it would be wholly unhelpful to simply think of them as wilfully negligent of their own health (Courtenay, 1998). In order to change the way men participate in their health, it will be necessary to change the medical community's perception regarding men's health, and attempt a gradual reconstruction of the meaning of masculinity (Courtenay & Keeling, 2000). However, not all men conform to the traditional masculine stereotype; some men do follow a healthy lifestyle, but change is essential for the increasingly large group of men who do not.

In the face of serious illness major complications can arise because of these masculine tendencies. If, as the literature suggests, men aspire to the perfect masculine stereotype; strong, brave, emotionally inexpressive, and insensitive to pain when faced with a serious illness with the potential to change their lives and their bodies, their sense of self may be threatened (Courtenay, 2000; Heidrich & Ward, 1992) by the tainting of their masculine image (Charmaz, 1995; Liss-Levinson, 1982).

This research evidence triggers a question regarding the utility of these stereotypes. How helpful or otherwise is it to perpetuate these images? As described above, masculinity holds different meanings for different people; therefore to subscribe to just one model is unhelpful. In viewing men in this way, stereotypes are likely to continue, and cause adverse affects on treatment and communication with male patients (Moynihan, 1998). As it is, men tend not to talk about their problems, whether they are related to medical (Sharpe, 1999) or emotional issues (Farrell, 1974). Hence, maintenance of stereotypes suggesting men should be strong and emotionally inexpressive will almost certainly inhibit men in talking openly about their feelings, especially in the context of medical consultations. Given that the vast majority of doctors are male (American Medical Association, 1996, cited in Alt, 2001) perhaps the health community is contributing to a self-perpetuating predicament? As a consequence of the prevalence of such gender stereotypes in society, it seems clear why men find it difficult to know which role to adopt when they are faced with illness. Especially when the illness in question threatens the organ identified as defining their masculinity. Given the idiographic nature of masculinity, it is preferable that research in this area moves away from a medical model of quantitative research, and towards a more qualitative approach (Montgomery & Santi, 1996; Moynihan, 2002). Subsequently, a method that targets these constructs at an individual level is required.

Having established an understanding of how the concepts at hand can be affected in times of illness, I will move on to discuss how these apply to cancer in general, and testicular cancer specifically.

Psychological Aspects Of Cancer

There is now an extensive literature on the consequences of chronic illness for an individual, and a consensus that these extend beyond the physical, to the point that it is taken for granted that psychological sequelae are virtually inevitable (Little, Sayers, Paul, & Jordens, 2000). Emotional responses noted include shock, anger, denial, fear, confusion (Liss-Levinson, 1982) depression and anxiety (Bloom, 2002; Epping-Jordan, Compas, Osowiecki, Oppedisano, Gehardt et al, 1999; Heidrich & Ward, 1992), as well as altered perceptions of mortality (Johnson, 1999). Additionally there are practical implications of experiencing cancer, such as impaired social functioning (Heidrich & Ward, 1992), economic strain, diminished physical health and well-being, pain, weakened relationships (Mantell, 1982) and impaired sexual functioning (Burkhalter, 1978; Schain 1980, 1981).

The cultural meaning imposed upon cancer most likely influences the accepted inevitability of such consequences, such that our society views the disease as a four-letter word (Dierkhising, 1987), a demon worthy of fear. Indeed a diagnostic label of cancer used to be interpreted as a death sentence (Bloom, 2002), and is still associated with trepidation about the disfiguring and incapacitating nature of treatment (Levin, Cleeland & Dar, 1985), and fear of pain and death (Burkhalter, 1978; Clarke, 1992), which may serve as an explanation for cancer being perceived as a larger threat than most other illnesses (Heidrich & Ward, 1992).

The National Institute for Clinical Excellence (NICE) (2004) has reviewed the research evidence on psychological aspects in this area in detail. Themes that emerge from a brief overview of the literature suggest that cancer sufferers view their body as permanently under suspicion, maintain feelings of anxiety about the future, and become particularly vigilant about health related issues (Breaden, 1997). Where patients have been through surgery in the process of recovering, there are recurrent themes of 'never feeling quite the same', or 'feeling incomplete' or 'less of a person' than previously (Epping-Jordan et al, 1999; Chapple & Ziebland, 2002). Reports of other negative implications of cancer, such as low self-esteem and disturbances of body image are also abundant in the literature (Mantell, 1982; Schover, 1987; Wood & Tombrink, 1983). However, it must be acknowledged that this is not the whole picture, as positive themes can also be drawn from quotes in the literature. Indeed, some people find that having a serious illness changes the focus of life in a very positive way, allowing them to find faith, feel lucky about life, and prioritise routine aspects of living very differently (Brodsky, 1999). Research has been criticised for neglecting to report on such positive psychological sequelae (Abbey, 1997; Bloom, 2002; Breaden, 1997).

Given the existence of such a broad range of cancers, a variety of treatments, side effects, and outcomes, not to mention the media representations of cancer as a deadly predator (Clarke & Robinson, 1999), it is easy to see how people assume that psychological well-being will be affected by diagnosis and experiences of cancer. There has even been some suggestion, that patients who have received a diagnosis of cancer can potentially develop symptoms of post-traumatic stress disorder (PTSD), as a result of the intensity of symptoms, such as fear of reoccurrence or death (Smith, Redd, Peyser & Vogel, 1999). Alter, Pelcovitz, Axelrod, Goldenberg, Harris et al (1996) also found evidence to suggest that cancer survivors have a higher rate of PTSD than is found in the general community. Consequently, if such vulnerability exists in cancer survivors generally, one might assume that there would be at least an equal risk of such an impact in the survivors of testicular cancer. One may even hypothesise that the vulnerability may be even greater in individuals with a testicular tumour, as this (and other genitourinary cancers) have the added issue of the cancer being located in the genitals (Jonker-Pool et al, 2004).

This makes intuitive sense, given that these cancers affect organs that are closely associated with self-esteem and sexuality (Rieker, Fitzgerald, Kalish, Richie, Lederman, Edbril & Garnick, 1989). This area is in receipt of a great deal of research attention, however, primarily in relation to breast and gynaecological cancers, and other women's ailments (Adshead, Khoubehi, Wood & Rustin, 2001; Chapple & Ziebland, 2002). The literature largely postulates the negative impact that these illnesses have on sexuality, body image, self-esteem and femininity of women. Although, some work has been done recently to examine the impact of prostate cancer on masculinity (Broom, 2004), finding that the majority of men experienced difficulties in their performances of masculinity when coping with investigations (trans-rectal procedures), treatments and side effects. These effects were also seen to have an impact on decision making of this group of men, as some prioritised potency and lifestyle before cure. Otherwise, as yet, little is known about the impact on such areas in men's cancers (Rieker, Edbril & Garnick, 1985). The current study aims to contribute to this neglected area of knowledge.

Testicular Cancer

Testicular cancer, although relatively rare in its incidence per se, is the most common cancer affecting young men in the Western world (Champion, 1996; Fleer, Hoekstra, Sleijfer & Hoekstra-Weebers, 2004). The age ranges documented in the literature vary but include men between the ages of 15 and 40 (Buetow, 1995; Gorzynski & Holland, 1979; Incrocci, Hop, Wijnmaalen & Slob, 2002; Raloff, 1994; Van Basten, Schraffoedt Koops, Sleijfer, Pras, Van Driel & Hoekstra, 1997). The UK lifetime risk for testicular cancer was recorded as 1:500 in 2002 (Cancer Research UK), and has more than likely increased since then, as incidence rates have been seen to steadily rise since 1911 (Coggan & Inskip, 1994). The exact cause of the tumour is unknown although there has been some speculation linking the increased incidence to changes in environmental factors (Raloff, 1994), specifically exposure to environmental oestrogen (Editorial, *Lancet*, 1995). Factors linked to increased risk of occurrence include undescended testes (Champion, 1996) and lack of exercise (Forman, Pike, Davey, Dawson, Baker et al, 1994).

Arguably, the period during which a diagnosis of testicular cancer is most likely to be received is the most significant stage in a man's life. It comes at a time when he is likely to be establishing himself in employment, social and domestic spheres. Given that testicular cancer in particular is said to be a young man's disease, a diagnosis will also be seen to arrive at a prime time of life, when sufferers would otherwise be very active (Ofman, 1993; Rudberg, Carlsson, Nilsson & Wikblad, 2002, Sheppard & Wylie, 2001). For instance, many men may not have achieved important life goals by the time of diagnosis, including purchasing property, establishing a career, getting married, and fathering children. Such goals may or may not be impeded as a consequence of the illness.

Prevalence statistics have shown that cancer in general, and testicular cancer in particular, is on the increase (Department of Health Statistics online at: www.statistics.gov.uk; Jemal, Tiwari, Murray, Ghafoor, Samuels et al, 2004; Raloff, 1994). In the last twenty years alone the incidence of the disease has doubled (Power, 2001), so it is no wonder that its profile seems to be lifting. Despite this however, with the advent of different treatment approaches and increasing success rates, there are now more young men than ever before surviving the disease. Indeed there is a gathering body of evidence suggesting cure rates close to 100%, subject to early detection of the disease (Brown, 2003; Champion, 1996; Parker, Tong, Bolden & Wingo, 1996). As a result of such developments, there is now a considerable population of men who are required to adjust to the consequences of surviving a potentially life threatening illness (Arai, Kawakita, Okada & Yoshida, 1997; Joly, Heron, Kalusinski, Bottet, Brune, et al, 2002; Rudberg et al, 2002).

Four main types of tumour occur in the testes in the category of germ-cell tumours (GCTs), which are tumours that originate in the germ cells of the testes and are rapid spreading malignant growths. Seminomatous tumours (ST) are the most common type of testicular tumour, which account for approximately half of all cancers originating in the testicle. This form of the disease is the most treatable and thus has the best prognosis. The remaining types of tumour are classified as nonseminomatous germ cell tumours (NST). Teratomas, which are most commonly found in children, but also occur in the adult population; embryonic GCTs, which account for 20 per cent of all testicular cancers and spread very quickly; and finally, choriocarcinoma, less prevalent, accounting for 1-3 per cent of testicular cancers, and currently associated with poor prognosis.

The treatment necessary to acquire cure for testicular cancer is dependent not only on the type of tumour, but also the stage of growth at the time of diagnosis. Consequently treatments available vary. In almost all cases the patient will undergo surgery to remove the affected testicle and a section of the spermatic cord, a procedure known as an inguinal orchidectomy. Very occasionally the cancer will necessitate bilateral orchidectomy, or the removal of both testicles. Frequently the surgery will be accompanied by radiotherapy or chemotherapy, either on an adjuvant basis or to treat metastatic spread of the disease. In some cases, again depending on the stage of the disease, a procedure called a retroperitoneal lymph node dissection (RPLND) is necessary, which removes the sympathetic nerve plexus, and frequently results in compromised sexual functioning (impotence, dry ejaculation and infertility) (Hawkins & Miaskowski, 1996). However, this procedure is not routinely carried out in the UK (Moynihan, 1987), and where this procedure is used attempts are now made to spare the nerve, in an attempt to minimise the impact on sexual functioning (Jacobsen, Ous, Waehre, Trasti, Stenwig et al, 1999). Obviously where such invasive treatments are involved there are likely to be a number of side effects, and as would be expected these vary widely dependent on the treatment in question, but include; fatigue, nausea, diarrhoea, hair loss, mouth ulcers and potential infertility (National Cancer Institute, 2003). Furthermore, every individual is different hence it is difficult to predict how any one man will respond to either the cancer or the treatment. Similarly the emotional impact of the disease too can fluctuate from one individual to another.

The receipt of a diagnosis of cancer can be distressing to anyone in and of itself. Indeed it would be expected that most people would be concerned about their likelihood of survival, rather than how they will feel once the experience is over. As far as testicular cancer is concerned, although the prognosis is excellent, there are still potential negative implications from the outcome of treatment. What is more, the intimate location of the illness coupled with the fact that the average sufferer of testicular cancer is likely to be young, might lead one to hypothesise that the experience of testicular cancer is likely to have a substantial impact on the life of a survivor.

Psychological Aspects Of Testicular Cancer

Given the large amount of evidence regarding the psychological impact that women's cancers have on their sufferers (Chapple & Ziebland, 2002; Schain, 1976), it seems reasonable to hypothesise that men may be affected in a similar way by testicular cancer, especially given that testicular cancer sufferers are usually young men in the prime of their active life, and with many ambitions ahead yet to fulfil. On the other hand, the rapidity of the diagnostic process and initiation of treatment, combined with the generally very good prognosis of this form of cancer, may negate the negative psychological effects seen in other cancers. As will be illustrated in the literature review, research to date has not determined which is the case. Potentially, both scenarios could be true, as different groups of men may respond differently to the illness, thus forming distinct groups of response types.

With regards to testicular cancer the early age at onset, the life stage issues, the sexual nature of the disease and its consequences and the nature of the surgery; all emerge as significant implications for men during their experience of illness. Whilst there is a research body that suggests a similar impact on men as there is on women, in terms of sexuality and body image (Gorzynski & Holland, 1979; Rieker, Fitzgerald & Kalish, 1990), relatively speaking there is a dearth of evidence in connection with men's cancers, describing the nature of this effect.

For obvious reasons, a major focus of existing research regarding testicular cancer is the impact of orchidectomy on sufferers of testicular cancer, as it is widely hypothesised that this is an influential factor in psychological well-being. Evidence was provided in one study, that suggests that loss of a testicle is rated by college-age men as one of the most humiliating experiences possible, in fact second only to being unable to maintain an erection during sex (Morman, 2000). This serves to further support the suggested significance of testicular normality, if men are to be viewed as sexually desirable (Clarke & Robinson, 1999).

Several studies have set out to examine different aspects of the impact of orchidectomy including; quality of life after surgery (Douchez, Droz, Desclaux, Allain, Fargeot et al, 1993; Joly et al, 2002), psychosocial implications for sexuality and masculinity (Moynihan, 1987) physical and psychological symptoms (Rudberg et al, 2002), impact on sexuality and fertility (Aass, Grunfeld, Kaalhus & Fossa, 1993; Arai et al, 1997; Caffo & Amichetti, 1999; Incrocci et al 2002; Jonker-Pool, Van der Wiel, Hoekstra, Sleijfer, Van Driel et al, 2001; Jonker-Pool et al, 2004; Kuczyk, Machtens, Bokemeyer, Schultheiss & Jonas, 2000; Nazareth, Lewin & King, 2001; Schover 1987), and patient satisfaction with prosthetic implants (Adshead et al, 2001; Incrocci, Bosch & Slob, 1999).

Research findings in these areas appear equivocal. Whilst some authors found that quality of life is impaired in survivors of testicular cancer (Douchez et al, 1993), others found that it actually improved in comparison with healthy controls (Fossa, Aass & Waehere, 1991; Rieker, et al, 1989), and further researchers found there to be no difference at all (Joly et al, 2002). In a similar way, evidence around sexuality is equally contradictory. Arai et al (1997) found in their quantitative investigation, that issues of fertility and sexuality remain an issue for survivors of the illness years after diagnosis and treatment. They linked this to a reduced sense of attractiveness in addition to physical impairments, leading them to conclude that the loss of a testicle is a profound and deeply symbolic experience for men, a view echoed by Brown (2003). However, significant differences in the Japanese health care system at the time may have contributed to this effect, in that infertile men were offered no alternative, such as sperm banking, only to remain childless. Again, other authors maintain that there is no significant difference between sexuality and masculinity of men with testicular cancer and that of controls, who either had undergone orchidectomy for other reasons, or had not had surgery at all (Blackmore, 1988).

It should be noted at this juncture however, that the majority of studies claiming to investigate the concept of sexuality following testicular cancer took a simple definition of sexuality, as opposed to the multidimensional concept discussed in the earlier section. They tended to focus on the medical view of sexuality, which may be more appropriately labelled sexual functioning, as they investigated issues surrounding impairments of sexual performance. Whilst this literature does not apply precisely to the concepts concerned in the current study, it is still of relevance, especially given that we have seen the significance attributed to sexual anatomy and performance in terms of disruption to masculinity and sense of self. The findings of this collection of studies are summarised briefly in table 1.

Table 1: A summary of evidence regarding sexual dysfunction following treatment for Testicular Cancer (TC)

Author, Year	Sample	Type of Study, Instruments	Findings
Blackmoore, 1988	20 TC 10 Orchidectomy non-TC 15 Healthy controls	Controlled study Self-report questionnaire	No significant differences between 3 groups. But in GCT group there were significant differences in pre- and post-operative scores for sexual intercourse, masturbation and sexual drive.
Ricker et al, 1989	223 TC 120 Healthy controls	Retrospective questionnaire study Some self-developed elements Psychometric qualities not reported	Majority of TC survivors did not have disabling psychological problems, but did have significantly more infertility and sexual performance distress. Sexual impairment is related to treatment and socio-demographic variables.
Tinkler et al, 1992	155 TC 121 Healthy controls	Retrospective study Structured questionnaire (No reliability / validity data)	Significantly larger proportion of TC survivors experiencing sexual dysfunction, including, reduced frequency of sexual intercourse, erectile dysfunction, ejaculatory dysfunction, and reduced intensity of orgasm.
Aass et al, 1993	76 TC No Controls	Longitudinal study Self-report questionnaires	A significantly larger proportion of men reported unsatisfactory sexual life at 6 months post-therapy in comparison to before therapy. 'Dry ejaculation' linked to RPLND, but other symptoms not related to treatment. Dissatisfaction shown to gradually decrease over time, but 30% still reporting difficulties at 3 years post- treatment.

Author, Year	Sample	Type of Study, Instruments	Findings
Bloom et al, 1993	85 TC 88 Hodgkin's controls	Standardised questionnaire study Incorporated some self developed items.	Survivors of TC had significantly more sexual dysfunction than controls as indicated by increased likelihood of erectile dysfunction and reduced orgasmic capacity.
Douchez et al, 1993	109 TC 107 Healthy controls	Retrospective study Interview using a questionnaire to elicit subjective perceptions	Found a higher incidence of ejaculatory dysfunction in TC survivors, linked to RPLND. 60% of TC group reported emotional problems during treatment phase.
Hartmann et al (1999)	98 TC No Controls	Retrospective study Self report questionnaire	Found differences in level of sexual functioning between different treatment groups. Patients receiving chemotherapy and secondary resection of the retroperitoneal tumour mass (SRRTM) as a combination treatment were more likely to report an unfulfilled desire to have children. RPLND and SRRTM were linked to ejaculatory dysfunction. Reports of reduced sex drive were limited.
Incrocci et al, 2002	157 TC 185 Healthy controls	Retrospective questionnaire study (Non-validated questionnaire).	20% reported reduced sexual activity and pleasure in sex. Interest in sex and satisfaction with sexual life did not differ from controls. A significantly larger proportion of TC group had erectile difficulties but this correlated with age. 52% felt that their body had changed after treatment.

With regards to body image, there is a literature that alludes to the impact that treatments have on survivors. The occurrence of orchidectomy, side effects of chemical therapies (such as hair loss and weight loss), and the scarring from other surgical procedures are suggested to be significant in the way a man views himself after the illness (Brodsky, 1995; Gritz et al, 1989; Monga, 1995; Sheppard & Wylie, 2001). One particular study demonstrated that almost a quarter of their participants felt less attractive as a consequence of the treatment (Gritz et al, 1989). This is supported by research surrounding the use of testicular prostheses, which suggests that surgery without the use of implants has significant effects on body image, sexuality and masculinity, which could otherwise be reduced if implants were offered (Adshead et al, 2001; Incrocci et al, 1999). Important factors cited in the process of decision making about the acceptance of a testicular prosthesis, included fear of loss of masculinity, concerns about self-image and wanting to feel 'whole' again, desire to look normal, and desire to conceal the loss of a testicle, especially to avoid disclosing the loss when commencing a new sexual relationship (Chapple & McPherson, 2004). However, it must be acknowledged that not all men opting for prosthetic implants are satisfied with the results. Some men view the implants as unnecessary, preferring not to have them fitted, and reasons noted for this decision were numerous. Chapple and McPherson's qualitative investigation of men's decisions regarding testicular prostheses found that men who decided to opt for a prosthesis, and those who did not, formed two distinct groups. The feelings described above are typical of the group who accepted a prosthesis. Whereas the group who did not have a prosthetic testicle felt that masculinity, sexuality and fertility would not be affected in the long run, or thought that the scrotal area did not look significantly different to before the surgery, or felt that the presence of only one testicle is in fact more comfortable than having two (Chapple & McPherson, 2004). This same study concluded that a number of men were discouraged from having the procedure by their doctor, and that the men themselves had a number of concerns about the safety of receiving silicone implants, independent of medical advice. This decision not to opt for a testicular prosthesis in itself may be indicative of a group of men who do not feel that the removal of a testicle reduces their sense of masculinity. In keeping with this theory, Moynihan (1987, 1998) found that men tended to deny that testicular cancer had any long-term effects on their masculinity.

However, when looking at self-concept, evidence would suggest that two elements, physical-self and identity, were significantly affected by treatment for cancers in general (Foltz, 1987) and GU cancer in particular (Montgomery & Santi, 1996). However, both of these studies failed to include testicular cancer, instead focussing around a number of other cancers, particularly breast cancer and cancer of the prostate, so the question still remains as to whether the effect would be the same in testicular cancer. Brodsky (1995), reports that the participants in his research appeared to have undergone change throughout the process of treatment. He acknowledged that the illness does amount to a traumatic event, with the potential to profoundly impact upon the individual's sense of self. Indeed he concluded that all four components of self (from Schain's model, discussed earlier) were under assault as the participants underwent different stages of the treatment process. It was thought that the worst of the experience occurred once treatment had ceased, and a large amount of the medical attention had been withdrawn, which was attributed to the reliance on denial during the initial stages of the illness (Ofman, 1995). However, alongside the trauma, he found that men had gleaned some positives from the experience, including the modification of priorities in day-to-day life to make more time for meaningful relationships (Brodsky, 1995). Indeed, Brodsky himself reports very similar experiences to those of his participants, as he personally experienced testicular cancer several years prior to carrying out the research.

In summary then, research investigating the psychological impact of surviving testicular cancer is at best equivocal, whether this is looking at quality of life, sexuality, masculinity or body image. However, there have been a number of flaws in the research carried out to date, which could account for some of the incongruous findings.

