GENDER DIFFERENCES IN ATTITUDES TO PRENATAL TESTING

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

ABSTRACT

Prenatal testing offers women the potential for more control over the birth of a disabled child by providing relevant information about the genetic and health status of the foetus during pregnancy. One of the factors that influences women's decision to terminate a pregnancy is her role of caring for children. Although there has been a change in men's role within the family in recent years, men generally are less involved in child-care in the home than women. Therefore, men are less likely to consider the possible burden of care a child with disability may place on the carer, and less likely to choose prenatal testing and termination of pregnancy than women. The aim of this study therefore was to research men and women's attitudes to prenatal testing and termination across thirty conditions that can be detected early in pregnancy.

Thirty-six women, all of whom had recently had a baby, and 20 men who had recently become a father to a newborn baby, participated in this study. Of the 36 women and 20 men were 19 couples. The entire sample completed attitudes to prenatal testing (ATP) questionnaire and a brief demographic questionnaire.

The results of the study found, that there was no significant differences in attitudes to prenatal testing and termination of pregnancy between men (n=20) and women (n=36) across all conditions. Similarly, there were no significant differences in attitudes to prenatal testing and termination between the paired women (n=19) and men (n=19) across high-burden and low burden-conditions. There was a trend however, that men were more interested in prenatal testing and termination for low-burden conditions than were women.

There was a high level of agreement between men and women regarding which conditions were more of less severe. There was also a level of agreement within the male group and within the female group regarding which conditions were more of less severe. The results of the study are not generalisable and therefore, further research is necessary to address the methodological limitations of the present study. The clinical implications of the study is that healthcare professionals need to be mindful that men's attitudes to prenatal testing are as developed as women's. Therefore, service providers should consider men by including them in such life changing decision-making concerning prenatal testing and termination of a foetus.

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ATP questionnaire :- Attitudes to Prenatal Testing questionnaire

ATP study:- Attitudes to Prenatal Testing study

SEACP:- Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing (study)

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CHAPTER 1: INTRODUCTION

1.1 Introduction and background

Psychosocial research on prenatal testing has been dominated by work on a small numbers of disorders for which prenatal tests have been available for some time. Most work has been done on testing for Down's syndrome, which is a chromosomal rather than a genetic disorder, and work has also been done on prenatal screening for neural tube defects, such as, spina bifida. Recent advances in DNA technology mean that prenatal tests are available for a number of disorders such as cystic fibrosis, which are genetic in origin, and the list of disorders for which genes have been identified is likely to increase greatly in length in the next few years. The application of tandem mass spectrometry will make it possible in the very near future to test hundreds of disorders using only one small blood sample (Hewison, 2000).

Very little is known about how people's attitudes to prenatal testing for one disorder relate to their views on testing for other disorders. A number of studies have examined generalised attitudes to genetic testing (e.g., Michie et al, 1995; Hietala et al, 1995) sometimes distinguishing prenatal testing from other kinds of programmes and sometimes comparing, at a group level attitude to testing for different disorders. Little attention has however been paid to similarities and differences in the attitudes held by individual people to testing for anomalies. Furthermore, the existence of social or ethnic differences in attitudes to prenatal testing for different disorders has not been studied and has therefore been the focus of a large-scale research project conducted by Hewison et al., (2000) titled, Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing (SEACP) of which the present study was a sub-study.

The SEACP study focuses on the views of women but acknowledges the need for the views of men to be investigated. Therefore, the present study investigates similarities and differences in the attitudes held by individual people, focusing on gender differences in attitudes to prenatal testing for different disorders. Similarities and differences will be investigated at an individual level within couples and between men and women at a group level.

It is acknowledged that attitudes are only one of the factors influencing the actual uptake of prenatal tests. Availability of prenatal tests, the practicalities, and "normal practice" in a particular hospital or clinic are also important influences, with the result that test uptake may, or may not, be related to attitudes to testing. For example it has become "normal practice" for most pregnant women to undergo screening with maternal serum alphafetoprotein and ultrasound and in some cases, if an abnormality is detected, to be referred for prenatal diagnosis (Marteau, 1991).

It is also recognised that attitudes towards prenatal testing have a complex relationship to attitudes towards termination. Some parents want test information to help them plan a life with a disabled child rather than to help them decide whether or not to terminate the pregnancy. (Rothenberg & Thompson, 1994; Schwartz-Cowan, 1994). Ideally, the nature of this relationship and the factors affecting it would need to be explored using qualitative methodology, which is one of the aims of the SEACP study, but unfortunately is beyond the scope of the present study. However, it is acknowledged that there is a need for qualitative research to explore in more depth, 'how' and 'why' men and women, individually and as couples, make their choices about prenatal testing and termination. Therefore, the present study is designed to obtain a snapshot look at gender differences in attitudes to prenatal testing rather than an in-depth analysis of the complexities mentioned above. The aims of the present study are set out below and in order to place the study in context the aims of the large-scale project are referred to also.

1.1.1 Aims of the Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing study.

The aims of the Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing (SEACP) large-scale study (Hewison, et al 2000) are three-fold. The first aim is to compare the attitudes of different social and ethnic groups to prenatal testing for a range of disorders. The second aim is to describe and compare, between disorders and between social and ethnic groups, the reasons offered by participants for similarities and differences in their attitudes. The third aim is to use the attitude data to try to devise a classification system for consent to prenatal testing, and to get feedback from potential users and representatives of user groups.

1.1.2 Aims of the present study

The aim of the present study was to investigate gender differences in attitudes towards prenatal testing, for a number of conditions that can be detected by a hypothetical non-invasive prenatal test. The questionnaire was designed to access attitudes to the conditions themselves and not designed to access attitudes to the technological aspect of the testing. More information about the questionnaire design is described later in the method section. The study was therefore, interested in looking at men and women's attitudes to conditions e.g. severe learning disability, cystic fibrosis, etc. However, it is acknowledged, that one can only speculate that choosing prenatal testing and termination for a particular condition has a relationship to attitudes to the condition or/and disability. This is a complex relationship that cannot be completely analysed or explored using only a quantitative method of research. Studies that have investigated attitudes to different conditions (e.g. Down's syndrome, cystic fibrosis etc) and more generally attitudes towards disability are reviewed.

It was apparent from the review of the literature that men are rarely included in research on issues of prenatal testing and termination. There has however, been some recent research on the affects of miscarriage on men and this is reviewed later with reference to men's experience of termination of pregnancy. Similarly, compared to the amount of literature on mother's role regarding childcare, there is limited recent literature on the father's role. Therefore, the burden of care experienced by fathers and mothers of children is discussed with only limited reference to literature concerning the father's role. In order to place the study in context the review will begin with general information about prenatal testing and reproductive choices, followed by a brief review of literature on eugenics and the 'perfect baby syndrome', the theory on attitudes, attitudes to disability, men and the unborn child and lastly burden of care.

CHAPTER 2: LITERATURE REVIEW

2.1.1 Prenatal testing

‘Prenatal testing’ is a broad term which is used to describe a number of procedures offered during pregnancy and often used to identify foetal abnormalities. There are three categories of prenatal testing procedures: prenatal screening, genetic testing and prenatal diagnosis. Screening tests produce a ‘risk figure’ that estimates the probability of the woman having a baby with an abnormality. The risk figure provided by the screening tests fall into either a ‘screen negative’ also referred as ‘low risk’ or, a ‘screen positive’ also referred to as ‘increased’ or ‘high risk’ test result.

Screening tests are non-invasive and are used as a way of dividing up women into, those who are low risk, and those who are at an increased risk of having a baby with an abnormality. Even though screening tests are non-invasive there is comprehensive literature expounding the view that there is an increase in psychological morbidity amongst pregnant women after experiencing prenatal screening (Marteau, 1992; Green, 1994; Thornton, Hewison, Lilford and Vail, 1995; Hewison, 1996; Michie, Smith, McClennan and Marteau, 1997).

Furthermore, factors associated with the uptake of prenatal screening procedure, including both women’s and health professional’s understanding of the attitudes to prenatal screening, have also been the focus of a large body of research (Marteau, 1992; Thornton, Hewison, Lilford and Vail, 1995; Hewison, 1996; Michie, Smith, McClennan and Marteau, 1997; Ryder, 1998).