Methodological Critique Of Previous Research

The research in this area can be criticised on several levels. A great deal of research has been carried out in different countries. Whilst the results may be representative of the population in these countries, it may not be possible to make generalisations to the UK population. Scandinavian and Japanese cultures are likely to have different constructions of masculinity and sexuality. Furthermore, there may be cultural variations in levels of disclosure in some of these studies, and this may vary too, dependent on the research method. In addition, the level of disclosure may vary over generations and some studies are quite old.

A further problem stems from the difference that may occur as a result of carrying out research retrospectively as opposed to prospectively (Incrocci et al, 2002), as participants' recollections can potentially become distorted with time, or they may evaluate situations differently following an experience of a serious illness (Fleer et al, 2004). A further methodological weakness is the limited use of validated measures in the majority of studies. For instance, Aass et al (1993) Blackmore (1988), Rieker, Edbril & Garnick (1985), Rieker et al (1989), and Tinkler (1992) all used non-validated measures at least in part of their methodology. Additionally, many of the studies had relatively small sample sizes, for example Blackmore (1988) and Aass et al (1993), who both had less than 80 participants, including control groups in the Blackmore study. Also few made any effort to consider statistical power and effect size, which subsequently places limits on the validity of the research and thus the generalisations that can be made from it.

Many of the authors researching these issues used traditional quantitative methods such as questionnaires or self-report scales (Arai et al 1997; Blackmore, 1988; Joly et al 2002; Montgomery & Santi, 1996; Rudberg et al, 2002; Sheppard & Wylie, 2001), which have variable utility dependent on the research questions being investigated. Whilst on occasions some research touched on the topics of interest in the current study, such as Arai et al (1997) and Blackmore (1988) in their attempts to investigate sexuality after testicular cancer, frequently the measures utilised were not subtle enough in their approach, leading to questioning of how severely the results would be affected by demand characteristics, and participants providing socially appropriate responses. For example, where self-report questionnaires were used, and compared to qualitative interviews (Sheppard & Wylie, 2001), they were found to have limited utility in highlighting the sexual difficulties experienced by this group of men, whereas qualitative interviews were viewed as comparatively more helpful in highlighting issues around sexual attitudes and body image. This led Sheppard and Wylie (2001) to conclude that the design of a specific questionnaire is necessary. The approaches used in the majority of the literature did not seem to appropriately access the issues under investigation in the current research project. Mostly, whilst claiming to look at issues of

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sexuality, the chosen questionnaires merely looked at problems with physical sexual functioning, the occurrence of which seems undisputed. Additionally, whilst some of the literature examined one topic of relevance to the current project, none investigated the several related concepts as broadly as is intended by the current research.

Consequently, it seems clear that further psychological research in the field of testicular cancer is required. Furthermore, in the absence of any relevant validated measures, the research will need to develop the methods already in existence, in an attempt to find a subtle, yet sensitive, idiographic technique for investigating the relevant concepts. Perhaps a move in the direction of a more qualitative approach would be most appropriate? Whilst qualitative research too, can be limited by some of the above weaknesses, it would facilitate access to information about which no ready-made measures exist.

In conclusion, in light of the sensitive nature of GU diseases such as testicular cancer, and the tremendous increase in media attention received by men's health (of which testicular cancer has been a significant feature), it seems pertinent that more is learned about the impact of this disease on its sufferers. The early age at onset, and the increasing number of survivors, serve to emphasise the importance of furthering our knowledge. Whilst the physical consequences seem well documented, little is known about the psychological costs regarding damage to the self, which of course may have important implications for the treatment of men who have suffered testicular cancer. Research to date has failed to reach a conclusion, which may in part be due to methodological weaknesses. Subtle, yet sensitive, methods of collecting data will be required to overcome any reluctance that men have in discussing these issues. The use of repertory grid technique may well be ideal for investigating idiosyncratic concepts such as masculinity and sexuality.

RESEARCH QUESTIONS

1. To what extent does perceived self-concept in survivors of testicular cancer change over time during the two years after the illness?

2. Do men's perceptions of themselves before the illness and perceptions of masculinity and sexuality differ? For example, their perceptions of themselves as a man, father, lover, and partner. Do these perceptions change significantly over time?

3. Which constructs contribute to the changes in masculinity elements over time?

4. Is repertory grid technique a useful tool for examining men's self-perceptions following the experience of an illness? Do participants feel the exercise accurately reflects their experience?

CHAPTER 2: METHOD

Clinical Context

The Leeds oncology clinic provides a regional service for men with testicular cancer across Yorkshire. The majority of men who are diagnosed and treated for testicular cancer in this area will be referred to the service. Whilst exact data are unavailable, staff report that approximately 90 new patients are seen each year. All men seen in clinic will undergo an orchidectomy. It is estimated that, of these, 47% will be treated with additional chemotherapy, 21% are treated with additional radiotherapy, and 32% are placed under close surveillance only. However, these figures may have been slightly different in past years, as a consequence of changes in recommended treatment regimen for stage 1 seminoma.

Theoretical Framework

Personal Construct Theory

The theoretical framework guiding the current study stems from Personal Construct Theory (Kelly, 1955). The principles behind Kelly's theory are summarised briefly in chapter one (see section 'The Concept of the Self'). Because Kelly was a mathematician as well as a psychologist he designed a method of monitoring personal construct systems in a numeric fashion, namely repertory grid technique. Bannister and Fransella's book (1986), a more recent manual by Fransella, Bell & Bannister (2004) and a further guide by Jankowicz (2004) provide a good outline of Kelly's ideas regarding repertory grids, and will form the basis of the following summary.

Repertory Grid Technique

This technique specifically attempts to ascertain a description of how someone else views the world, or part of it, through the completion of various simple rating scale procedures (Jankowicz, 2004). Consequently a grid can be about anything and will form an idiographic measure of an individual's perceptions. In a manner of speaking, repertory grids form a useful means of carrying out structured interviews, to capture an individual's viewpoint about a defined subject area. The method also has the benefit of integrating qualitative and quantitative research methods. This method has previously been used to consider the changing self-perceptions of medical students during their training (Latchford & Madill, 2004), of women during their transition to motherhood (Smith, 1999), and perceptions of nurses about their clinical practice (White, 1996).

With reference to the current research, this method should facilitate access to the individual's own perceptions, regarding the effects testicular cancer has had on them. Furthermore, it is argued that personal construct methods provide a more subtle approach, when targeting concepts that participants are likely to be sensitive about. In other words, it attempts to overcome participants responding in a manner they view to be appropriate or rational, as they might on a questionnaire. A more subtle approach such as this helps participants to feel comfortable when giving less conventional responses, thus allowing the research to access more accurate reflections than otherwise might be possible.

Kelly used a variety of methods to collect data for clinical and research purposes, however he was very keen to develop a method which could capture the constructs of individuals, without losing their perceptions in statistical calculations (Smith, 1995). In this way, Kelly's approach holds benefits for this research over some quantitative methods, where participants' perceptions are expected to fit neatly into categories, perhaps limiting access to some of the issues. Using methods taken from personal construct theory overcomes these difficulties, allowing access to the individual's idiographic perceptions. Some perceptions will be shared where participants have had similar experiences of the illness and treatment, and some of course will be different. For these reasons, it is suggested that repertory grids provide the most suitable means of collecting data in this instance. Repertory grids allow an individual's set of constructs to be examined in relation to a significant experience, such as illness, thus allowing examination of how an individual views their life in relation to this specific event. Not only is this method potentially more sensitive to the idiosyncrasies of the participants than a questionnaire could be, it also has the advantage that it can be used to generate both qualitative and quantitative data, as opposed to purely qualitative methods such as interviews. Consequently, it is hoped this method will enable collection of breadth and depth of information, and may be transferable to other groups of men dependent on context and culture.

Design

A cross-sectional design was used to compare the perceptions of men at different stages post-illness. Data were generated using a combination of qualitative and quantitative methods, throughout part one and part two of the study respectively. In order to elicit accurate changes in the perceptions of participants, a longitudinal design would be preferable. The planning and implementation of such a study would require approximately three years, which was not feasible on this occasion, given the time restrictions placed on the current project.

The study was separated into two parts. The first part was qualitative and served to generate the tool for data collection in the subsequent main study. The main body of the investigation utilised repertory grid technique, which in a sense is a mixed method: however, for the purposes of this study it was used primarily to collect quantitative data.

Ethical Clearance

The Leeds (East) Research Ethics Committee was approached for ethical clearance. In the first instance approval was granted in July 2004. However, after requests from participants to undertake the interviews away from the clinic setting, a significant amendment was submitted, which was subsequently approved in September 2004. At a later interval, following some recruitment difficulties, a further amendment was sought to facilitate recruitment by mail. This second amendment was approved in February 2005. Appendix 1 includes approval letters.

Participants

Criteria for inclusion in the study were as follows: all men, aged 16 and over, who had previously received treatment through the clinic, and were in remission of symptoms for at least 6 months prior to participating in the study. Patients were excluded if they were currently experiencing either psychological distress, a relapse in symptoms, or where a clear conflict of interest was identified. The criteria specifically did not stipulate treatment modality, as it was the intention that the criteria be broad enough, to enable a generally representative sample. The same criteria applied to both the first and second parts of the research. Recruitment was carried out using a convenience sampling method, in that participants who were at the correct time stage for participation at the time of recruitment were approached.

Measures / Materials

Three lots of materials were produced for use in this study:

- Invitation letter, information leaflet and consent form.
- Semi-structured interview schedule.
- Repertory Grid

1. Invitation Letter, Information Sheet and Consent Form

Three different information sheets were developed at various stages. One for the initial recruitment, where participants were interviewed in clinic, one for the first amendment to the protocol that gave participants the option to be interviewed away from clinic, and a final one for the second amendment, whereby participants were recruited by post (see appendix 2). Essentially all three sheets contained the same information: however, the wording was altered slightly at each stage to allow for amendments in protocol. The corresponding invitation letter (appendix 3) remained the same until recruiting participants by post, at which stage the wording was modified (appendix 4). Together, the letter and the information sheet provided information in connection with the purpose and aim of the study, reasons for the patient being asked to participate, what participation would entail, confidentiality surrounding the information gathered, reassurance regarding the voluntary nature of the research and the lack of impact on their medical care, what they were required to do if they wished to participate, a contact number for the principal researcher to enquire further about the project, and a contact number for a Consultant Clinical Psychologist for use should they feel distressed after engaging in the research. The Flesch Reading Ease score was calculated for the information sheet, in order to ensure adequate readability. The three sheets were so similar in nature that they each obtained an identical score of 57.2.

A standard consent form (appendix 5) was used, which remained unchanged throughout the study.

2. Semi-Structured Interview

In the first part of the investigation a semi-structured interview was used as the means of data collection. In the absence of any known structured interview schedule, one was designed specifically for use in this study (see appendix 6). The interview contained 14 questions, which were used as starting points for a discussion about the patient's experiences and perceptions. The investigator used suitable prompts to explore areas of relevance in more detail. The development of the interview schedule was informed by the literature available on masculinity and issues surrounding cancer experiences, specifically with regards to male malignancies such as testicular and prostate cancers (see chapter 1).

3. Repertory Grid

For ease of comparisons a generic grid was designed solely for use in the second stage of this investigation. There were two stages to the development of the grid. Firstly, the elements for the grid were determined. These were generated by the investigator and again were informed by the literature, as discussed above. The elements chosen were thematically related to the questions from the semi-structured interview. Secondly, the constructs of the grid were developed from analysis of the interview data. (Appendix 7 provides a copy of the final grid used in data collection).

PART 1: SEMI-STRUCTURED INTERVIEWS

Piloting

The nature of the semi-structured interview was such that it was necessary to pilot the schedule on individuals who had experienced testicular cancer. However, as it was equally important to maximise the number of participants available for the sample, the pilot was carried out with men who were not at exactly the correct time stage to fit inclusion criteria for the study (n=2). Otherwise, they met all other criteria for suitability. At this stage, the schedule was being examined for applicability, understanding on behalf of the participants, and timing.

The Consultant Oncologist identified participants for the pilot study randomly from forthcoming clinic lists. They were then sent copies of the relevant information literature. Subsequently, they were approached by the researcher at their clinic appointment, and were asked if they wished to participate. If they agreed, a consent form was signed, and an arrangement was made to carry out the interview following their appointment with the doctor.

Following the pilot, it was deemed that the interview schedule was providing an appropriate breadth and depth of information on relevant topics, and that the timing of the interview was satisfactory. Participants were asked if they could think of other important areas that they thought should be included in the interview, however as none were identified in the pilot, the schedule was used in its original form.

Procedure

As discussed above, participants were recruited from four different time stages, for a cross-sectional comparison; 6, 12, 18 and 24 months post-treatment. With regards to each time phase, a range of one month in either direction was permitted, for example, 5-7 months, 11-13 months, etcetera. The procedure was identical for each of these groups.

Recruitment in Clinic

Patients at the correct time stages to meet inclusion criteria were identified from a database of clinic patients. Clinic lists were then used to identify which patients would be coming to clinic during the phase when they would fulfil the correct criteria. The list of patients who met the inclusion criteria was then reviewed by the Consultant Oncologist to sift for participants who might not be suitable for extraneous reasons. Potential participants were thus identified, and were therefore sent the letter of invitation and information sheet in the mail, approximately two weeks prior to their clinic appointment. During this time, the principal investigator was contactable by a telephone number provided on the information sheet, to offer further information about the study. Once in clinic, the patients were approached in person by the researcher, whilst they were waiting for their appointment to see the doctor, and asked whether they were willing to take part. Patients who wished to participate were asked to sign a consent form, and arrangements were made to undertake the interview. Where participants did not attend clinic on their initial expected date, if a further appointment was scheduled within the appropriate time limit, they were asked to participate as normal.

The interviews were carried out either in clinic, after they had seen the doctor, or at a mutually convenient location, at a later date. In reality, the majority of the interviews were completed through visits to the participants' homes. Where interviews were carried out in clinic, they took place in a private room, and only the researcher and participant were present. Similarly, where home visits were carried out, attempts were made to find a quiet environment to interview the participant alone.

Immediately prior to the interview, the investigator confirmed that the participants were in agreement to the interview being recorded on audiotape. All participants agreed with this aspect. Throughout the interviews, the general format of the schedule was followed, however, the investigator prompted participants to explore and clarify some areas in more detail, with a view to revealing participant's constructs of their experiences. The notion of making sense of experience by examining its contrast (Kelly, 1955) was mentioned briefly at the outset of the interview. At times when potential constructs were mentioned, participants were also asked to elicit the contrasting pole of the construct. They were instructed to generate this by thinking of the initial meaning they had discussed, and then describing what the opposing pole might be. For example, if a participant talked of being angry, he would be asked "Angry as opposed to what?"

The content of the conversation was recorded verbatim during the interview, where possible. The audiotapes were used at a later point to ensure accuracy and completeness of the written documentation.

At the end of the interview, participants were given a further opportunity to ask any questions they might have. The investigator also ensured that the participants were not feeling distressed by discussing their experiences. Where this was even a mild concern, participants were given advice and appropriate telephone numbers, to ensure that they could contact someone for support if they wished. Finally, the participants were thanked for their contribution to the research.

Analysis

The qualitative data from the interviews was analysed using a qualitative content analysis to identify the common themes emerging from the data in an open ended way (Smith 2000). This provided a list of themes for the constructs, which were analysed separately by the investigator and three independent assessors. A meeting was then held to discuss the themes highlighted by each individual until a consensus on the labels for the final constructs was determined. These labels were then integrated into the final grid (appendix 7).

PART 2: REPERTORY GRIDS

Piloting

Initially, the grid was piloted on a group of male peers (n=3), for ease of understanding and timing of completion. The second stage of piloting involved patients (n=2). This highlighted one cell of the grid that was deemed inappropriate. This cell involved participants making a rating on the construct 'sexual feelings / lack of sexual feelings', when referring to the role of 'self as a father'. However, it was decided that both the element and the construct were important to the overall grid, so the decision was made to leave the grid unmodified, and to blank out the cell in question. Consequently, as the grid remained essentially unchanged, the data from the two pilot participants were included in the main sample.

Procedure

Part 2 of the investigation also used a cross-sectional design to compare groups of men at 6, 12, 18, and 24 months post-treatment, subject to the range mentioned earlier. The procedure was identical for each of these groups. However, because of the amendment to protocol the procedure was slightly different where participants were recruited through post (regardless of time stage). For this reason the two recruitment methods will be discussed separately, before going on to describe the interview procedure.

Recruitment in Clinic

The protocol for recruiting participants in clinic for this element of the study was identical to that of part 1 (see above). Again, a large proportion of the interviews were carried out through home visits.

Recruitment by Post

Potential participants were identified from the same database of patients. Patients who were shortly going to be at the correct time stage to fulfil inclusion criteria, but who were not attending a clinic appointment in the near future, were sent a letter and information sheet. A reply slip and a pre-paid envelope were included, and participants were requested to return the slip, with their contact details, if they wished to take part. The investigator then contacted the participants by phone, on the number provided, to arrange a convenient time and location for the interview. Where necessary, the investigator answered queries about the research over the telephone, at this juncture. In most cases, as above, the grid completion exercise was carried out as a home visit. However, in some cases the participants found it more convenient to attend the hospital. In such cases, a clinic room in the Psychology Department at St James's Hospital was used. Signed consent was obtained from all participants before commencing the interview.

Standard instructions for completion of the grid were given at the start of the exercise (see appendix 8). The investigator worked through the grid exercise, in person, with each participant. This enabled clarification of the procedure and any uncertainties during the task. The participants were required to make ratings (1-7), along the rows of constructs, taking one row at a time, systematically. The investigator made notes of the ratings as they were proceeding.

Following completion of the grid, the participants were asked a selection of questions in connection with the process of the exercise. This was designed with the intention of obtaining a measure of validation (see appendix 9 for a list of the questions). Again, at this point, further time was allowed for participants to ask questions, and they were thanked for their participation.

Analysis

Quantitative data from the repertory grids was analysed using PREFSCAL 3-way 3-mode multidimensional unfolding, to highlight the relative distances between the various elements, at the different time points. This analysis was carried out using a beta version of SPSS. Euclidean distances between the elements were calculated for each time stage using multidimensional scaling. In this instance Euclidean distance is defined as the straight-line distance between any two specified elements. Descriptive statistics were also carried out to summarise the data for each time phase. The validation data was reduced to nominal categories and summarised using a basic tally.

CHAPTER 3: RESULTS

The results of the study have been separated in three parts. Firstly, the qualitative data from part 1 of the study will be summarised. Secondly, the analysis of qualitative data from administration of the repertory grids will be reported. Finally, the validation of the grids will be discussed. A summary of information regarding participants and demographics will be presented first.

Participants

As the research protocol changed during the study to facilitate recruitment of an optimum number of participants, it is not possible to identify the exact number of participants who were eligible to take part in the research in total, throughout the duration of the project. However, 92 were identified as suitable to meet the appropriate criteria overall (plus an extra two who participated in the interview piloting, who did not fully meet the criteria in terms of time stage). Of these, 88 were approached. Reasons for not approaching the remaining four included current litigation on the part of one family, severe learning difficulty, substance misuse and in another case the man was being followed-up out of area. Of the 88 potential participants, 65 were approached for recruitment in clinic and 27 were included in postal recruitment. From the clinic recruitment method 41 (63%) agreed to participate, and from the postal recruitment method 6 (22%) responded. This resulted in total uptake of 47 (53%): 10 in part 1 of the study, and 37 in part 2 (in addition to the 2 participants in the pilot of the interviews). A breakdown of the groups, by time stage, for both parts of the study is shown in table 2.

Table 2: Breakdown of groups by time phase

Time Phase (Post-Treatment)	Stage1 No. of Participants	Stage 2 No. of Participants	Mean (Months Post-Treatment)	Range (Months Post-Treatment)
6 months	2	12	6.7	5.6 - 8.16
12 months	3	9	12.5	10.7 – 14.0
18 months	3	9	18.5	16.3 – 19.2
24 months	2	7	25.1	23.0 – 26.9

Demographics

The project involved only male participants, 100% of whom were from white backgrounds. Attempts were made to recruit participants from diverse backgrounds where they fulfilled the research criteria, however, all those approached opted not to participate. Forty-three participants (91%) were currently in a relationship, and only 4 were single. Of these, 24 (51%) already had children (See table 3). The mean age of participants was 38 years (range 20-62), which is slightly higher than might be expected from the age range documented in the literature, as several of the participants were older than is typical for this illness (Table 4).

Table 3: Demographics - Relationship status.

		Total n (%)	Part 1 (%) n = 10	Part 2 (%) n = 37
Relationship Status	Married	24 (51%)	7 (15%)	17 (36%)
	Partner	19 (40%)	3 (6%)	16 (34%)
	Single	4 (9%)	0 (0%)	4 (9%)
Parental Status	Children	24 (51%)	6 (13%)	18 (38%)
	No Children	23 (49%)	4 (9%)	19 (40%)

Table 4: Demographics - Age (n=47)

	Total		Part 1		Part 2	
	Mean	Range	Mean	Range	Mean	Range
Age (years)	38	20-62	37	20-55	39	23-62

Cancer Stage and Prognosis

All of the men who participated in the study fell into the 'good prognosis' group. Five types of tumour were present in the group: seminoma, germinoma, teratoma, embryonal carcinoma and mixed germ cell tumour. Thirty-eight (81%) had stage 1 disease, 4 (9%) had stage 2a, 2 (4%) stage 2b, 1 (2%) had stage 3, and 2 (4%) had stage 4 disease. Table 5 summarises the medical data.