There are three prenatal screening methods, used to estimates the risk of foetal abnormality, and are sometimes offered to women with a significant risk of having a baby with an abnormality. The three screening methods are, ‘taking a medical history' (Royal College of Physicians, 1989), 'biochemical' or 'maternal serum screening' which is often, but not always, offered at antenatal clinics (Green, 1994), and 'ultrasound' which is used to monitor the growth and development of the foetus and generally used routinely within antenatal clinics (Royal College of Physicians, 1989).

Taking a medical history is usually the first screening method employed to identify some women at increased risk of foetal abnormality. For example, certain characteristics of women such as, increased maternal age (35 years and over) are associated with increased risk of the baby having an abnormality. There is an increase in the incidence of chromosomal abnormalities, in particular Down's syndrome associated with increased maternal age. The screening test for neural tube defects is often referred to as maternal serum alpha-fetaprotein. The tests for chromosomal abnormalities are generally referred to as, maternal serum screening, Bart's test or the triple test. The number of biochemical markers found in the woman's blood or maternal serum are calculated to be able to, obtain risk figures for neural tube defects and chromosomal abnormalities (Wald et al., 1992). The ultrasound scan is used to determine the number of foetuses, to estimate their gestational age as well as to look for foetal abnormalities.

In summary, prenatal screening; genetic testing and prenatal diagnostic testing such as, amniocentesis and chorionic villus sampling, offers women the potential for more control over the birth of a disabled child by providing relevant information about genetic and health status of the foetus during pregnancy. However, because there are no therapeutic interventions available for most conditions which testing detects, the options available following a positive diagnosis consists of preparing for a life with a disabled child or terminating the pregnancy (Rothenberg & Thompson, 1994; Schwartz-Cowan, 1994). Such options present a mother or/and family with extremely difficult and complex choices and decisions to make.

2.1.2 Reproductive choices and decision-making

Detecting foetal abnormalities is an important part of antenatal care and as prenatal tests increase so do women's reproductive choices, this can present pregnant women with very difficult and complex decisions to make. The accessibility of prenatal diagnostic tests and selective abortion means that many people are confronted with life and death choices. Such bleak and difficult decision-making is unique in people's lives and the serious nature of the decision is rarely experienced in any other domain of life (Hewison, 1996).

Such decision-making is further complicated by the fact that, even with the progressive technology of prenatal testing, the affordability of the tests continues to be a problem making it impossible to screen for many conditions (Green and Stratham, 1996). Furthermore, prenatal tests do not always provide a conclusive diagnosis and certain tests may put the life and well being of foetus at risk. 'For example, diagnostic tests that are available for chromosomal abnormalities require samples of foetal cells that are obtained by invasive means and as mentioned above, carry an increased risk of miscarriage or possible damage to the fetus.

Many women will not take the risk of using a procedure that may induce miscarriage and thus the approach currently adopted is to try and find ways of identifying subgroups of women who are at significantly increased risk of carrying an abnormal fetus. Diagnostic tests which are invasive are then only offered to the women who fall into these subgroups, for example, screening for Down's syndrome follows this type of procedure.

Down's syndrome is probably the most well known example of a routine screening test potentially leading to termination, although screening for neural tube defects (e.g. spina bifida) is also commonplace. Routine screening can vary depending in which part of the country people live. In some areas, couples are now routinely screened for cystic fibrosis carrier status and in Wales population screening for Duchenne muscular dystrophy is offered. There generally seems to be a tendency for an increase in screening, both in terms of the number of pregnant women tested, and the number of conditions that are detectable (Shakespeare, 1998).