Table 5: Breakdown of tumour types, staging and treatment

		Total (%)	Part 1 (%) n = 10	Part 2 (%) n = 37
Tumour Type	Seminoma	33 (70%)	4 (9%)	29 (62%)
	Germinoma	1 (2%)	0	1 (2%)
	Teratoma	10 (21%)	4 (9%)	6 (13%)
	Embryonal Carcinoma	1 (2%)	1 (2%)	0
	Mixed Germ Cell Tumour	2 (4%)	1 (2%)	1 (2%)
Disease Stage	Stage 1	38 (81%)	9 (19%)	29 (62%)
	Stage 2a	4 (9%)	0	4 (9%)
	Stage 2b	2 (4%)	1 (2%)	1 (2%)
	Stage 3	1 (2%)	0	1 (2%)
	Stage 4	2 (4%)	0	2 (4%)
Treatment Type	Radiotherapy	29 (62%)	5 (11%)	24 (51%)
	Chemotherapy (BEP)	11 (23%)	2 (4%)	9 (19%)
	Chemotherapy (Carboplatin)	4 (9%)	0	4 (9%)
	Chemotherapy (TIP)	1 (2%)	1 (2%)	0
	Surgery Only	2 (4%)	2 (4%)	0

Part 1: Qualitative Analysis – Construct Elaboration

Qualitative data were gathered in the ten interviews that took place as part 1 of the study. As discussed previously, the results were analysed for themes emerging from the transcripts using a content analysis. The grid to be produced from the themes was limited to ten-by-ten dimensions as any larger would have proved too time consuming for data collection purposes. Consequently, the themes that were most frequently used and most closely linked to the literature were selected for use in the final grid: however, other relevant themes will also be presented.

Generally speaking, the men who were interviewed fell into three categories (n):

- Men who recognised that the experience of testicular cancer had initiated changes in their lives and their self- perceptions (6).
- Those who in essence contradicted themselves by replying (when asked directly if they thought there had been any changes) that there hadn't, but went on to describe changed feelings at a later point in the interview (2).
- Men who consistently reported no changes as a consequence of the cancer (2).

Detailed description of the overall themes will be discussed under the headings of the construct labels, as these were generated (by the researcher and three independent assessors) from the key themes of the data as per the description in chapter 2. Table 6 provides a summary of the constructs generated by the participants, presented as clusters.

Table 6: Clustered summary of constructs

	Constructs	
Cluster Label	Primary Pole	Contrasting Pole
Confidence	Self-confident	Shy / Introverted
	Self-conscious	Uninhibited
	Confident	Lack of confidence
	Faith in own abilities	Don't take opportunities
	Embarrassed	Confident
	Shy	Outgoing
	Introverted	Sociable
	Reserved	Outgoing
	Lonely	Sociable
	Comfortable	Self-conscious
	Confident	Uneasy / Unsure
	Embarrassed	Unashamed
	Insecure	Confident
	Confident	Self-doubting
	Accepting	Insecure
Self-Other Relationship	Considers others	Self-centred
	Generous with time	No time to spare
	Sympathetic	Self-obsessed
	Loyal	Self interested
	Not self focussed	Selfish
	Loving	Selfish
	Giving to others	Selfish
	Willing to give of themselves	Insular
	Caring (x2)	Selfish (x2)
	True to self	Self pretences

	Constructs	
Cluster Label	Primary Pole	Contrasting Pole
	Caring	Disinterested
	Supportive	Not caring
	Supportive	Neglectful of needs
Motivation	Standing up for self	Passive
	Aggressive	Passive
	Proactive	Indifferent
	Complacent	Decisive
	Proactive	Complacent
	Have an opinion	Passive
	Active	Giving up
	Fighting spirit	Passive
	Decisive	Drifting
	Patient	Apathetic
	Forceful	Apathetic
	Resilient	Giving in
	Controlling	Helpless
	Outspoken	Conformist
	Enthusiastic	Apathetic
Life Satisfaction	Fortunate	Unlucky
	Satisfied	Unfulfilled
	Mundane	Varied
	Content	Dissatisfied
	Content	Regretful
	Happy	Lonely / Dissatisfied
	Deprived	Satisfied
	Frustrated	Content
	Content	Sad
Mood / Security	Angry	Happy
	Calm	Angry
	Stable	Feuding
	Peaceful	Hectic
	Relaxed	Stressed
	Stressed	Calm
	Anxious	Relaxed
	Reassured	Anxious
	Frightened	Secure
	Reassured	Scared
	Fearful	Comfortable
	Fearful	Un-phased
	Laid back	Stressed out
	On edge	Calm
	Apprehensive	Blasé
	Bored	Excited
Future Outlook	Happy go lucky	Miserable
	Optimistic (x2)	Pessimistic (x2)
	Euphoric	Despairing
	Cautious	Carefree

	Constructs	
Cluster Label	Primary Pole	Contrasting Pole
Success	Achieved	Stuck in a rut
	Breadwinner	Inferior / Wimp
	Successful	Failure
	Successful	Not fulfilling dreams
	Breadwinner / provider	Squanderer
	Achiever	Underachiever
	Provider	Parasite
	Failure	Success
	Ambitious	Satisfied with mediocrity
	Competitive	Participative
Sexuality	Attractive to opposite sex	Unacceptable
	Attractive	Ugly
	Fertile	Infertile
	Incomplete	Complete
	Incomplete	Full
	Macho	Lack Sexuality
	Randy	Exhausted
	Macho	Sensitive
	Flirty	Friendly
Behaviour in relationships	Loving	Distant
	Has close relationships	Distant
	Comfortable expressing emotions	Holds back emotions
	Open	Aloof
	Passionate	Indifferent
	Loving	Unfaithful
	Honest	Underhand
	Faithful	Deceitful
	Honest	Deceitful
	Trustworthy / Dependable	Unreliable
	Understanding	Conceited
Strength	Fragile	Indestructible / Invincible
	Strong	Feeble
	Healthy	Ill
	Inferior (x2)	Normal (x2)
	Fit	Incapacitated
	Tiredness	Vitality
	Mortal	Young
	Committed	Defeated
Thinking Style	Philosophical	Nihilistic
	Analytical	Accepting
	Self aware	Lacking vision
	Reflective	Unfocussed
	Materialistic	Content
	Focussed on financial security	Living for the day
	Materialistic	Fulfilled

Confident – Self-Conscious

It was commonly mentioned among participants that confidence was affected following the experience of testicular cancer. One participant described feeling insecure about their identity after the illness, *"I was asking myself questions about am I the same person as before? A lot of self-doubt comes into it…start feeling over-critical. I suppose it does make you feel insecure"* (Participant 9). A further participant mentioned having lost confidence in his abilities across a number of areas in his life, *"I feel once you've had a diagnosis of cancer you feel a lot more vulnerable. I've lost a lot of confidence that I never expected. Once it (support from family) stopped I realised that my life's carried on but it's changed me…I feel different in terms of confidence and how I feel about myself physically…feel inadequate sometimes"* (Participant 10).

In particular men described feeling self-conscious about certain elements of their appearance, such as baldness following chemotherapy, *"It was weird going bald… I was really self-conscious initially, but I knew it would come to an end"* (Participant 2). Additionally, men cited embarrassment about the appearance of their genitalia following surgery, with regards to strangers, current sexual partners and potential new partners, *"…a bit self-conscious since (the illness)…haven't needed to go in communal changing rooms since, but that would bother me…wouldn't be able to have one-night stands now, because I would have to go into all the gory details of the operation. I used to flirt with women whether I was attracted to them or not, but I wouldn't now"* (Participant 6). One particular participant reported some self-consciousness around this issue, in relation to what his children might feel about the appearance of his testicles, *"Children are inquisitive and it's important to be open and honest, so I might consider the option of a prosthesis to appear normal (if I'm going to have children)"* (Participant 3).

Participants described this shift in their self-perception as originating from a sense of feeling incomplete, *"As a man I'm incomplete because I have lost a testicle"* (Participant 5). In order to combat these feelings, a number of men cited the use of humour with their friends, *"I used to joke about it. Possibly used to use humour to deflect from the way I was truly feeling: 'only half the man I used to be'…I don't feel inferior for only having one testicle anymore"* (Participant 3). Furthermore, the men frequently used comparisons with potential scenarios, different to their own, to minimise the grounds for distress in their own case, for instance by comparing themselves to single men in the same position, *"In the early stages it was a bit weird. I was offered the option of another type of testicle…the fact I was married at the time made me feel comfortable with myself. I didn't feel I needed to. I would have possibly felt differently if I was single"* (Participant 3). A further comparison was made to women who have had mastectomy following breast cancer, *"I think it's probably worse for a woman to have breast cancer and lose a breast…it's more outwardly disfiguring, but again it is a loss of a bit of yourself that's the sex you were designed to be"* (Participant 7). Such comparisons may serve as a function of reassurance that other people's situations are worse than their own.

Caring – Selfish

A number of participants suggested that they had become more caring and thoughtful to other people since the illness. They described being less selfish and considering the thoughts of others a great deal more, *"I'm less focussed on myself and more worried about other people now. Getting married – I never thought that would happen. I imagine if I'd not had cancer I would have wasted so much money on expensive cars, rather than thinking of being happy by getting married and having a baby"* (Participant 6). Some men described this as a sudden awakening as to the importance of those around them, especially friends, parents and children, and one which improved their emotional communication, *"…I was, er, complacent with family…didn't appreciate what I had…the people in my life. It's made me tell people things that I should have told them years ago…my parents for example…made me less lazy about telling people how much they mean to me…I'm generally more expressive and it's brought us closer together…It highlighted the need to be an open and expressive parent"*(Participant 5).

Relaxed – Stressed

Whilst some men reported increased stress levels having overcome testicular cancer, because of the uncertainty of the future, others felt quite the opposite. For example, times leading up to medical check-ups were highlighted as being especially stressful: one participant pointed out this behaviour appears to form a cycle, *"I tend to live my life in three month chunks…feel relieved after a check up, then the cycle starts again. The closer the appointment is, the more stressed you get…generally more aware and looking for signs that it might have come back"* (Participant 9).

Of particular note is the fact that numerous men reported the most stressful time to be the waiting periods between the diagnosis and receiving staging scan results, and then again before commencing treatment, *"When he did the scan, I saw his eyes widen, and I knew...my worst fears were confirmed. Waiting to have more tests was pretty horrible. It took a couple of weeks...having to sit around thinking; 'it might be spreading'...I was pretty anxious"* (Participant 7). It seemed that the majority of men would have preferred to be active in dealing with the problem as quickly as possible, and access to information during any periods of delay was perceived as greatly important, *"The doctors dealing with me initially...examining me...didn't tell me anything. (It was) really frightening...I needed to know, to be told as it was happening. I didn't want to have to read it"* (Participant 4).

On the other hand, a commonly expressed view was that men believe they have a clearer ability to reflect on situations following the illness. They feel better able to assess the severity of a problem, and the value in becoming stressed about it, *"I am less stressed now. Small things to do with work used to stress me and I would get a bee in my bonnet over it for ages, but now I can come home and forget about it. My ability to classify what is trivial has improved; I can put things into perspective and it has made me more relaxed"* (Participant 5).

Active - Passive

Frequently, participants stated that they tended to be much more active in taking up opportunities and making decisions following the illness, *"(I'm) decisive for a change. I tended to let things drift before...there was nothing wrong, but nothing was perfect either...now I've changed a lot of things...Don't want to sit here and end up retiring and thinking 'I didn't do anything'. Something comes along that makes you think you won't have a tomorrow – you decide I'll do it today"* (Participant 4). This seemed to be associated with an increased awareness of the consequences of passively drifting in life and a desire to embrace every opportunity, *"...Feel like I want to get on with things...don't feel like I want to mosey along and do nothing with my life"* (Participant 6).

Content – Unfulfilled

A generally greater sense of contentment was discussed by a number of men, in that they felt able to take a step back and evaluate their lives, deciding that they were content in their current situation and had no need to compete in the rat race, *"I did far too much work before... (I) liked the thrill of the large pay packet, but I didn't need it, so I don't anymore...I feel happier and content...I stepped out of the rat race and realised that I didn't want to run the run the race anyway"* (Participant 4). A further participant described feeling curious about whether overwork could have contributed to acquiring the cancer, and consequently is content to be less competitive in his career, *"I definitely haven't felt as driven in my work life as I did before...I always asked why, what could I have done to avoid it?...was it to do with work stress?...It's only a job...to be healthy and content would be my plan now"* (Participant 10).

Optimistic - Pessimistic

There were mixed views surrounding this theme, although participants frequently connoted its significance. Some stated how important they felt it was to stay positive, both during and after the experience, *"(My partner) did my worrying for me. I had faith that the doctors knew what they were doing...I always felt it would be all right in the end. Bad things might happen but it doesn't really matter"* (Participant 4). However, others felt that the experience had changed their outlook, making them worry more about the uncertainty of the future and realise that they are not indestructible, *"You start seeing your own mortality...what's the future going to hold... (it) brings old age to you early: a different perception of yourself. Wonder will I ever see my grandchild grow up...realised that might not be a reasonable expectation"* (Participant 1). Generally, thoughts of missing out on watching younger loved ones mature were a major concern, *"I start to think; 'what if something does come back, will everything be okay?' I look at my kids and think; 'what are things going to be like if it doesn't work out; oh god, if I'm not here...I really want to see them grow up"* (Participant 9). In some cases, it was felt that this sense of increased pessimism resulted in a need to live life more cautiously, *"You have to factor it in when planning for things. It makes you slightly more cautious...if I drove into a wall I would leave behind a lot of problems"* (Participant 7), however it is important to note that this particular man had not yet purchased property and felt concerned about doing so with a pre-existing medical condition.

Feeling Sexual – Lack of Sexual Feelings

A large proportion of the participants mentioned some concerns surrounding their ability to perform sexually after the loss of a testicle, *"I don't feel right; I've got one ball and that's it. It doesn't ruin my life, but I am conscious that I'm not complete in that area. It's specific to masculinity…it would be different if it was my finger I lost. I never felt as macho as other men…I'm at risk of feeling even less so now…"* (Participant 10). Whilst these concerns were expressed, they were often described as having resolved relatively quickly, *"It affected the way I felt for a while…there was a period of inactivity…the way I felt changed a little bit…the prosthetic was bigger than I thought. It looked different initially, but things got back to normal quite quickly"* (Participant 4).

As much as men seemed to be concerned about their own altered perceptions of sexual performance, they reported anxieties regarding their partners' perceptions also, *"I was wondering what does the wife think? Does it feel different to her?…Because it feels different to me down there…I didn't have a fake one put in. Then I asked my wife…it took longer to get around to ask her than it would before…she reassured me, but then I don't believe her. I tend to think she's just saying that"* (Participant 9). Other men cited their partner's involvement in reassuring them about their performance as particularly significant, *"I was self-conscious at first, but my wife helped me to get over that…helped to reassure me that there's nothing wrong and things are still working"* (Participant 3).

Successful – Failure

A more remarkable finding stems from a number of men describing an unusual feeling of success and elation at having overcome the experience, *"…I don't know how to describe it…a sense of achievement almost. Something bad happened, and I got through it"* (Participant 4). It was portrayed that the public image of cancer played a large part in this sense of achievement, *"It's a weird thing… (I) feel more special now, more life experience… Have overcome something big…something to boast about; getting over 'the big C'"* (Participant 1).

Alongside the sense of success however, some men reported circumstances resulting in them feeling a failure, *"I worry about being able to provide…it's a bit outdated, but I* *still feel as a bloke you should at least contribute half way financially, physically and emotionally. We are both keen to have children…the prospect of not being able to provide that makes me feel a bit of a failure"* (Participant 7).

Appreciating Life – Wanting More

This construct is quite closely linked to the idea of an increased level of contentment following testicular cancer. Men talked of an increased awareness of the value of what they have in their life, *"I'm happier with what I've got rather than wanting something hugely ambitious in years to come. The experience has made me appreciate the immense value of what I have…I appreciate the smaller things…values and priorities have changed"* (Participant 5). Furthermore, the emphasis on materialistic possessions is depicted as diminished following the illness, *"Before I would have admired someone who earned lots of money, but now its irrelevant. It's better to appreciate the value of what you've got, and not be materialistic"* (Participant 4), along with the importance of physical appearance, *"…someone like Vin Diesel would have been admirable before…a macho man…a physical presence…(with women) I would only have been looking at their body…that's not important now…much less materialistic. I like nice things but it's not the be all and end all"* (Participant 6).

Strong – Weak

Commonly, men indicated the importance of emotional strength in overcoming the illness, in that some felt they discovered an element of strength that they did not know they possessed, *"It (testicular cancer) has given me the experience of showing resilience and emotional strength in overcoming things. I'm in a position to say I have gained positives from it. I'm pleased with how I dealt with it – bounced back – didn't sit down and feel sorry for myself…It's given me self-esteem"* (Participant 5). Despite this there was an acknowledgement that the illness can leave you with a weakened sense of physical strength and well-being, *"Your body suddenly isn't healthy, you are not in control of things…my body is a permanent reminder of illness; the lack of a testicle, the scars from surgery, and tattoos from radiotherapy"* (Participant 10). Such an awareness of physical vulnerability was cited as responsible for a more mature approach to life, *"…I've started looking after myself a lot more, although it may not look it. I realised how fragile I potentially am. If you don't look after yourself no one else will…*

I'm more aware of things connected to my health and safety. I bought a car with airbags…unheard of previously…I used to be a bit of a risk taker" (Participant 4).

Other Themes

In addition to the above themes, which formed the constructs for the repertory grid, the participants highlighted a number of other relevant issues, which will now be discussed briefly.

Perceived Pressure from Medical Professionals

Men talked of the fact that they felt pushed into considering issues, such as having children, which they had either never considered before, or had already decided were not part of their future, *"I'd never really considered children…I was forced to consider it. The hospital pushed a lot…pushed me to go to the assisted conception clinic; I felt like a fraud. I was forced into giving a sample; I didn't have much choice. Other couples there were desperate for children, whereas I knew I didn't want them. I felt like I was wasting their time"* (Participant 4). It appears that in extreme cases men feel they are forced into things that they would rather not do.

Communication with Professionals

Communication was emphasised as particularly important by men in both parts of the study. Whilst not all men mentioned this, a significant number suggested that they would have benefited from an opportunity to talk about their feelings, a service which they felt was not offered to them, *"They met the targets to treat me medically, which is wonderful, but I felt that medical staff did not have time for aftercare. It's a huge part of living with cancer. It's a massive thing to be told you have cancer; your whole life just stops. It surprised me that at no point did anyone offer me the opportunity to talk through how I was feeling emotionally with the experience. If I had…it may not have affected me in the long run the way I feel it has"* (Participant 10). Additionally, it was highlighted that patients can feel dismissed if medical staff demonstrate a sense of routine, as the patient finds it difficult to perceive their experience in this way, *"Initially I was told I needed chemo, then the plan changed to radiotherapy…I felt like the focus changed…suddenly not as seriously ill, so felt a bit dismissed really (by the doctors),* *but as a patient the focus is still there for you…when having scans the doctor looked as if he didn't understand why I was so worried"* (Participant 9).

Financial Concerns

The financial implications of the illness tended to be highlighted by the younger group of participants. Whilst there were a group who already owned their own homes prior to the illness, and benefited from having their mortgage paid-off through critical illness cover, the men who had not yet purchased property or obtained life insurance described increased anxieties about their financial situation, *"It's a bit of a worry in case anything crops up again…the financial implications…life insurance quote is now £200 per month…it's a worry in terms of trying to buy a house and get married"* (Participant 7).

Summary of Qualitative Findings

In summary, whilst some men reported no changes in their feelings or self-perceptions following the illness, the majority of participants stated that changes had occurred to some extent. In the case of these men, some significant themes emerged from the transcripts.

Self-confidence of testicular cancer sufferers appears to be impeded for at least a short while after the illness. This impact can be general, but tends relate specifically to physical appearance, and a sense of being incomplete as a man. Consequently, at some level, this notion overlaps with the theme surrounding sexual feelings, both of which relate to sexuality, masculinity and body image. Men tended to report a level of concern about their sexual performance following testicular cancer, which often receded in time, and they noted various sources of reassurance with regards to these aspects of their experience. Wives and partners were seen as significant in reassuring about sexual performance, and comparisons between their own situation and that of others seemed to serve as self-reassurance for some men.

The experience of testicular cancer appears to highlight the importance of interpersonal relationships, making men feel more caring, affectionate and emotionally expressive towards important people in their lives. This is linked with an increased appreciation of the simple things in life, and a reduced focus on materialistic ambitions and physical attributes. Generally men seem more content with their life after the illness and see less reason to be competitive at a career level. This also corresponds with the construct connected to stress. Men tend to experience an increase in stress levels during the illness as might be expected, however, after recovery is complete they perceive themselves as having a greater ability to put problems into perspective, and consequently feel better equipped to manage their stress. Overall, this seems to result in an improved quality of life in the long-term, rather than a diminished one.

As a consequence of this greater appreciation of life, men seem to be less passive in their lives following the illness. They report being more assertive, decisive, proactive and less complacent, which has links to masculinity. This results in men taking up opportunities that they would perhaps not have considered prior to their experience, and ultimately making changes in their life.

Despite the positive changes that men may make following the illness, they also report an increased sense of pessimism about the future. Generally men fear what the future may bring and worry about a recurrence of the cancer. In such situations, men are fearful about the consequences for offspring, and have a sense of regret about loved-ones that they won't see growing up. Additionally, young men who have yet to establish themselves financially have a sense of pessimism about their financial outlook and the prospect of investing in property.

Somewhat contradictorily a number of men experience a sense of success and exhilaration after the experience of testicular cancer, or a sense of strength and emotional resilience, despite the reports of increased pessimism about the future. However, this is not the case for all, and some perceive themselves as failing when they find they are unable to conceive children following the cancer. Also the physical changes that occur following the cancer and its treatment mean that whilst they may feel emotionally stronger, men are likely to feel physically more vulnerable, which may lead to a weakening of their body image. As a consequence men are likely to improve their level of awareness of health related issues after recovery.

Part 2: Quantitative Analysis

Choice of Analysis

There are a number of potential ways to analyse repertory grids. Jankowicz (2004) promotes the use of content analysis; Leach, Freshwater, Aldridge & Sunderland (2001) suggest hierarchical cluster analysis, multidimensional scaling (MDS) and principal components analysis (PCA) for analysing elements and constructs separately. However, the issue of analysis becomes more complex when trying to analyse a large number of grids simultaneously, as in the case of the current study, as the majority of methods are designed for analysis of single cases or small case series.

The current study is innovative in that little research has been done in this area, and the method has not previously been utilised in this way. Hence, the purpose is exploratory rather than attempting to be conclusive. Consequently several methods of analysis were considered. With respect to the analysis of multiple repertory grids there are two key ways of running data analysis: the use of a standard statistical package such as SPSS, or the use of a purpose built package for repertory grids. There are advantages and disadvantages to both methods. However, the main drawback to many of the purpose built packages is that they have not been recently updated, therefore they are designed to run with DOS systems, and are not compatible with contemporary operating systems such as windows XP. Furthermore, they were initially intended for use with individual grids and therefore have less utility for the analysis of large data samples. Consequently, the decision was made to use SPSS (version 12.01).

Initially multidimensional scaling (ALSCAL) was used to analyse the elements, and principal components analysis (with a varimax rotation) to analyse the constructs. MDS works by extracting a pattern from the data through calculating the relative distances between the objects in the data matrix, before plotting the objects and relative distances in two-dimensional space on a geometrical picture. PCA is a tool for reducing large amounts of data, producing higher order factors and information on how variables cluster together.

Following the initial analysis two experts in analysis of grids were consulted; Professor Chris Leach, University of Huddersfield, and Professor Richard Bell, University of

Melbourne, Australia. During conversations with Richard Bell a method called multidimensional unfolding was recommended, which analyses constructs and elements simultaneously, whilst sequentially taking into account the different time stages. This method is appropriate given that all the grids have elements and constructs in common. Multidimensional unfolding is not dissimilar to MDS in that it also plots the relative distances between elements and constructs in a two-dimensional diagram. These diagrams can then be utilised in a subjective interpretation of the patterns and changes. The programme used to carry out this analysis was a beta version of SPSS software held by Richard Bell, which is not currently commercially available.

The data was analysed with PREFSCAL 3-way 3-mode multidimensional unfolding, examining the 6, 12, 18, and 24 month groups sequentially. The decision was made to omit PCA as a means of analysis, as it was not considered that the output added significantly to interpretation. Instead, a selection of key elements was examined to identify changes over the time stages ('me before the illness', 'me now', 'me in five years', 'ideal self'), to aid in the interpretation of the diagrams. These elements were chosen as they were seen to represent the participants' perceptions of their own life over time, in terms of how their current life may be different from their pre-illness experience, and how they hope it will progress in the future. Descriptive statistics were also carried out on the above-mentioned elements, and elements associated with masculinity and sexuality for all constructs, at each time stage. Mean values were used to plot differences over time. Similarly, Euclidean distances between key elements were used to graph distances in support of the multidimensional unfolding plots.

Research Questions

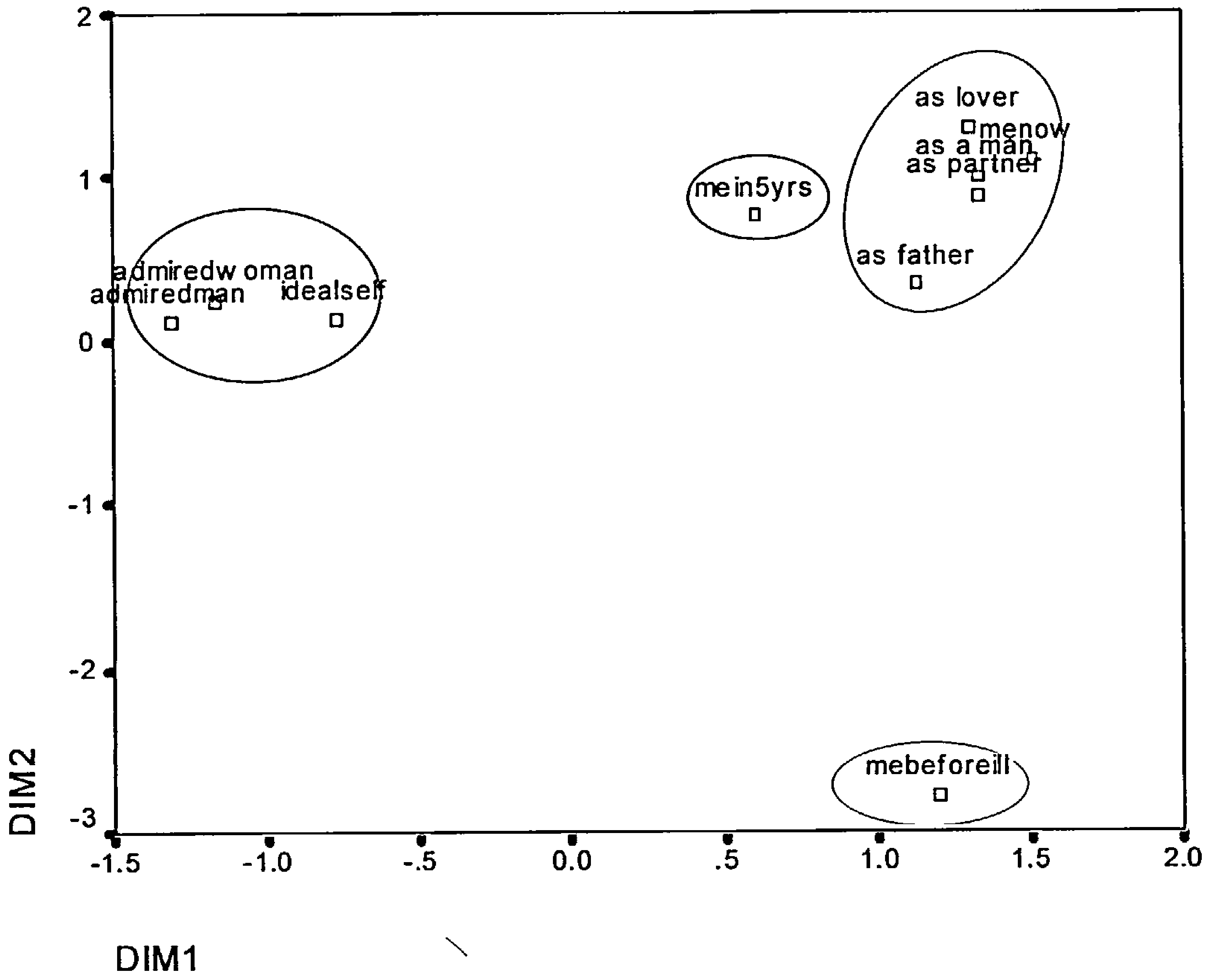
1. To what extent does perceived self-concept in survivors of testicular cancer change over time during the two years after the illness?

Table 7 represents the percentage of men from each group who noted differences in their self-perceptions from before the illness to now, across each construct. It is important to note that this data does not represent the direction of the change, merely that the specific percentages of men noted in their ratings that a difference was apparent. It is evident from the figures in the table that generally, a large proportion of participants (ranging from 35% to 70%) felt there had been change in their self-perceptions across this period depending on the construct. Some variation between groups is evident, and clearly not all constructs were significant in each individual's ratings of change, however the percentages appear large enough to say with relative confidence that change occurs in men's self-perceptions over the period between their life before the illness and the time of the grid completion. Of note is the fact that the 12-month group less frequently rated change in confidence and activity levels than the other groups. Likewise, the 24-month group less frequently noted changes in the construct in connection with caring, but more frequently highlighted changes in sexual feelings.

Table 7: A table summarising the percentage of men who noted change in each construct from before the illness to the time of grid completion

	Percentage change: 'me before' – 'me now' (n)				
Construct	6 months	12 months	18 months	24 months	Total
Confident – Self-conscious	42% (5)	22% (2)	67% (6)	71% (5)	49% (18)
Caring – Selfish	50% (6)	56% (5)	56% (5)	14% (1)	46% (17)
Relaxed – Stressed	83% (10)	67% (6)	56% (5)	71% (5)	70% (26)
Active – Passive	50% (6)	11% (1)	67% (6)	71% (5)	49% (18)
Content – Unfulfilled	67% (8)	56% (5)	78% (7)	43% (3)	62% (23)
Optimistic – Pessimistic	42% (5)	67% (6)	78% (7)	57% (4)	59% (22)
Feeling sexual – Lack of sexual feelings	25% (3)	22% (2)	33% (3)	71% (5)	35% (13)
Successful – Failure	17% (2)	44% (4)	56% (5)	29% (2)	35% (13)
Appreciating Life – Wanting more	67% (8)	67% (6)	78% (7)	71% (5)	70% (26)
Strong – Weak	50% (6)	78% (7)	78% (7)	71% (5)	68% (25)

Figures 1-5 represent two-dimensional plots of the elements from the multidimensional unfolding analysis taken at each of the four stages. Figure 1 is an example of a modified plot to demonstrate the clustering of the elements.



Key

— Ideal cluster — Future self

— Past self — Relationship cluster

Figure 1: Modified two-dimensional plot to demonstrate the clustering of elements (6-month group)

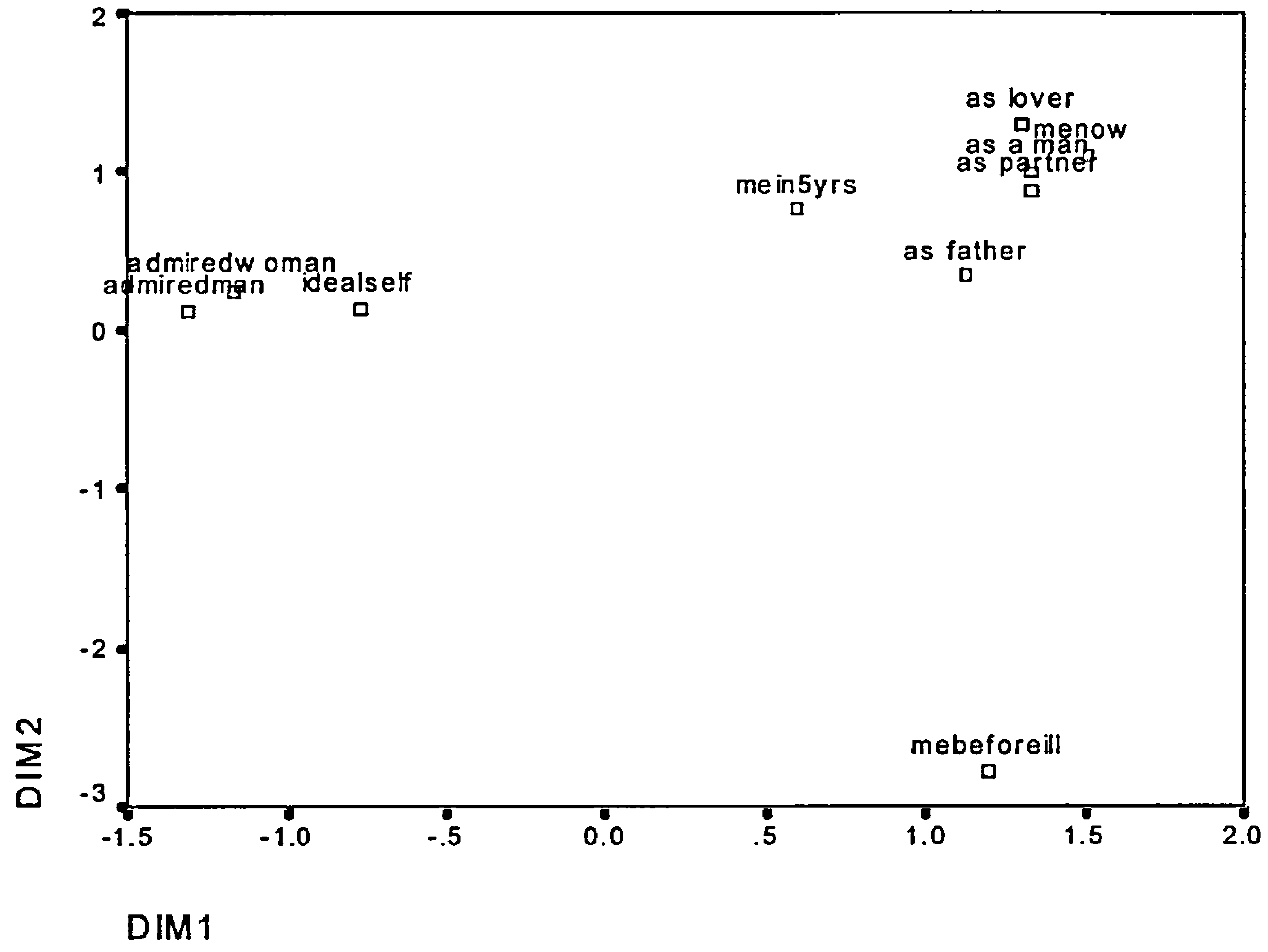


Figure 2: Two-dimensional plot for elements only (6-month group)

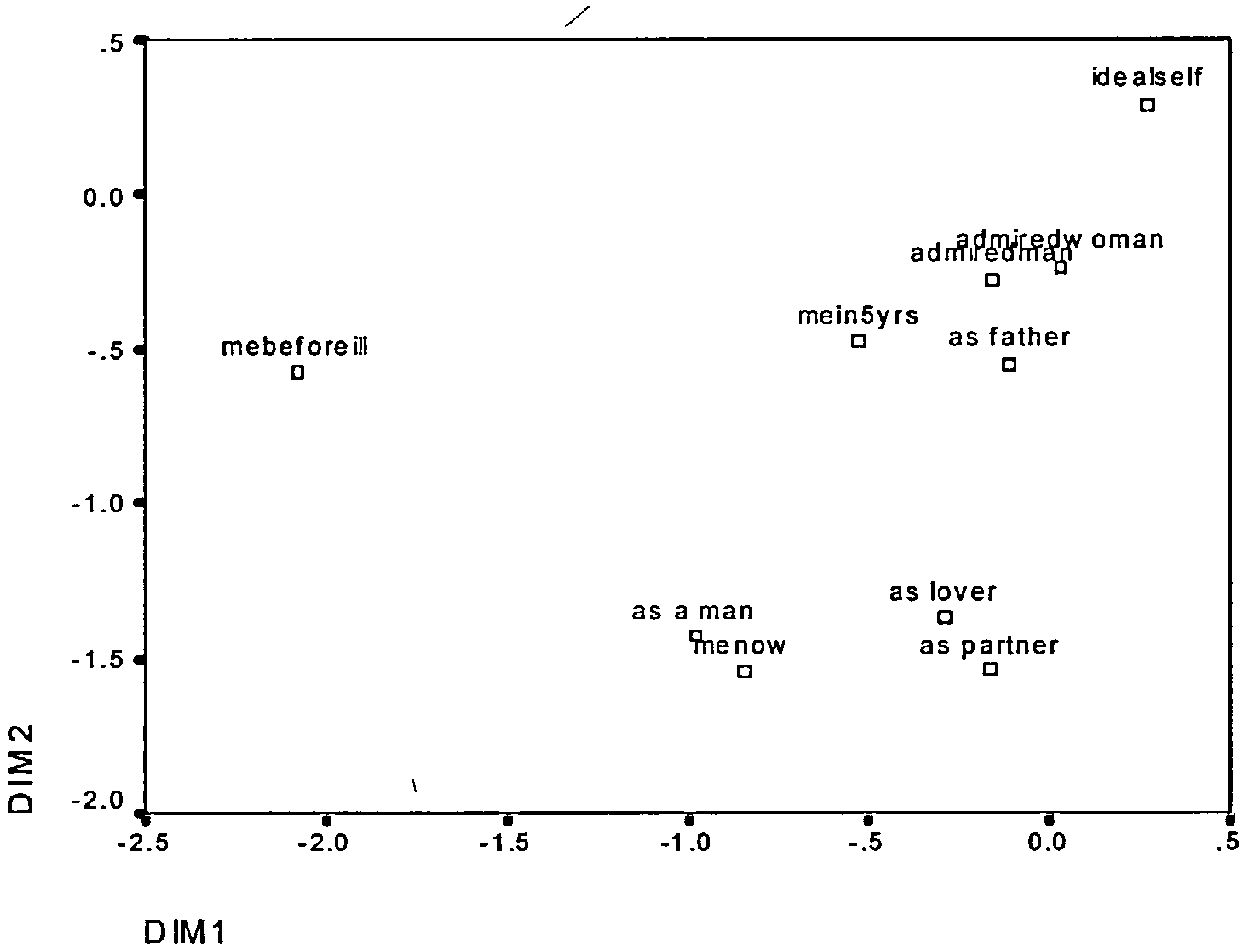


Figure 3: Two-dimensional plot for elements only (12-month group)

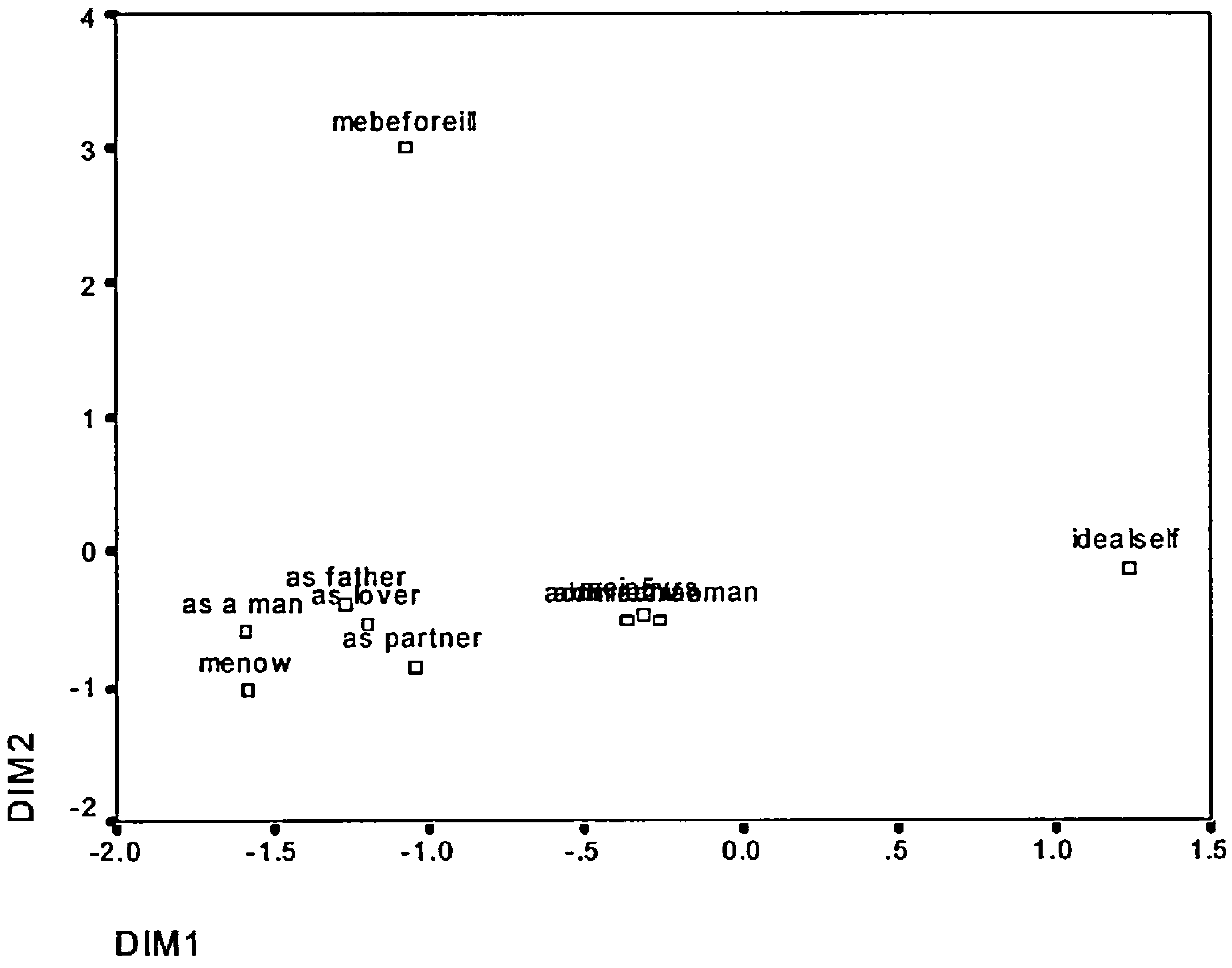


Figure 4: Two-dimensional plot for elements only (18-month group)

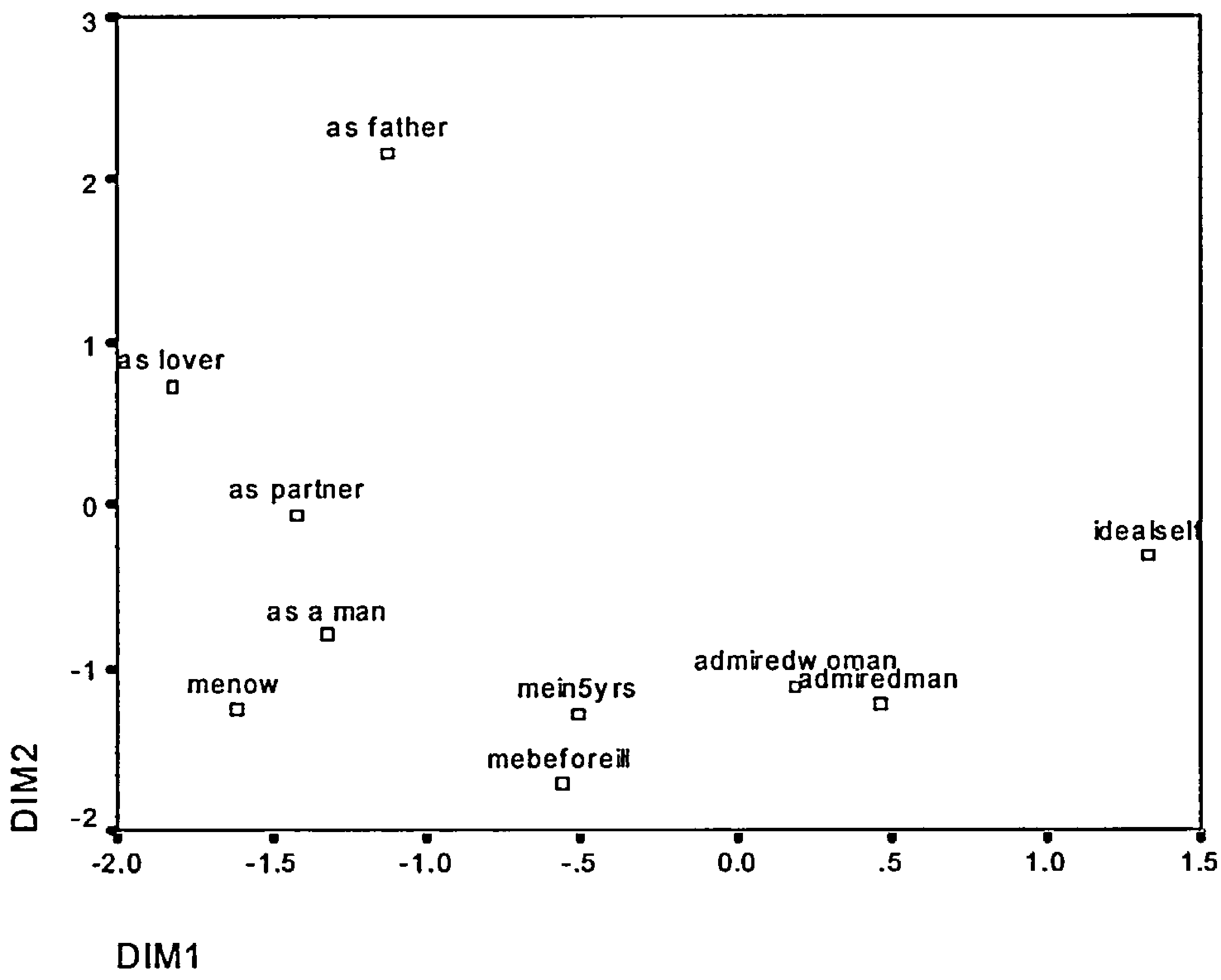


Figure 5: Two-dimensional plot for elements only (24-month group)

As can be seen in the plots above, patterns emerge from the data that are suggestive of patients experiencing some changes in self-perception as a consequence of testicular cancer. There is a prominent tendency that 'me before the illness' as an element is isolated on its own in the first three stages, but by 24 months post illness the other elements are more closely aligned with this one. This data is also represented numerically in tables showing the Euclidean distances between elements for each of the four time stages. These tables can be found in appendix 10. Combination plots of constructs and elements can also be found in the appendices (appendix 11). These were left out of the main analyses as it was found that they did not significantly add to the interpretation. The main pattern observed from these plots showed that ideal self is most closely associated with positive constructs, whereas the other elements are more separate, as would be expected.

When the element plots for each stage are examined a number of patterns emerge. Firstly, the elements seem to form four clusters in areas of space within the plots; an ideal trait cluster, a relationship cluster, future self, and past self. The ideal trait cluster containing the elements 'ideal self', 'a man I admire' and 'a woman I admire'. Similarly, there is a relationship cluster, including elements such as 'father', 'lover' and 'partner'. Whilst these clusters shift position on the plot at each stage, the elements within the clusters remain aligned with one another. Secondly, the 'ideal self' element seems to be further away from the others to some degree, at most stages. This makes intuitive sense in that people tend to see their ideal as being distant from their current self-perception. These observations are supported by the following graphs representing the distances between key elements, and the changes across time (figures 6 & 7).

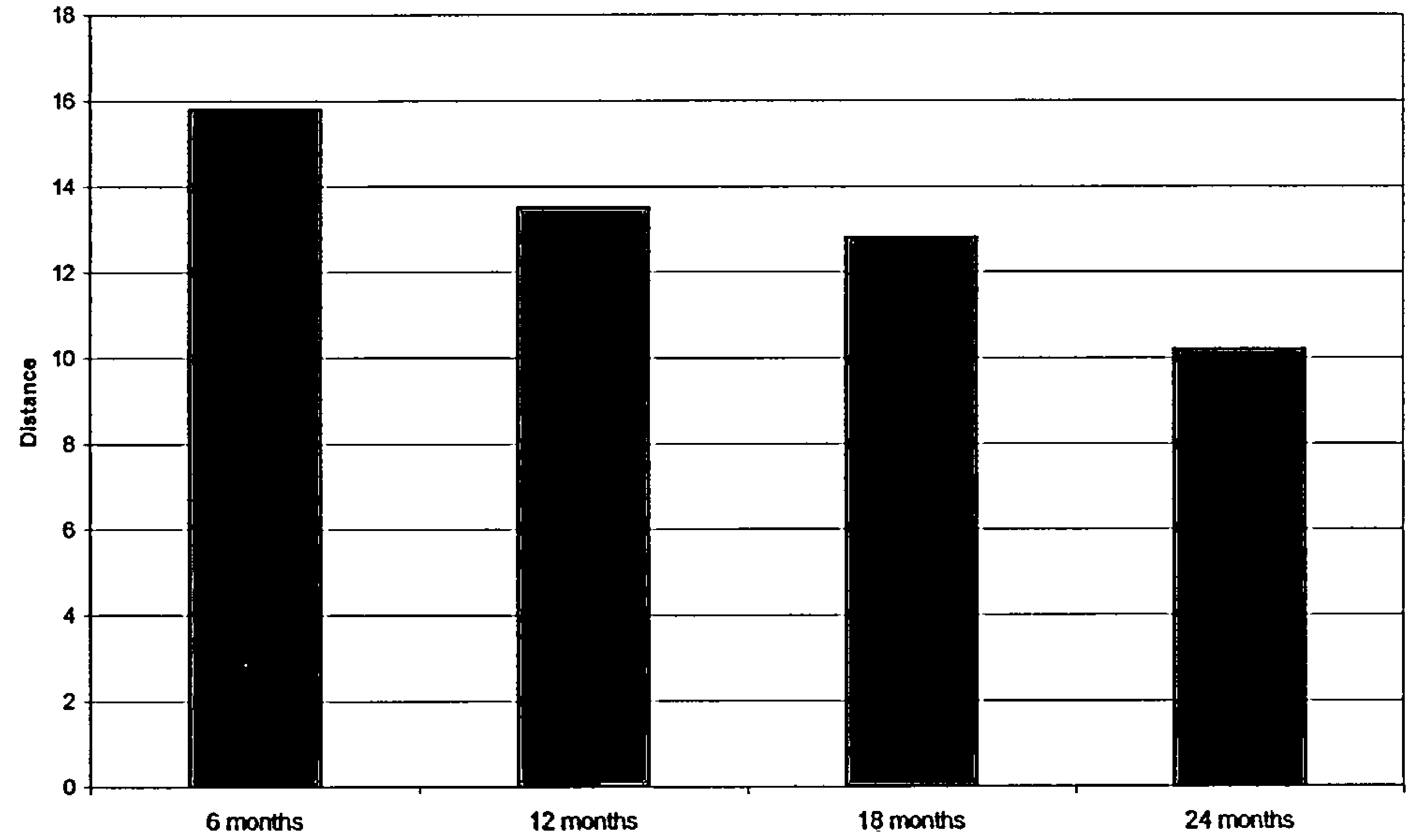


Figure 6: Bar chart representing the Euclidean distances between the elements 'me now' and 'me before the illness' over time

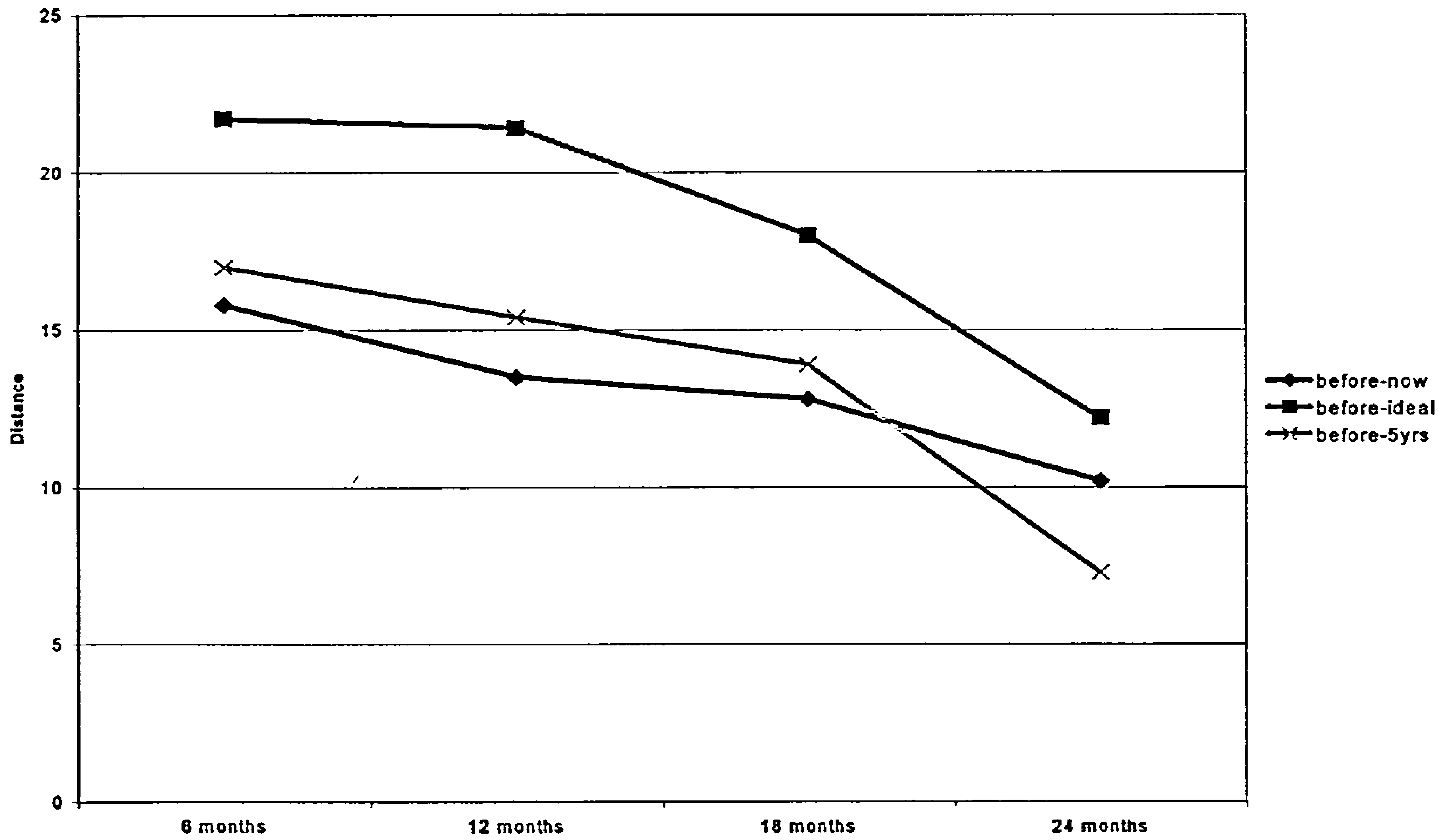


Figure 7: Line Graph showing patterns in Euclidean distances over time

Each of the above graphs demonstrates the tendency for the distance between key elements to reduce over time following the illness, perhaps reflecting a process of adjustment by the time men have reached 24 months post illness.

In summary, self-perceptions as represented in Euclidean distances and the multidimensional unfolding analysis show changes in patterns at each time phase, suggesting that the self-concepts of men who have suffered testicular cancer change as a result of the illness. Of particular note is the fact that the element 'me before the illness' is more closely aligned with other elements in the 24 month stage, yet is distinctly isolated prior to this stage, suggesting that transitions in self-concept occur over time, which may reflect a process of adjustment in the participants.

2. Do men's perceptions of themselves before the illness and perceptions of masculinity and sexuality differ? For example, their perceptions of themselves as a man, father, lover, and partner. Do these perceptions change significantly over time?
In examining figures 1 – 5 with respect to the masculinity / sexuality elements described above, it is possible to see that these elements form a cluster and remain aligned to each other throughout time. It is difficult to determine from these plots whether the self-concepts linked to these elements are any different to the other self-concepts. However, the fact that they cluster together is an indication that the grid is working in the way it was intended. It makes intuitive sense from the literature reviewed in chapter 1 that men would rate these elements, which form part of the same multidimensional concept, in a similar way. The changes in these elements over time will now be examined.

In terms of elements connected to sexuality and masculinity, the element 'me before the illness' was used as a point of reference for these comparisons, based on clinical experience suggesting that oncology patients are inclined to refer to their memories of life before the illness as a natural benchmark. This element was compared to the elements related to perceptions of masculinity and sexuality, such as 'me as a man', 'myself as a father', 'me as a lover', and 'me as a husband / partner'. Figure 8 represents the relationship between all of these elements and the changes over time.

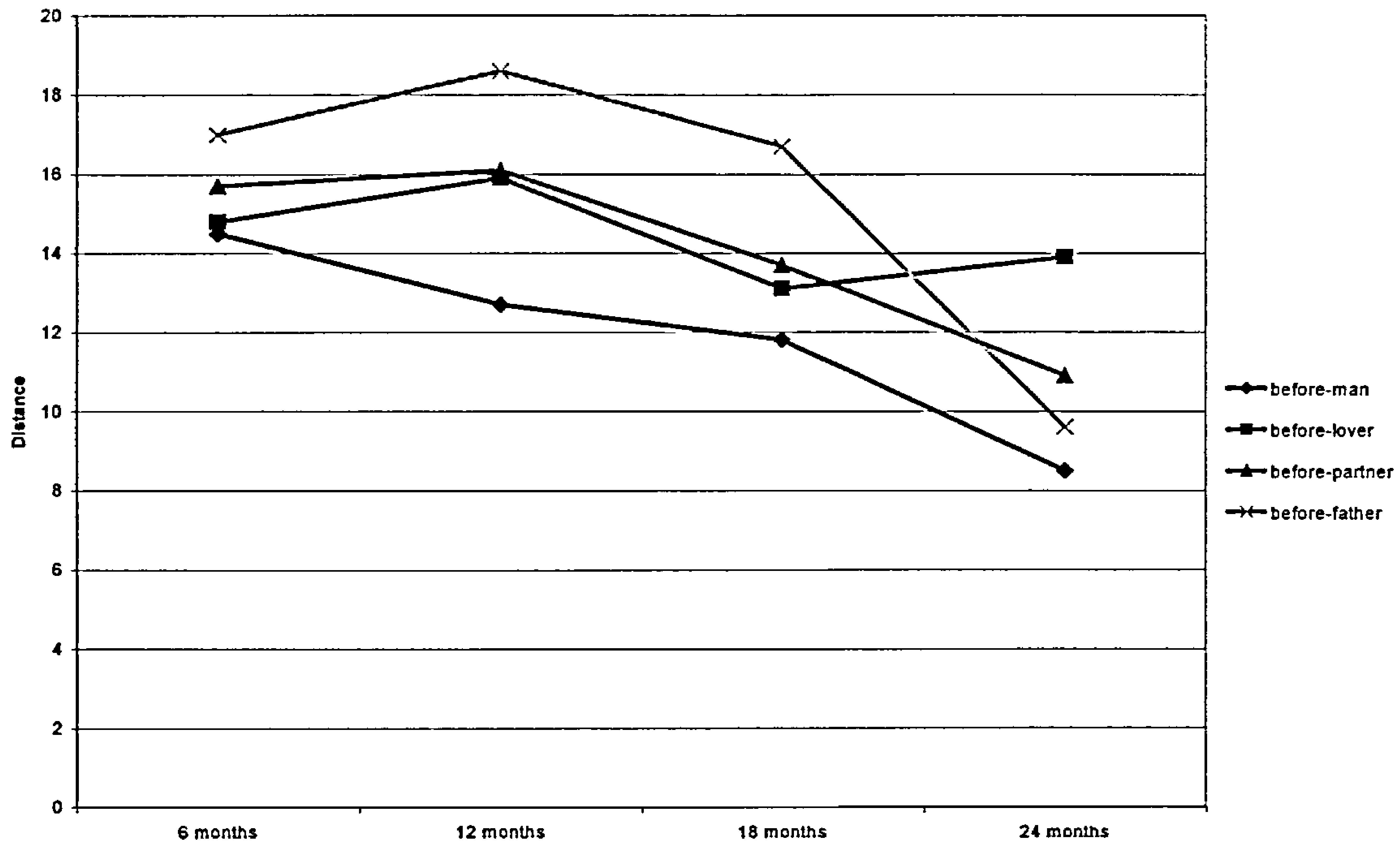


Figure 8: Line graph showing the relationship between 'me before the illness' and masculinity / sexuality elements over time (Euclidean Distances)

As can be seen from this line graph, three of the four elements show a tendency for the distance between them and 'me before the illness' to reduce in each group with time. Specifically, in terms of the relationship with 'me as a man', the distance between the elements reduces further with each time phase. This suggests that the sense of self as a man is becoming more closely aligned to the sense of self before the illness as time progresses. The distances between the reference element and 'myself as a father' and also 'me as a husband / partner' increase between the groups over the initial 12 months following the illness, however over a further 12 month period rated by the corresponding groups, they reduce substantially. Again this suggests that the man's sense of himself in these roles over time may be realigning with his perception of how his life in this domain was before the illness. The initial increased distance between the elements may be accounted for by a period of uncertainty immediately after the illness. However there is no such consistent pattern where the element 'me as a lover' is concerned. The distance between this element and the reference element fluctuates in an inconsistent manner over the various groups, perhaps suggesting that the process of adjustment takes longer in the case of men's perceptions of themselves as a lover.

Having identified that men's self concepts appear to change following the experience of testicular cancer, and that within this experience perceptions of sexuality and masculinity are important, given that they too seem to fluctuate, an attempt will now be made to identify what contributions the constructs make to these changes.

3. Which constructs contribute to the changes in masculinity elements over time?

Descriptive statistics were calculated for all constructs with respect to the masculinity / sexuality elements. This was repeated separately for each time phase. Tables 8 – 11 summarise the mean construct values for the elements 'me as a man', 'myself as a husband / partner', 'me as a lover' and 'me as a father' over the four different time stages. Where these ratings are concerned it is important to remember the values of the rating scale and the weighting towards each pole of the construct: the constructs were each rated on a 1-7 scale, a score of one relating to the extreme of the left hand pole (for example very confident) and a score of seven relating to the extreme of the right hand pole (for example very self-conscious).

As can be seen in table 8, participant's perceptions of themselves as a man are rated fairly similarly across all constructs, the mean scores ranging between 2.1 and 3.0. However, whilst variations are small some interesting patterns can be observed in the data. When rating their perceptions of themselves as a man the 12-month group rate themselves as being less confident than the other groups. The data suggests that there is a trend in the men gradually feeling more confident from 12 months onwards. Men's ratings of selfishness gradually reduce over time, with the 24-month group rating this lower than all others, however, alongside this there is also a gradual reduction in their ratings of contentment and success. This might suggest that whilst men feel more content with their lives in this role to begin with, as time progresses they begin to feel less successful and move towards wanting more out of life as a man again. In a similar vein ratings of optimism also drop in the 24-month group, despite an increase being evident in the 12 and 18-month groups. In some senses this corresponds with the data from the qualitative stage of the research, in that men note changes in these constructs during different stages of their experience: however, the patterns do not always seem to fit with the descriptions from the interviews, although the apparent pattern of adjustment by 24 month post-illness corresponds with the changes observed in the multidimensional unfolding analysis discussed above.

Table 8: Table comparing mean construct values for the element 'me as a man'

Construct	6 months	12 months	18 months	24 months
Confident – Self-conscious	2.3	3.0	2.7	2.4
Caring – Selfish	2.8	2.7	2.6	2.3
Relaxed – Stressed	2.9	3.3	3.2	2.6
Active – Passive	2.4	2.2	2.4	3.1
Content – Unfulfilled	2.7	2.9	2.9	3.0
Optimistic – Pessimistic	2.7	2.1	2.2	2.9
Feeling sexual – Lack of sexual feelings	2.4	2.3	2.7	2.4
Successful – Failure	2.2	2.4	2.8	3.0
Appreciating Life – Wanting more	2.3	2.2	2.7	2.6
Strong – Weak	2.4	2.7	2.3	2.6

Table 9 examines the participant's perceptions of themselves as husbands or partners. Again there is little variation in the mean ratings across constructs. From this data, it is evident that the later groups rate themselves as feeling less confident in this role, perhaps suggesting that the role of partner is less of a focus until 18 months post illness when men feel well on the road to recovery. Similar patterns occur with other constructs in connection to this role, such that there is a general trend for participants in later groups to rate themselves as more caring, more relaxed and more passive in this role than the earlier groups. Ratings on the construct optimistic / pessimistic fluctuate across the different groups in a less consistent manner, with the 24-month group giving the lowest rating of optimism for this role, despite the fact that ratings in connection with sexual feelings indicate that men's sexual urges gradually increase over the different time phases. This finding coincides with reports from the qualitative data, in that men feel less inclined towards sexual activity shortly after the illness, however once they feel reassured about their physical capabilities this aspect improves as time progresses. In a similar manner to the data for the role of a man (table 8), here too the data indicates that men in the 24 months post-illness group rate themselves higher on the scale of appreciating life / wanting more, suggesting that men return to wanting more out of life following a longer time-lapse since the illness.

Table 9: Table comparing mean construct values for the element 'myself as a husband / partner'

Construct	6 months	12 months	18 months	24 months
Confident – Self-conscious	2.3	2.3	2.4	2.7
Caring – Selfish	2.8	2.9	1.9	2.1
Relaxed – Stressed	3.0	2.8	2.9	2.6
Active – Passive	2.3	2.9	2.7	2.7
Content – Unfulfilled	2.3	2.4	2.1	2.4
Optimistic – Pessimistic	2.7	2.2	2.2	2.9
Feeling sexual – Lack of sexual feelings	2.8	2.7	2.6	2.3
Successful – Failure	2.3	2.3	2.0	2.3
Appreciating Life – Wanting more	2.1	2.1	2.0	2.4
Strong – Weak	2.5	2.4	1.9	2.4

Data for the element 'me as a lover' is represented in table 10. The patterns in this data are less similar to the element 'me as a partner' than might be expected, but once again there is little range in the mean scores. Ratings indicate that participants in the later groups perceive themselves to be more caring, but less relaxed than the men in the early groups. Confidence about this role appears to be higher in the 12-month group, but reduces again by 24 months. Likewise ratings indicate an increase in contentment and success, but a reduction in optimism at around 12 – 18 months; however these construct ratings balance out again in the 24-month group. The finding that an increase in contentment and success would coincide with a reduction in optimism is somewhat contradictory and difficult to explain. Furthermore, contrary to the findings for the element of partner, ratings suggest that the later groups appreciate life more in the role of a lover than the earlier groups, which links to the descriptions from the qualitative interviews, and is supported by a moderate increase in ratings of sexual feelings across the time stages.

Table 10: Table comparing mean construct values for the element 'me as a lover'

Construct	6 months	12 months	18 months	24 months
Confident – Self-conscious	2.8	2.4	2.7	3.2
Caring – Selfish	2.8	2.7	2.1	2.4
Relaxed – Stressed	2.5	2.7	2.6	2.7
Active – Passive	2.7	2.7	2.3	2.7
Content – Unfulfilled	2.9	2.1	2.4	2.9
Optimistic – Pessimistic	2.8	2.1	1.9	3.0
Feeling sexual – Lack of sexual feelings	2.6	2.6	2.6	2.4
Successful – Failure	2.7	2.4	2.4	3.0
Appreciating Life – Wanting more	2.3	2.2	2.2	2.1
Strong – Weak	2.3	2.4	2.1	2.6

Men's perceptions of themselves in the role of a father are summarised in table 11. With regards to this particular element the mean results paint a confusing picture. Again this data suggests that men are more self-conscious about themselves in the role of father following a longer time-lapse since the illness. Although ratings also indicate that men feel they are more caring and more relaxed in this role after a longer period. Yet men in the later groups also rate themselves as less successful and less fulfilled than men in the earlier groups.

Table 11: Table comparing mean construct values for the element 'me as a father'

Construct	6 months	12 months	18 months	24 months
Confident – Self-conscious	2.2	2.0	2.7	3.0
Caring – Selfish	2.2	2.1	1.8	2.0
Relaxed – Stressed	3.1	2.8	3.0	2.6
Active – Passive	2.3	2.0	2.3	2.6
Content – Unfulfilled	2.2	1.7	2.3	2.9
Optimistic – Pessimistic	2.2	2.1	2.0	2.7
Feeling sexual – Lack of sexual feelings	*	*	*	*
Successful – Failure	1.9	2.2	2.0	3.0
Appreciating Life – Wanting more	2.0	1.3	2.1	2.0
Strong – Weak	2.0	1.7	2.0	2.1

* Data is missing for this element-construct combination.

Validation of Grid Process

4. Is repertory grid technique a useful tool for examining men's self-perceptions following the experience of an illness? Do participants feel the exercise accurately reflects their experience?

Following completion of the grid, participants were asked questions about the validity of the method in accurately representing their perceptions. Participants' responses to these questions were reduced to nominal data. Table 12 summarises the tally of participants who responded either yes, no or unsure to these questions for each of the time periods. Figure 8 provides a visual representation of this data. Overall, the majority of the participants felt that the completion of the grid exercise was relevant to their experience of testicular cancer. They also concluded that the constructs and elements were logical and relevant. Furthermore, the vast majority also felt that the grid exercise accurately reflected their experiences. For example, where participants felt that changes had occurred as a result of their experience with the illness, they felt that this was elicited through the grid, and where they considered that the illness resulted in no changes, they felt that this too was accurately reflected.

Table 12: Summary of participants' responses to validation questions

	Responses		
	Yes (%)	No (%)	Unsure (%)
1. Did you find completion of the grid exercise relevant to your experience of testicular cancer?			
6 Months	8 (67%)	3 (25%)	1 (8%)
12 Months	6 (67%)	2 (22%)	1 (11%)
18 Months*	6 (75%)	0 (0%)	2 (25%)
24 Months	3 (42%)	2 (29%)	2 (29%)
Total	**23 (64%)**	**7 (19%)**	**6 (17%)**
2. Did the constructs and elements make sense to you? Could you see how they were relevant?			
6 Months	10 (83%)	1 (8%)	1 (8%)
12 Months	(89%)	0 (0%)	1 (11%)
18 Months*	7 (88%)	0 (0%)	1 (12%)
24 Months	7 (100%)	0 (0%)	0 (0%)
Total	**32 (89%)**	**1 (3%)**	**3 (8%)**
3. Would you say the exercise accurately represented your experience, i.e. elicited change where there was some?			
6 Months	9 (75%)	1 (8%)	2 (17%)
12 Months	8 (89%)	0 (0%)	1 (11%)
18 Months*	8 (100%)	0 (0%)	0 (0%)
24 Months	6 (86%)	1 (14%)	0 (0%)
Total	**31 (86%)**	**2 (6%)**	**3 (8%)**

* Stage contains one set of missing data

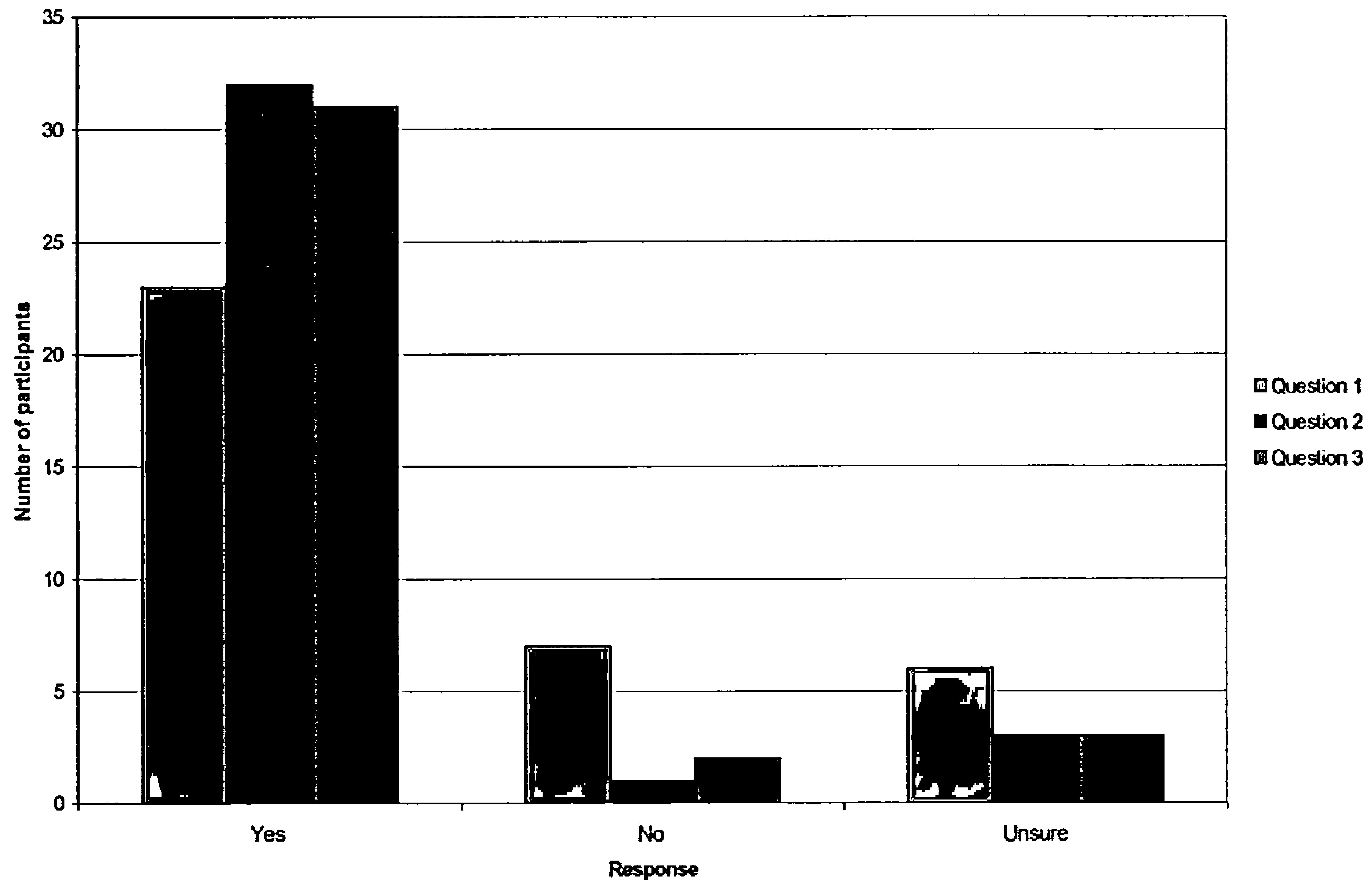


Figure 9: Bar chart to represent participant responses to validation questions

CHAPTER 4: DISCUSSION

The aim of this study was to examine whether or not the experience of testicular cancer has an impact on men's self-perceptions generally, and with specific reference to sexuality, body image and masculinity. This chapter summarises the results together with a discussion of the findings in the context of what is already known in this field. In addition, the limitations of the study will be presented, along with a discussion of the implications of the findings for men with testicular cancer. Future suggestions for research will also be made.

Summary of Findings

Both qualitative and quantitative methods were used to investigate the aims in this study. Overall, the study demonstrated that the experience of testicular cancer results in changes to the way men feel about themselves, which change over time.

The qualitative element of the study suggests that men who have survived the illness tend to fall into three main categories:

1. Men who acknowledge the impact the illness has had on the way they feel about themselves
2. Men who deny any changes to their self-perception as a result of the illness, yet later recount changes that have occurred.
3. Men who consistently describe having experienced no changes as a direct consequence of the illness.

The interviews highlighted a number of areas thought to be of relevance in the changes, including:

- The way a man feels about his body after the illness, including particular concerns about the appearance of genitalia and sexual performance
- Changes in general level of confidence
- Changes to the way a man views his relationships with key individuals and a greater sense of selflessness
- The extent to which life is valued
- Changes in stress levels

- Increased activity levels
- Increased concerns about the future
- Initial changes in sexual drive
- Feelings of success at having overcome the illness
- An increased awareness of the frailty of the body, and an increased sense of mortality

These themes formed the constructs for the quantitative part of the study.

The quantitative element of the study supported evidence of change occurring in self-perceptions as a result of the illness. Aspects of sexuality and masculinity were seen to be relevant in these changes. The various constructs are weighted fairly equally in the changes suggesting that all constructs contribute to the differences observed between the four different time stages. However, further patterns emerge in the mean construct values, some of which support and some of which contradict the other findings. Repertory grid technique was evaluated as a useful tool for examining men's self-perceptions of their illness experience.

The findings will now be discussed in more detail in the context of the research questions and the existing literature base.

Review and Discussion

Changes in Self-Perceptions

The results indicate that 80% of the men in the qualitative interviews noted some changes in their self-perceptions as a result of the illness, although some of these men denied having noticed any changes when asked directly. Quantitative data show a similar pattern in that changes in scores between 'me now' and 'me before the illness' were noted ranging from 35% of participants to 70% dependent on the construct in question. The constructs rated as having changed most often included relaxed – stressed, optimistic – pessimistic, content – unfulfilled, appreciating life – wanting more, and strong – weak. It is therefore evident that whilst changes do occur in self-perceptions as a result of testicular cancer, not all of them are negative ones. Indeed the qualitative interviews provided strong evidence of positive changes that occur in a man's life as a result of the illness, such as an increased appreciation of the value of many things in life, leading to a greater sense of contentment. This finding is supported by evidence from Brodsky (1995; 1999), who found that men's lives were affected in a positive way by testicular cancer, which is perceived to be a life-threatening experience. Specifically, intimate relationships were found to be of greater value than career goals in his participants who found they could live life with greater 'fullness' than previously, a finding that directly maps onto the conclusions of the qualitative dimension of the current study.

However, both the literature and the evidence from this study indicate that not all outcomes are positive where testicular cancer is concerned. Arai et al (1997) found that testicular cancer had a negative impact on the sexuality and fertility of survivors a number of years after the illness. This evidence is supported by the findings of the current study, albeit with regards to slightly different aspects of the cancer experience. However, to look at the illness experience as negative for some and positive for others is far too simplistic. Given that many of the qualitative interviews highlighted the simultaneous presence of difficult and beneficial changes in self-perceptions, it is likely that the true picture combines a complex mix of factors.

There are individual differences in the way men respond to a crisis of this kind, and indeed some experience negative changes in their self-perception, such as a lowering in confidence, which can include an impact on their sense of masculinity, as well as their confidence in physical appearance and sexual performance. Additional negative changes to the perception of the body were also noted including an increased sense of mortality and fragility. This seems to indicate that some men become increasingly aware of their body following the experience of testicular cancer and what it takes to be masculine. In some cases men reported a tendency to compare themselves to male friends and role models in an attempt to reassure them that they don't fall short of the masculine ideals of strength and resilience. Evidence from examination of elements linked to sexuality and masculinity revealed that they too are different across the four time stages, leading to a conclusion that these elements contribute to the overall changes in a man's self-perceptions following the illness. Whilst not all men noted changes in sexual and masculine perceptions, in those who did this was stated to be a significant issue in their life. Unfortunately there is little evidence from the existing literature in support of this finding because of the absence of closely related research. However, studies of sexual function suggest similar findings within their subject of reference (Aass et al, 1993; Tinkler et al, 1992), in that participants noted changes in their levels of sexual satisfaction following the illness.

Negative implications of surviving the disease are not restricted to men's perceptions about their physical being, rather factors were also highlighted that indicate changes in perception regarding quality of life issues. The qualitative interviews pointed to a potential increase in pessimism about the future following the illness. It may be that this pessimism originates from different sources in different men, dependent on their circumstances. It appeared that the group of men who had children (or grandchildren) were reporting increased pessimism about the likelihood of seeing these loved ones grow up, because of concerns about reduced life span should the disease recur. In contrast, younger participants appeared to have a different set of concerns; such as anxieties about the potential to successfully conceive children, or worries about the financial viability of their future if they were not yet established in their own homes. Whilst these worries are varied in nature the validity of the concerns remains, and it is easy to see how they might lead to an increased pessimism about the future. Whilst the general literature on cancer is replete with evidence surrounding uncertainty about the future, this aspect is not well documented in testicular cancer literature where the prognosis is generally very good.

But what of the men who reported no changes in their self-perceptions as a consequence of the illness? Here, a number of possible explanations exist. Firstly there is a potential that this group of men possess a different set of skills, strategies, or support networks that facilitate better coping with the illness, resulting in no changes to self-perceptions following the illness. Secondly, these individuals may have had markedly different personality types prior to the illness, which would set them apart from the group of men who felt differently about themselves following the illness. Alternatively, there is also a chance that this group of men were avoiding acknowledging changes that in reality were experienced.

It is impossible to identify from this research which hypothesis provides the most viable explanation. Evidence from the literature suggests that men have difficulties talking about emotionally provocative issues (Good, Dell & Mintz, 1989), which applies to patients and doctors in the case of discussing issues of sexuality in testicular cancer (Caffo & Amichetti, 1999). Indeed, previous evidence suggests men have been found to deny the impact of testicular cancer (Moynihan, 1987; 1998), as well as refusing to acknowledge illness, pain and suffering more generally (Courtenay, 1998). This avoidance of problem disclosure has been noted as one of the factors involved in delays in seeking medical advice about the symptoms men have detected (Gascoigne, Mason & Roberts, 1999), which was the case in a number of the participants of this study, although this factor was not explicitly investigated. Indeed, an unwillingness to acknowledge difficulties is noted as a particular feature of masculinity, which has been perceived as a relative weakness in males (Courtenay, 1998; Farrell, 1974; Sabo & Gordon, 1995). Certainly it is a less than helpful strategy. This theory can also be supported to some extent by evidence from the current study. This stems from descriptions provided by participants in the qualitative interviews. A number of participants described strategies used to minimise the presentation of the true extent of their distress, the primary one being the use of humour. This too is noted in the literature (Chapple & Ziebland, 2004). Men joking with their friends about the impact of the illness resulting in them being "only half the man they used to be" could be taken as a means of avoiding the gravity of their feelings. Furthermore, men were seen to reassure themselves of the acceptability of their position by making comparisons between themselves and other people whom they perceived to be in a worse situation. Such comparisons included the relatively poorer situation of a single man with testicular cancer, because of the need to find a partner after the removal of a testicle, and women with breast cancer who were required to have a mastectomy, which was perceived by a number of men to be worse than the loss of a testicle. This finding is supported by evidence from Taylor & Lobel (1989), who suggested that people suffering adversity during times of serious illness tend to create positive illusions by making 'downward evaluations' and 'upward contacts'. In other words by comparing their situation to people both better and worse off than themselves, individuals are better able to cope with serious illness via an increase their motivation and hope. So it seems there is a potential that men who stated they had not noticed any changes as a consequence of the illness, may have been avoiding disclosure of what they felt to be embarrassing and sensitive problems. Furthermore, there is also a risk that the men who did report changes were underreporting the extent of them, but this cannot be determined from the data collected in this study. Perhaps this risk was heightened by the gender difference between participants and researcher? It seems important to consider the relevance of the researcher's gender in this instance, given that the interviews in particular required some level of disclosure about intimate aspects of sexual experience. Potentially the presence of a female researcher may have limited the number of participants willing to take part in the study, as some groups of men may have felt uncomfortable discussing these issues with a young female. For instance, younger patients may have felt embarrassment in discussing such concerns, and members of the Asian community may hold specific cultural beliefs about discussing these issues generally, but also more specifically with a female. In any case, the evidence would seem to suggest that male medical professionals and male patients alike need some assistance to feel open to discuss sensitive issues such as sexuality.

Despite reports in the literature that men don't talk about their experiences, generally once they had agreed to participate and were aware of expectations of the research, the participants were happy to express their feelings in a relatively easy manner. On occasion their readiness to disclose intimate details was somewhat surprising. However, the accuracy and extent of these disclosures cannot be determined. Where men chose not to participate in the research, it is possible that discomfort in discussing these issues was a factor in the decision. Nonetheless, the extent to which these discussions were largely comfortable and open would not have been envisaged from the picture portrayed in feminist literature, which suggests that there should be no gender difference between participants and researcher to prevent discomfort in disclosing (Gurney, 1985).

Patterns were observed in these changes over the four different time phases that were suggestive of a process of adjustment over time. The Euclidean distances highlighted a reduction in distance between certain key elements and the element 'me before the illness' at each time stage. Whilst the participant's perception of themselves before the illness may not remain stable over time, this is less pertinent in the case of the current study, as the distance between the two perceptions are of primary interest, and these show consistent decline over time. This would tend to indicate that with the addition of time men's perception of themselves returns to be aligned with their perception of themselves pre-illness. Evidence in support of this adjustment process comes from

Aass et al (1993), who found that sexual dissatisfaction is high in this group of men at six months post-illness which gradually decreases over the three years following the illness. Hence, it seems that men change their self-perceptions as a result of the illness, but that these perceptions gradually return to being similar to how they were before the illness, thus indicating that men are more vulnerable to these changes at the initial stages of the illness and shortly afterwards. Consequently the support received in the initial months may be crucial in the man's emotional recovery from the illness, as well as his physical recovery.

Clinical Implications

The implications of this study are most significant for the professionals in contact with men during the initial recovery period and for the first 12 months after the illness. It is possible that men would benefit from additional support during this phase of their recovery. The exact nature of this support could take many forms, however suggestions from the participants in the current study include:

- A support group for men with testicular cancer, which may be facilitated in part by men who have recovered from the illness.
- A formalised opportunity to meet other men who had been through the experience, either within or outside the clinic.
- A scheduled session with a professional in the early stages of illness with a specific view to discussing emotional adjustment.
- Broader promotion of the availability of specialist professionals such as psychologists or counsellors to enable the patient to seek out appropriate assistance.

These ideas for new service provision could be provided in keeping with recommendations made in the National Institute for Clinical Excellence (2004) guidelines for supportive and palliative care.

The Utility of Repertory Grid Technique in the Examination of Self-Perceptions Following Testicular Cancer.

The majority of participants in the current study evaluated repertory grid technique as a useful means of summarising self-perceptions following the illness experience. Overall 64% found the grid exercise to be relevant to their experience of testicular cancer, 89% felt that the elements and constructs were relevant to their experience and made sense to them personally, and 86% felt that the completed grid successfully represented the changes that had occurred (or not occurred) in an accurate manner. In the case of the significant minority who did not relate to this method of data collection, the reasons stated often surrounded the allocation of numerical ratings to their feelings about the experience. It seems that a small group of men would have preferred to use a conversation as a means of conveying their feelings. Difficulty in relating to the grid task may originate from a number of factors, one of which may be the use of generic constructs in the grid. The potential exists that the limited sample in part 1 of the study resulted in constructs that were not representative of those from the testicular cancer population as a whole.

However, generally speaking from the participants' point of view repertory grid technique provides an acceptable, appropriate means of evaluating their perceptions about their lives following the illness. Indeed, the results of the current study seem to indicate that men's perceptions surrounding the illness experience were in keeping with theory from Kelly (1955), in that the participants were acting as scientists within their own environment by constructing a story around their illness in order to incorporate any changes into their construction of the world. The comparisons participants made with the experiences of other people might be taken as an example of this, in that they are making observations from their environment and integrating them into a logical explanation of their current situation, along the lines of the commonality and sociality corollaries highlighted by Kelly (1955). Perhaps this link provides an explanation regarding why participants related well to this method for data collection?

From a data collection perspective repertory grid technique provided a quick, concise and idiographic method of evaluating participants' perceptions, although analysis of the data is complex. Whilst it is evident from past research that this method is useful in looking at individual case studies, the current study highlights that the method can be useful when investigating cohort groups too. Furthermore, repertory grid technique would be especially useful as a tool if it were possible to do a longitudinal study of this kind. The benefit of this technique for data collection is the flexibility of constructs and elements, which could be adapted to an individual in less structured circumstances than were required by the current study.

Limitations of the Study

The current study was an innovative and exploratory investigation. Every attempt was made to carefully develop and design the study in a transparent manner, being cautious in choosing methods that were useful and valid in the absence of pre-existing measures. However, it is inevitable that some limitations become apparent. Limitations arise from four key areas in the current study, namely the study design, the sample, the chosen method, and analysis. Each of these areas of limitation will be discussed in turn.

Study Design

The cross sectional design of the study presents as one of the major limitations of this research. The aim of the research was to examine whether there are changes in self-perceptions of men with testicular cancer across time after the illness. Whilst it was possible to draw some inferences about this using the cross sectional design of the current research, a longitudinal design would have been preferable.

As it is, the cross sectional design is likely to have limited the extent to which changes can be attributed to time phases convincingly. With the current design it is possible to make tentative suggestions that there are changes over time, by making comparisons between the groups, but it is not possible to state with certainty that these changes do not originate from other, unrelated differences in the groups. On the other hand, there is no apparent reason to believe that cohort effects are present in the current study. Especially since the level of consistency in the patterns observed across the groups suggests that this is unlikely. Nonetheless a longitudinal design would allow direct comparisons of the same individuals at different time stages, thus allowing for more firm conclusions to be drawn from the results. However, with the time constraints of the current study a longitudinal design would not have been possible.

Sample

The research attempted to recruit a representative sample of participants by sourcing and recruiting from a regional clinic. However, as a consequence of administrative complications in identifying appropriate participants during the initial stages of the project, it is not possible to be sure that all appropriate participants were approached. Consequently the people approached in clinic may not have been representative of the clinic's overall population. Furthermore the convenience sampling method used to recruit participants in this research may also have limited the representational aspect of the sample. At first glance it would seem that the sample age range was not representative of the testicular cancer population, given the typical range quoted in the literature. However, National Statistics Cancer Registrations from 2002 indicate that the sample in the current study is actually an accurate picture for this patient population, showing ages typically spanning between 15 and 65 years. Unfortunately, diversity in ethnic background was almost certainly underrepresented in the final sample.

Difficulties in recruiting participants for the later groups resulted in an uneven number of participants in each group and a broader range of spread around the time-phases than was originally intended, which may have impacted on the patterns observed in the results. However, as Euclidean distances are calculated on mean space between the items in question this is less likely to be an issue.

Chosen Method

Repertory grid technique was utilised for data collection in this study because of the idiographic nature of its rating system, and also as a consequence of the absence of any structured measures that would fit with the purpose of the study. Whilst this technique has been utilised in other studies wanting to observe changes in individual's perceptions over time, these have often been either individual case studies, or small case series (Latchford & Madill, 2005; Smith, 1999). Whereas the current study set out to compare larger groups of men in similar situations, in the hope of being able to make some more general statements about the self-perceptions of this population. Hence the current method was innovative in its use on this occasion. As a consequence, there are few if any other studies that provide a comparison with this one, resulting in limited evidence to support the findings of this work.

The decision was made to use a generic repertory grid for data collection in this instance; derived from interviews with men from this population and the present literature base. Consequently the resulting grid was not truly idiographic in the sense intended by Kelly (1955). The rationale for this was to facilitate comparisons between the four groups more readily. Whilst this was probably achieved by the use of the grid, some of the idiosyncrasies of participants may have been lost in channelling the participants' perceptions in this way. However, the combined use of interviews and a generic grid can be seen as a positive compromise to obtain the most in-depth data for comparison. Additionally there is a possibility that a sub-section of the participants did not find it easy to relate to the constructs and elements included in the grid, and would have found the grid more applicable if they had produced their own constructs and elements individually.

The chosen method is also limited in that it does not allow links to be made between individual differences and the changes that occurred, as no other data besides basic demographics were collected on the participating men. Extra data was intentionally not collected, as a result of the time demands and thought required for participants to complete the grid. However, as a consequence it is not possible to determine from the current data whether the changes observed in this study relate to other factors such as psychological well being, for example symptoms of anxiety or depression present at the time of grid completion.

Analysis

As mentioned previously, there are few up-to-date statistical programmes that will readily interpret large groups of grid data in the manner attempted in this study. The aim here was to take into account the four different groups of men as separate entities and sequentially account for any changes over time. However, this type of analysis is somewhat complex, and the output requires a considerable amount of subjective interpretation, as with all qualitative research. The limitation of this is that the researcher may be biased in their interpretation of the narrative given by the participants, and in this case the plots generated by the multi-dimensional unfolding analysis. In order to minimise the impact of bias in the current study attempts have been made to be transparent throughout. Furthermore, the grid was validated by respondents in order to ensure accurate representation of the participants' perceptions.

Additional analyses were attempted in order to support the interpretations of these data plots. The element 'me before the illness' was used as a point of reference in the majority of these comparisons. However, the act of requesting participants to rate themselves before the illness involves making a retrospective judgement about their qualities at least 6 months previously. Clearly such retrospective judgements are open to limitations caused by the intrusion of inaccuracies in the participant's perceptions.

Future Directions for Research

This study adds to the body of research in connection with the psychological implications of testicular cancer, and in doing so has highlighted further areas of research requiring attention.

Because little research has currently been carried out in this field, what is known about the psychological after-effects of testicular cancer is limited. Consequently the contribution of the current preliminary study, whilst small, is important. Factors such as the increasing prevalence and cure rates for the disease and the early age of onset clearly demonstrate the importance of expanding on the findings of the current study. The following are some suggestions for necessary research.

Combined Qualitative and Quantitative Research

This particular study attempted to utilise both qualitative and quantitative approaches, and in so doing revealed the importance of each of these methods individually and in combination. Whilst quantitative data can provide numeric tendencies for larger samples, qualitative data allows for the depth of information to be explored fully, which is critical when a research area is in its early stages of development. In the current research the qualitative interviews provided a wealth of information offering significant insights into how different men felt during and after the experience of testicular cancer. Because the primary aim of the interviews was to elicit constructs for use in the grid, on occasions it was not possible to explore these issues in as much detail as the researcher might have liked. Future studies could extend the qualitative dimension of the current study, and the study carried out by Brodsky (1995), by using longer interviews with the primary purpose of finding out about issues of masculinity, sexuality and body image in detail. Such research would benefit from the use of a detailed structured analysis using other qualitative methods such as discourse analysis or grounded theory.

Thus far, many of the attempts at quantitative research in this area have been unable to target the issues under examination in the current study, for example the studies by Blackmoore (1988), Rieker et al (1989) and Douchez et al, (1993), which attempted to examine sexuality in men with testicular cancer by utilising a questionnaire about sexual functioning, rather than sexuality. The result was a valuable increase in knowledge about sexual dysfunction following testicular cancer, but not information regarding the concept of sexuality as defined by the current research in chapter 1.

Development of a Monitoring Tool

In order to improve upon the quantitative research already completed in connection with sexuality, it would be helpful to design a measure specifically relevant to men with testicular cancer, which targets the concepts of interest in this research. Future research could work on the development of such a tool, which could subsequently be piloted and standardised for use with men in research, or as a clinical monitoring tool to highlight when men are experiencing difficulties with regards to their self-perception. Potentially, it may be useful to simplify the grid used in the current study for this purpose. Repertory grid technique has been utilised for a number of years in The Self Image Profiles (SIP) (Butler, 2001) for assessing self-image in children and adults in different circumstances, but perhaps this technique could also be utilised in the assessment of self-perceptions throughout serious illnesses such as testicular cancer?

Longitudinal Research

Bearing the above suggestions in mind, the research in this field would benefit from a longitudinal approach. This would facilitate a reduced subjectivity in information about the progress men make over time, and would allow for more accurate comparisons to be made between different time stages. This method proved useful in the study by Aass et al (1993), however again this study focused more on sexual dysfunction. A longitudinal design would be likely to improve the quality of material obtained in both qualitative and quantitative research, especially if future studies were able to utilise a specially designed quantitative measure, or indeed repeated the use of the current repertory grid.

Specific Factors Involved in Coping

The findings in the current study highlighted a difference in the way some men cope with the experience of testicular cancer. However, the study did not attempt to determine what these factors might be. Ideally future research might investigate these factors in more detail in an attempt to identify risk factors for poor coping, which could facilitate decisions about the provision of additional support.

The Influence of Professional Support for Men with Testicular Cancer

One of the factors highlighted by the men involved in this research was a lack of support from professionals, regarding the emotional dimension of the illness. Whilst many noted that support from family was provided, and was a crucial part in their recovery, some felt that this was not sufficient. In these cases the men felt they would have benefited from some input from professionals or perhaps support from other men who had been through the experience. Patient satisfaction with their care is a crucial consideration in current NHS policy, and one that is important to examine further. Men with testicular cancer appeared extremely satisfied with their medical care, from anecdotes in the current study, however their emotional management may be less satisfactory. Perhaps certain stages in the treatment and recovery process are significant in requiring additional support, for example the periods of waiting between diagnosis and treatment. Understanding men's needs through additional research could serve to improve patient satisfaction in their emotional care. However, any new supportive strategies would require careful planning, implementation and evaluation, which will now be discussed.

Piloting of Support Methods

Taking the above suggestion into account, if a shortfall in support mechanisms for men with testicular cancer were discovered, it would be important to trial the use of a variety of supportive approaches. The discussion highlighted a list of suggestions made by men in the current research. Future research could focus on consultation with this group of men around the provision of such support to expand on these ideas. Any decisions to implement new interventions would require careful planning, outcome evaluation and clinical trials where possible, which could also be an important focus for future research in this area.

Conclusion

Men's health is becoming an increasingly common focus for research, yet relatively speaking there is still far less research about men's health than that of women, especially where psychological well-being is concerned. The increasing prevalence of illnesses such as testicular cancer is concerning, and the early age at onset led to a hypothesis that men may suffer a depletion in their self-concept as a result of the illness. Consequently this research aimed to discover whether this was the case, and if so whether changes in sexuality, masculinity and body image play a role in the perceived changes.

The study found that differences in self-perceptions exist between men at different stages post-illness. Men appear to fall into one of three categories as to whether they have experienced any changes: those who are able to see and acknowledge that the changes exist, those who deny the presence of changes initially, but later note changes in some areas, and finally those who consistently report that no changes in their perception of themselves have occurred as a result of the illness. Changes in perceived masculinity, sexuality and body image are an issue for some men, but not all. Where these changes are present they can raise considerable concerns for the individual in question. All constructs in the current study appeared to contribute to the differences in patterns of self-perception observed between the four groups. Questions were raised about the level of emotional support offered to men experiencing this disease, and whether more could be done with regards to service provision at certain key stages of the illness experience. Men also may experience difficulty in disclosing their level of distress around the experience of testicular cancer and subsequent treatment with orchidectomy, which highlights areas for future research.

In this instance repertory grid technique was found to be a useful and viable measure of men's self-perceptions. Use of this method in a longitudinal study may reveal differences between the four time stages that could be interpreted with more confidence. However, the development of a specific monitoring measure would also be advantageous to further research in this field.

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APPENDIX 1

Ethical Approval Letters

NHS

Miss Anita Wraith
Clinical Psychology Training Programmes
15 Hyde Terrace
Leeds
LS2 9JT

Leeds (East) Research Ethics Committee
Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street
Leeds
LS9 7TF

Enquiries to Ann Prothero
Ethics Secretary
Direct Line 0113 (20) 65652
Email: a.d.prothero@leeds.ac.uk

Dear Miss Wraith,

01 July 2004

Full title of study: A Research Project to Investigate the Psychological Effects of Surviving Testicular Cancer: Impact on Body Image, Sexuality and Masculinity.
REC reference number: 04/Q1206/2

Thank you for your letter of 23 June 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chairman

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site: Leeds Teaching Hospitals NHS Trust
Principal Investigator: Miss Anita Wraith

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Application dated 13/03/2004
Investigator CV dated 01/03/2004
Protocol dated 01/03/2004
Covering Letterdated 12/03/2004
Summary/Synopsis dated 01/03/2004

An advisory committee to West Yorkshire Strategic Health Authority

Letter from Sponsor dated 10/03/2004
Peer Review dated 17/02/2004
Statistician Comments dated 17/02/2004
Compensation Arrangements dated 02/02/2004
Interview Schedules/Topic Guides version 1 dated 01/03/2004
Copy of Questionnaire, repertory grid example version 1dated 01/03/2004
Letters of Invitation to Participants dated 18/03/2004
Participant Information Sheet version 2 dated 23/06/2004
Participant Consent Form version 1dated 01/03/2004
Response to Request for Further Information dated 23/06/2004
Supervisor's CV dated 01/02/2004

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

We shall notify the research sponsor, and the Leeds Teaching Hospitals NHS Trust that the study has a favourable ethical opinion.

Statement of compliance *(from 1 May 2004)*

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q1206/2 **Please quote this number on all correspondence**

Yours sincerely,

Ann Prothero

Co **Dr P R F Dear**
Chairman

Cc: Research and Development Department, LTHT

Enclosure Standard approval conditions SL-AC2

NHS

Miss Anita Wraith
Psychologist in Clinical Training
Clinical Psychology Training Programmes
15 Hyde Terrace
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Beckett Street
Leeds
LS9 7TF

Enquiries to Ann Prothero
Ethics Secretary
Direct Line 0113 (20) 65652
Email:a.d.prothero@leeds.ac.uk

23 April 2004

Dear Miss Wraith,

Full title of study: A Research Project to Investigate the Psychological Effects of Surviving Testicular Cancer: Impact on Body Image, Sexuality and Masculinity.
REC reference number: 04/Q1206/2

The Research Ethics Committee reviewed the above application at the meeting held on 06 April 2004.

Documents reviewed

The documents reviewed at the meeting were:

Application dated 13/03/2004
Investigator CV dated 01/03/2004
Protocol dated 01/03/2004
Flow chart dated 01/03/2004
Letter from Sponsor dated: 10/03/2004
Peer Review dated 17/02/2004
Statistician Comments dated 17/02/2004
Compensation Arrangements dated 02/02/2004
Interview Schedules/Topic Guides version 1dated 01/03/2004
Repertory grid example, version 1 dated 01/03/2004
Questionnaire version 1dated: 01/03/2004
Letters of Invitation to Participants dated 18/03/2004
Participant Information Sheet version 1dated: 01/03/2004
Participant Consent Form version 1 dated 01/03/2004
CV for Peter G Harvey dated 01/02/2004
CV for Dr G Latchford dated 16/03/2004
CV for Dr B Gough dated 16/03/2004
CV for Dr J D Chester dated 16/03/2004

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information below.

NHS

Miss Anita Wraith
Psychologist in Clinical Training
Clinical Psychology Training Programmes
15 Hyde Terrace
Leeds
LS2 9JT

Leeds (East) Research Ethics Committee
Room 5.2, Clinical Sciences Building
St James's University Hospital
Beckett Street
Leeds
LS9 7TF

Enquiries to Ann Prothero
Ethics Secretary
Direct Line 0113 (20) 65652
Email:a.d.prothero@leeds.ac.uk

23 April 2004

Dear Miss Wraith,

Full title of study: A Research Project to Investigate the Psychological Effects of Surviving Testicular Cancer: Impact on Body Image, Sexuality and Masculinity.
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CV for Dr G Latchford dated 16/03/2004
CV for Dr B Gough dated 16/03/2004
CV for Dr J D Chester dated 16/03/2004

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chairman

Further information or clarification required

1 Can you provide us with further information on the plan to deal with any issues of risk or distress arising during the interviews with participants?

2 How will patients be selected and invited to take part in the validation group interviews/presentation? Will posters or letters of invitation be used and will a patient information sheet be prepared?

3 Headed paper should be used for the patient information sheet.

4 Pages 2 and 3 of the information sheet have a different date . to page 1.

When submitting a response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates. Failure to do this will delay consideration of the revisions.

The Committee will issue a final ethical opinion on the application within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points.

The Committee expects to receive a response from you by no later than 21 August 2004, otherwise we shall consider the application to have been withdrawn.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Communication with sponsor and host organisations

This communication is confidential but you may wish to you to forward copies to your sponsor and/or host organisation(s) for their information.

REC reference number: 04/Q1206/2 Please quote this number on all correspondence

Yours sincerely,

Ann Prothero

Co **Dr P R F Dear**
Chairman

APPENDIX 2

Information Sheet

The Psychological Effects of Surviving Testicular Cancer: A Research Project

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

The aim of this project is to find out if men who have been treated for testicular cancer experience any changes in the way they feel about themselves, and to investigate what form these changes take. The research will take place over the course of 12 months, although each participant will need to be interviewed on only one occasion. The results of the study will contribute to a thesis for a qualification in Clinical Psychology.

2. Why have I been chosen?

The project hopes to find male participants who have recently undergone treatment for testicular cancer at St James's University Hospital in Leeds. This includes those who have had surgery, and either chemotherapy or radiotherapy, as their treatment. The research is only intending to look at men who have completely finished their course of treatment. The plan is to look at four different groups of men, each at different stages after their treatment (6,12,18, and 24 months after the treatment has ended), and compare the feelings of each group. Over the course of the project it is hoped that a total of 60 men will participate in the study. Everyone who is at approximately the right stage to take part in the study will be invited to participate.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, of which you will also be given copy to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

4. What will happen to me if I take part?

The project will require participants to have one interview with the researcher, to fill in a form relating to their feelings about themselves. Each interview will last between 30 and 60 minutes, and will take place, at a time location that is mutually convenient to you and the researcher. The interviews will be audio taped to allow the researcher to type transcripts of the discussion, but these tapes will be destroyed as soon as the research is complete.

The interviews will take place with one, female researcher in the room. Unfortunately, it will not be possible to offer the option of a male researcher as an alternative. If this is a concern, please feel free to mention it to the researcher or doctor at your clinic appointment. You will not be pressured to participate if this remains a concern.

In the interview, the researcher will ask you to discuss how you feel about yourself in relation to certain roles in your everyday life. Together, the researcher and yourself will complete a form to summarise your opinions. When a number of these have been completed, the results for each group will be compared, to see if there are any differences between the men at different stages after their treatment.

5. What are the possible disadvantages and risks of taking part?

There is a small chance that some participants may find it distressing to talk about their experiences of their illness. If you find that you become distressed after the interview with the researcher, you could contact one of the following for support:

Firstly, you might find it helpful to approach your General Practitioner to discuss your feelings.

Alternatively, you could contact *Peter Harvey*, a Clinical Psychologist from the *Department of Clinical and Health Psychology* at St James's. His contact number is 0113 2065897, and he would be happy to arrange to see you to discuss any concerns.

6. What are the possible benefits of taking part?

It is not likely that there will be any clinical benefit for you as an individual from participation in this study. However, we hope that the information we get from this study may help us to provide more effective support for future patients with testicular cancer.

7. What if something goes wrong?

In the unlikely event that you are harmed by taking part in this research project, there is no special compensation arrangement. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms may be available to you.

8. Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

9. What will happen to the results of the research study?

Once the results of the study have been analysed they will be written up in the form of a doctoral thesis, to contribute to the researcher's qualification in Clinical Psychology. At a later date there is a chance that the study will be submitted for publication, however at this time it is not known when or where the results are likely to be published. It is intended that a brief summary of the findings of the research will be posted directly to all participants once the project has ended. Participants will not be identified in any of these documents, at any time.

10. Who is organising and funding the research?

The research is being organised solely by the researcher and her research supervisors. The project is not being funded by any outside agency, and the researcher is not being paid to carry out this research.

11. Contact for Further Information

If you require any further information about this study you should contact: ***Anita Wraith***, Psychologist in Clinical Training, at **Clinical Psychology Training Programmes, 15 Hyde Terrace, Leeds, LS2 9JT**

Consumers for Ethics in Research (CERES) publish a leaflet entitled "Medical Research and You". This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from the researcher inviting you to take part.

APPENDIX 3

Invitation Letter

Date____________________

Name
Address
Address
Address
Address

Dear ____________________

An Invitation to Participate in a Testicular Cancer Research Project

We are writing to invite you to participate in a research project that is taking place through the testicular cancer clinic at St James's University Hospital.

The project is aiming to find out if the experience of this illness has any effect on the feelings of the men who have survived, following completion of their treatment. Please find enclosed an information sheet giving full details of the study, and what would be required if you choose to participate. It should be noted that you are under no obligation to take part in this project, and your medical support will not be affected by your decision.

We will be present in the clinic at your next appointment, and will be available if you wish to ask questions or get some more information. If you choose to take part you will be asked to sign a consent form and undertake an interview, in clinic at the end of your next appointment.

We look forward to seeing you.

Yours sincerely

John Chester
Consultant in Medical Oncology

Anita Wraith
Psychologist in Clinical Training
Chief Investigator.

APPENDIX 4

Invitation Letter (Postal Recruitment)

Date____________________

Name
Address
Address
Address
Address

Dear ____________________

An Invitation to Participate in a Testicular Cancer Research Project

We are writing to invite you to participate in a research project that is taking place through the testicular cancer clinic at St James's University Hospital.

The project is aiming to find out if the experience of this illness has any effect on the feelings of the men who have survived, following completion of their treatment. Please find enclosed an information sheet giving full details of the study, and what would be required if you choose to participate. It should be noted that you are under no obligation to take part in this project, and your medical support will not be affected by your decision.

We would like to ask you to read through the information sheet and think about whether you wish to participate. If you choose to take part you will be asked to sign a consent form and undertake an interview, at a convenient time and location of your choice. **If you wish to take up the opportunity, or would like to receive more information, please return the reply slip in the envelope provided as soon as possible, and someone will get in touch to arrange the interview.**

Your time is greatly appreciated.

Yours sincerely

John Chester
Consultant in Medical Oncology

Anita Wraith
Psychologist in Clinical Training
Chief Investigator.

APPENDIX 5

Consent Form

Patient Identification Number for this Study:

CONSENT FORM FOR RESEARCH STUDY

Title of Project: Surviving Testicular Cancer: A Research Project

Name of Researcher: Anita Wraith

Please initial to confirm

- I have read the information sheet for the above study. ☐
- I have had the opportunity to ask questions about the study, and to discuss it with family and friends. ☐
- I understand the purpose of the study, and how I will be involved. ☐
- [I understand, and accept, that if I take part in the study I will/may not gain any direct, personal benefit from it.] ☐
- [I understand that all information collected in the study will be held in confidence and that, if it is presented or published, all my personal details will be removed.] ☐
- I give permission for responsible individuals from regulatory authorities to have access to my medical notes where it is relevant to my taking part in the research. This is on the understanding that no personal details which might identify me will be presented or published without my permission. ☐
- I confirm that I will be taking part in this study of my own free will, and I understand that I may withdraw from it, at any time and for any reason, without my medical care or my legal rights being affected. ☐

I agree to take part in the above study.

Signed ____________ Date ____________

Person taking consent ____________ Date ____________

Researcher (if different from above) ____________

*1 Copy for Patient, 1 Copy for Researcher, 1 Copy for Hospital Notes

APPENDIX 6

Semi-Structured Interview Schedule

1. How do you feel about yourself following the experience of testicular cancer?

2. Have your feelings about any aspect of yourself changed? If so, in what way and why? If not, why not?

3. Looking back to how you were before the illness... How did you view yourself back then?

4. How has your vision of yourself in the future changed? Perhaps how you might see yourself in five or ten year's time?

5. Imagine yourself as you would ideally like to be (in terms of personal characteristics as well as physically and materialistically). Do you feel that this ideal image has changed at all? In what way?

6. How do you feel about yourself as a man after experiencing the illness?

7. How do you feel about yourself in the role of husband / long-term partner since the illness?

8. What are your feelings about yourself as a lover now?

9. How have your feelings about your body changed as a result of the illness or the treatment?

10. Putting yourself in the role of a father, have your feelings changed about yourself in this role following your illness?

11. Imagine a male figure that you admire... What characteristics do you find admirable in a man, and do you feel this view has changed since the illness?

12. Now think about the above question in terms of a woman that you admire.

13. Having thought about the above issues, have there been any other changes to your feelings about yourself since your illness?

14. Can you think of anything else that you feel is important for me to consider that we have not covered in this interview?

APPENDIX 7

Repertory Grid

1	Me before the illness	Me now	Me in 5 years time	My ideal self	Me as a man	Me as a husband/partner	Me as a lover	Myself as a father	A man I admire	A woman I admire	7
Self Confident											Self conscious
Caring											Selfish
Relaxed											Stressed
Active											Passive
Content											Unfulfilled
Optimistic											Pessimistic
Feeling Sexual											Lack of Sexual Feelings
Successful											Failure
Appreciating Life											Wanting More
Strong											Weak

APPENDIX 8

Repertory Grid Instructions

As you will probably have read in the information sheet you received in the post, the aim of this project is to find out whether the experience of testicular cancer affects the way men feel about themselves. The method I am using to do this is called Repertory Grid Technique. This will involve you rating your feelings about certain roles on a numeric scale and entering the numbers on this grid.

Look at the words written on the opposites sides of the grid and imagine they are on a continuum. Imagine that the words on the left define the "1" end of a 7-point scale and the words on the right define 6the "7" end of the scale.

I would like you to give each of these elements a rating 1,2,3,4 etc. depending on which end of the scale you think that the role is closest to. Rate each element along the top of the grid, taking one row at a time, moving left to right, and rating all the elements before moving on to the next row.

For example, taking the first element on the first row, if you think that before the illness you were very confident you would rate this as 1 or 2. However, if you think that you were very self-conscious before the illness you would rate it as 6 or 7, and if you think you were somewhere in the middle you might score it as 4.

APPENDIX 9

Validation Questions

1. Did you find completion of the grid exercise relevant to your experience of testicular cancer?

2. Did the constructs and elements make sense to you? Could you see how they were relevant?

3. Would you say the exercise accurately represented your experience, i.e. elicited change where there was some?

4. Can you think of anything else that should have been included, but that was missed out?

APPENDIX 10

Euclidean Distance Tables

Table 13: A table of the Euclidean distances between each element at 6-months, as analysed using MDS

	Me before	Me now	Me in 5yrs	Ideal self	Me as a man	Me as a partner	Me as a lover	Myself as a father	A man I admire	A woman I admire
Me before	.000									
Me now	15.811	.000								
Me in 5yrs	16.971	12.806	.000							
Ideal self	21.656	20.075	12.767	.000						
Me as a man	14.457	9.950	11.269	17.205	.000					
Me as partner	15.652	10.817	11.446	16.492	8.367	.000				
Me as lover	14.765	11.576	13.784	17.972	10.724	9.434	.000			
Myself as father	17.000	13.964	11.446	14.283	11.225	10.392	12.689	.000		
A man I admire	19.925	17.804	12.042	10.583	15.492	15.362	15.906	12.329	.000	
A woman I admire	20.025	17.861	12.124	10.392	15.620	15.362	16.155	11.832	4.899	.000

Table 14: A table of the Euclidean distances between each element at 12-months, as analysed using MDS

	Me before	Me now	Me in 5yrs	Ideal self	Me as a man	Me as a partner	Me as a lover	Myself as a father	A man I admire	A woman I admire
Me before	.000									
Me now	13.454	.000								
Me in 5yrs	15.427	11.269	.000							
Ideal self	21.354	17.407	11.402	.000						
Me as a man	12.728	8.660	10.296	17.493	.000					
Me as partner	16.125	14.595	13.565	16.186	13.638	.000				
Me as lover	15.937	14.387	12.490	15.362	12.490	9.055	.000			
Myself as father	18.574	17.205	12.042	12.610	15.133	12.767	11.446	.000		
A man I admire	19.391	15.264	10.392	10.583	14.422	16.793	14.967	13.601	.000	
A woman I admire	19.570	15.556	10.344	9.000	15.330	15.716	14.457	12.961	6.403	.000

Table 15: A table of the Euclidean distances between each element at 18-months, as analysed using MDS

	Me before	Me now	Me in 5yrs	Ideal self	Me as a man	Me as a partner	Me as a lover	Myself as a father	A man I admire	A woman I admire
Me before	.000									
Me now	12.845	.000								
Me in 5yrs	13.928	11.790	.000							
Ideal self	18.028	15.875	7.000	.000						
Me as a man	11.832	9.000	10.583	14.387	.000					
Me as partner	13.675	11.832	8.544	11.576	8.426	.000				
Me as lover	13.077	10.863	8.660	11.576	8.544	7.348	.000			
Myself as father	16.733	14.595	10.677	13.304	12.410	10.536	12.042	.000		
A man I admire	16.310	13.379	8.367	8.185	11.916	10.344	10.909	10.583	.000	
A woman I admire	16.062	13.077	7.616	7.550	11.489	9.644	10.247	11.314	4.243	.000

Table 16: A table of the Euclidean distances between each element at 24-months, as analysed by MDS

	Me before	Me now	Me in 5yrs	Ideal self	Me as a man	Me as a partner	Me as a lover	Myself as a father	A man I admire	A woman I admire
Me before	.000									
Me now	10.247	.000								
Me in 5yrs	7.280	9.165	.000							
Ideal self	12.207	16.186	9.274	.000						
Me as a man	8.485	7.937	6.245	11.958	.000					
Me as partner	10.909	10.583	8.124	11.402	6.403	.000				
Me as lover	13.892	11.832	12.000	15.748	10.050	8.246	.000			
Myself as father	9.644	11.662	9.899	13.266	8.185	8.485	11.045	.000		
A man I admire	10.344	14.142	8.944	9.274	11.619	11.489	15.620	12.961	.000	
A woman I admire	9.487	13.820	8.426	8.660	11.045	10.630	14.866	11.874	4.359	.000

APPENDIX 11

Combination Plots

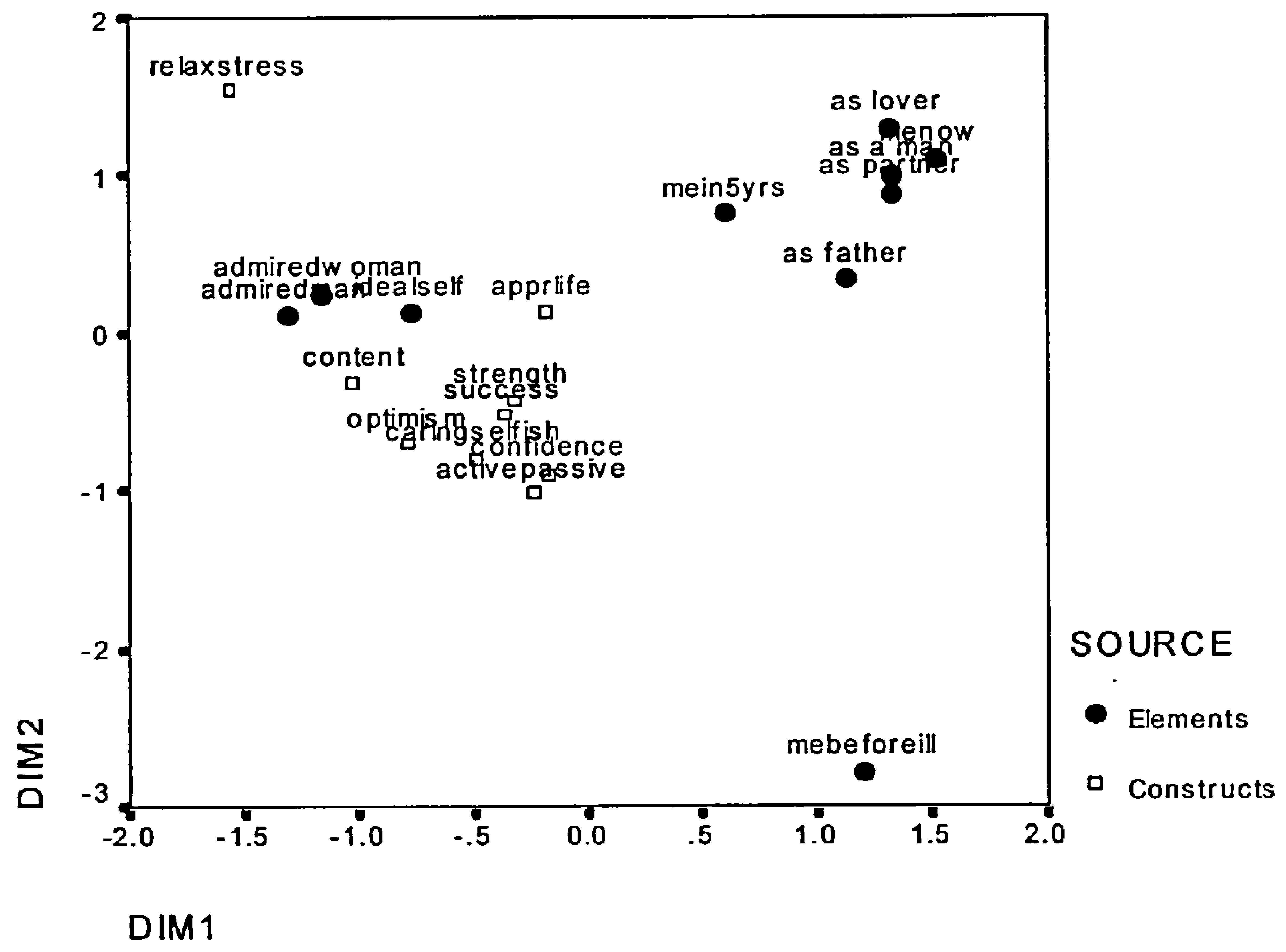

Figure 10: Two-dimensional plot for elements and constructs combined (6-month group)

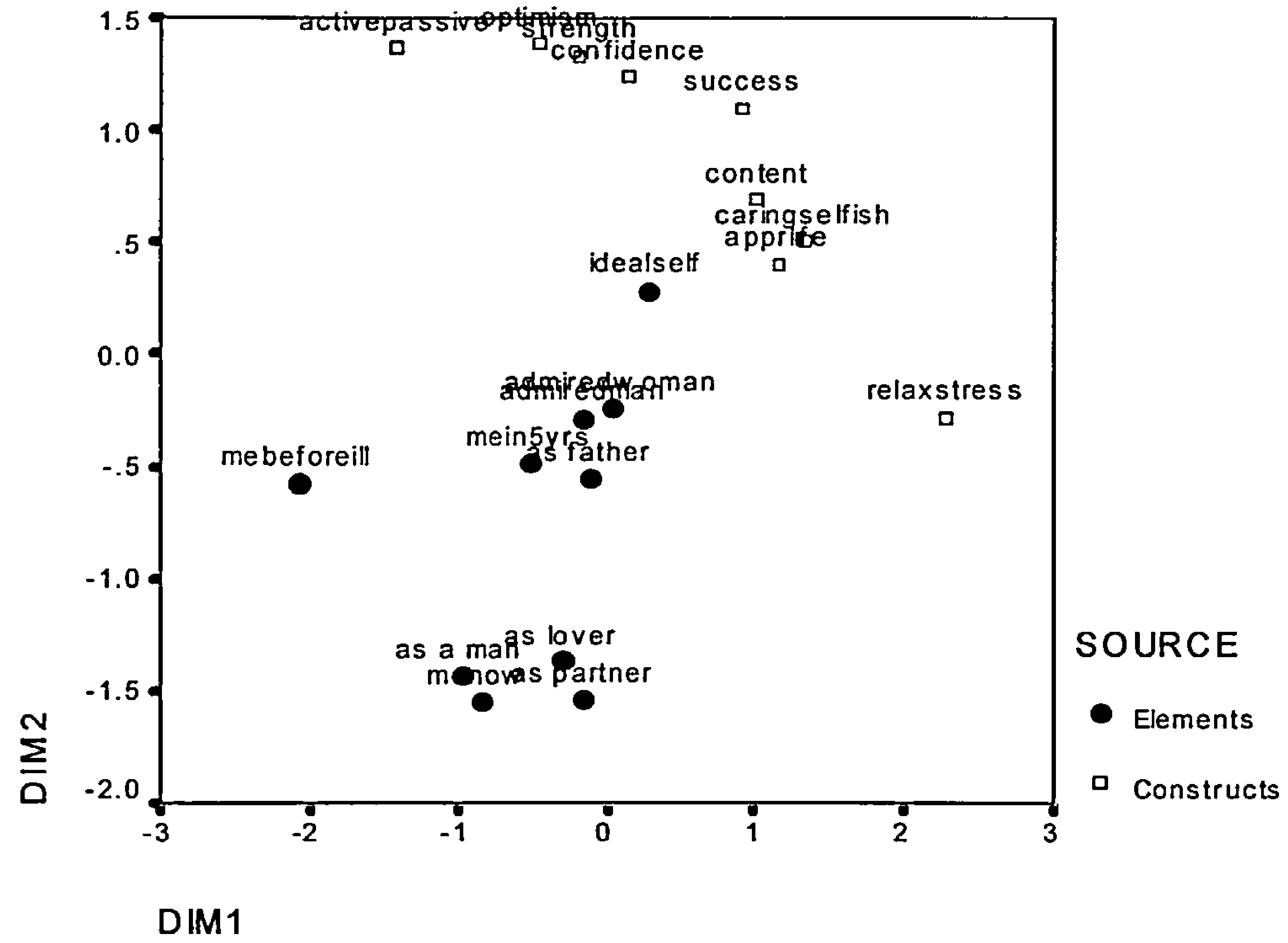

Figure 11: Two-dimensional plot for elements and constructs combined (12-month group)

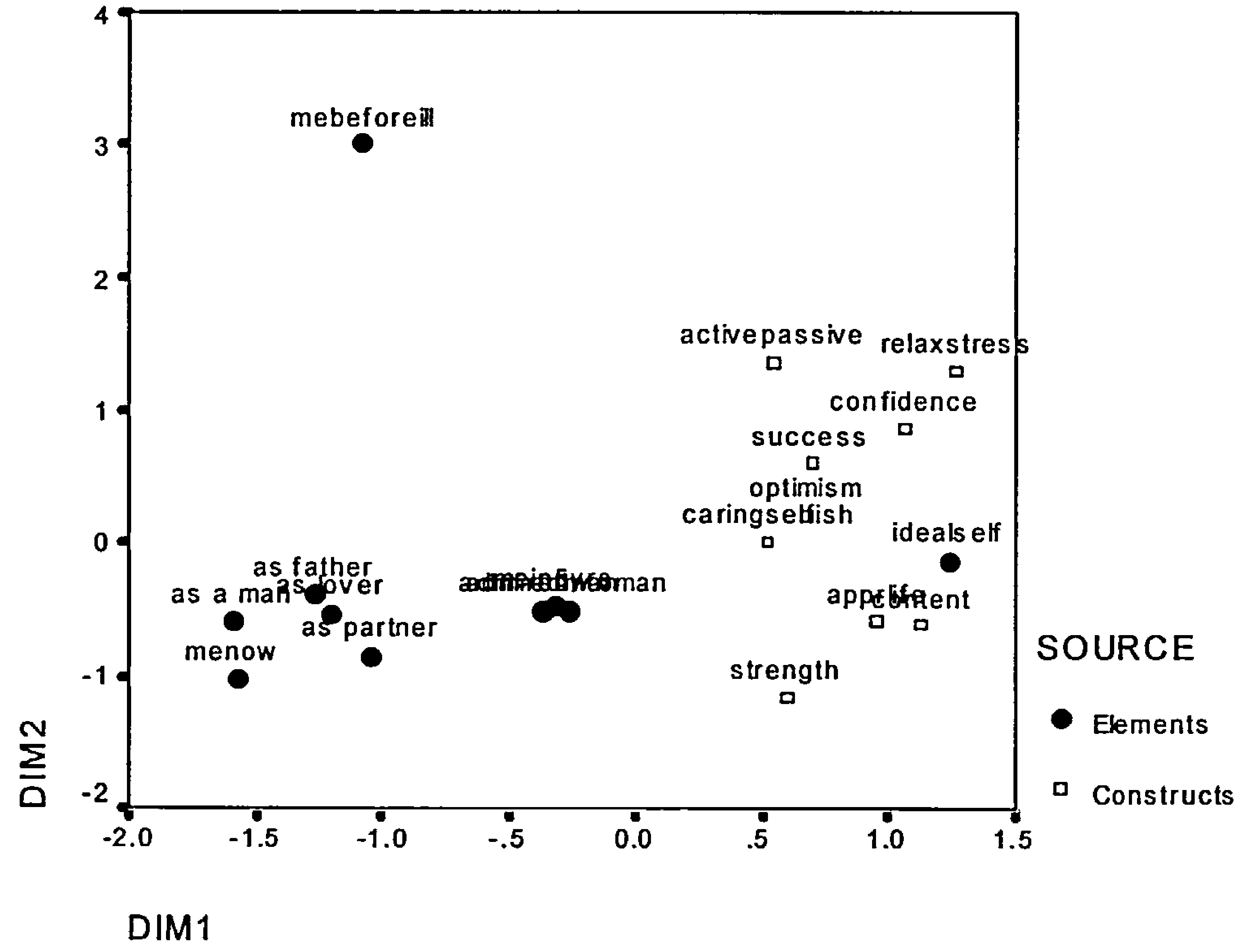

Figure 12: Two-dimensional plot for elements and constructs combined (18-month group)

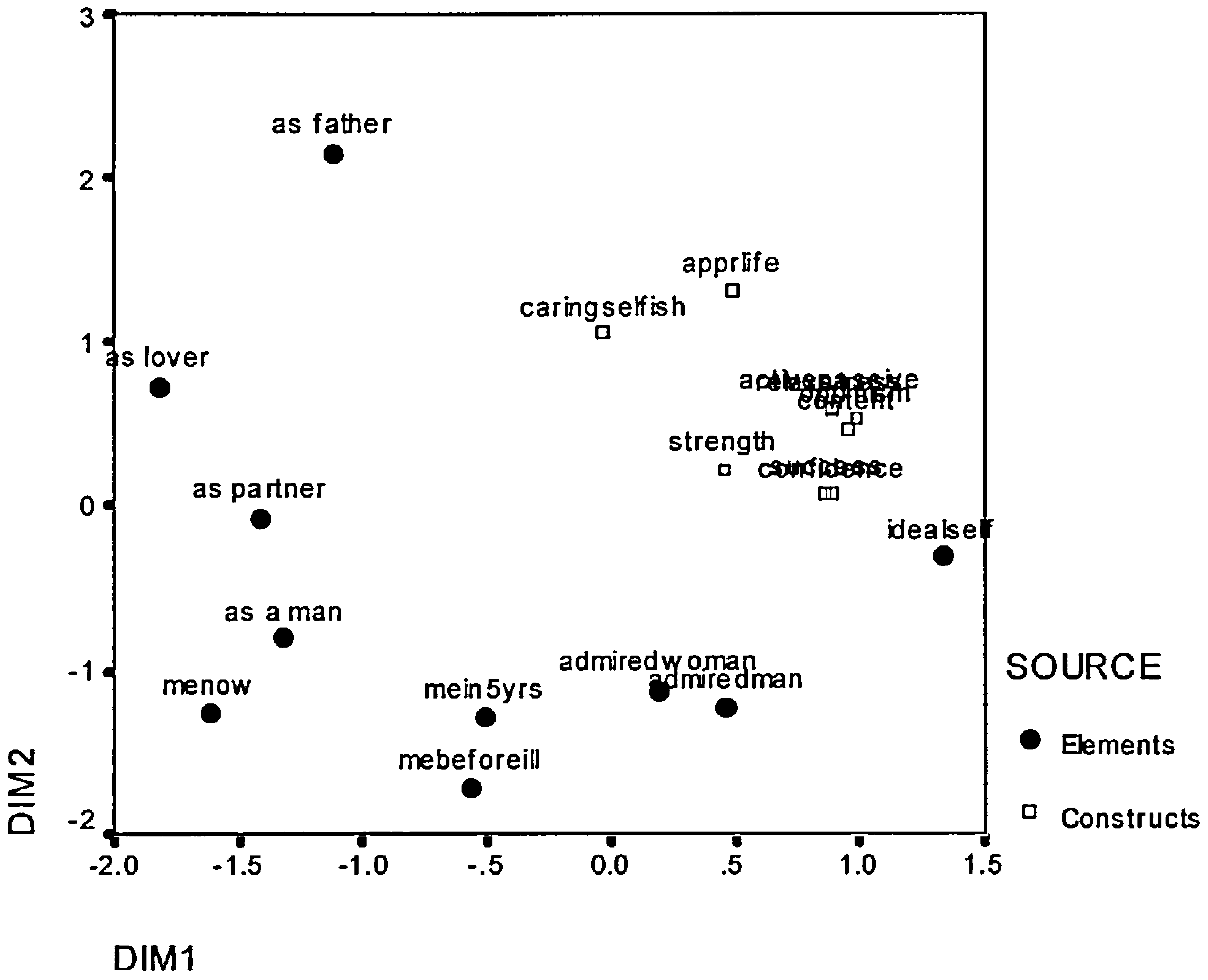

Figure 13: Two-dimensional plot for elements and constructs combined (24-month group)