Consequently, as screening becomes more prevalent and the number of genetic conditions that can be tested for during pregnancy is increased, many more couples will be confronted with decisions about terminating affected pregnancies (Green and Stratham, 1996). Tom Shakespeare (1998) strongly argues; *"these decisions became more complex when the condition is something like predisposition to breast cancer or colon cancer, rather than impairment like achondroplasia, or a disease such as Huntington's"* (Shakespeare, 1998 p. 667, 668). He points out; *"it is important to highlight the collective and social effects of the many individual decisions to terminate affected pregnancies, the context of culture and values in which these decisions are taken, and the role of science in contributing to this state of affairs"* (Shakespeare, 1998 p. 668). This emerging trend, that is the ability to prenatally diagnose the presence of certain disabilities and chronic illnesses is causing a moral debate in our society (e.g. Richards, 1989; Shakespeare, 1998).

In summary prenatal testing was first used for a selective group of high-risk women including those who had already given birth to a child with disability, who were over the age of thirty-five, and who had a family history that included a member with a disability (Rapp, 1984). It has become common practice, however, for most pregnant women to undergo screening with maternal serum alphafetoprotein and ultrasound and, if a suspected abnormality is detected, to be referred for prenatal diagnosis (Marteau, 1991). The early detection of an affected fetus allows the expectant couple a chance to either prepare for the birth of an infant with disability or to terminate the pregnancy. Some investigators have suggested that simply offering prenatal diagnosis may suggest that it is ethically acceptable to terminate the pregnancy if an affected fetus is found (Pueschel, 1991).

2.1.3 Eugenics and 'designer' babies

Despite the modern world of genetic research and discovery there continues to be limitations concerning technological capabilities and scientific knowledge, and there are limitations concerning resources and practicalities (Green and Stratham, 1996). Thus, those concerned about a 'Brave New World' of eugenics have less to be anxious about, and those looking forward to genetic utopia may not have so much to be optimistic about. However, when gene therapies become a reality the detection of genes connected with major impairments currently produces the possibility of genetic counselling and prenatal testing and termination, not effective cures or therapeutic interventions. For prospective parents this means that genetic screening presents them with additional moral and political dilemmas. (Shakespeare, 1998).

Tom Shakespeare (1998), comes from the position that accepts the women's right to choose, but opposes social and cultural pressures for selective termination of disabled people. He eloquently argues, that "*screening technologies offers solutions to what is then defined as a problem: technological interventions insidiously shift the ground towards what has been variously called 'tentative pregnancy' or the 'perfect baby syndrome' or the 'designer baby syndrome' or the supermarket syndrome', by which I mean the expectation that medical experts will deliver a baby free from impairment or illness, and that it would be selfish for people not to avail themselves of this power*" (Shakespeare, 1998 p. 666). Thus the dividing line between health and disease becomes blurred, and social experience becomes more 'geneticised'.

In America, Jeremy Rifkin (1998), one of the strongest opponents of the 'genome intrusion', believes that the concern over a re-emergence of eugenics is justified but as some believe misplaced. Professional ethicists diligently look for any signs that are indicative of the Nazi type nightmare emerging in any form of medical practice. However, one can argue that the eugenics doctrine is already influencing medical practice and is at work reshaping the ethical priorities of society. Rifkin (1998) expresses seemingly contradictory points of view, which demonstrate how complex are the concerns of individuals for their children and the difficulty of deciding their social responsibility. He states that "*technologies that begin with the worthy aim of alleviating inherited illnesses, such as cystic fibrosis, will lead to the elimination of foetuses for trivial differences, such as left-handedness or colour blindness, as soon as we understand the genetic causes. On the other hand, there are some people who want their children to share the same disability as they have inherited, such as deafness* (Rifkin, 1998, p.34).

Rifkin (1998) argues that it is unhelpful to view today's prenatal testing practices as eugenic. However, he does acknowledge that eugenic outcomes can be promoted by the medical profession and by the context in which the reproductive decisions are made which can often undermine the capacity of free choice. Shakespeare (1998), more specifically proposed that obstetricians are the main profession to hold eugenic attitudes, he reported that they were more directive in their advice to pregnant women, and more likely to support the termination of a fetus with a range of genetic conditions than either geneticists or genetic counsellors (Marteau et al., 1994).

Shakespeare (1998) gives the following examples; *"In cases of Down's syndrome, 94% of genetic counsellors, 57% of geneticists, but only 32% of obstetricians reported counselling in a non-directive way. The majority favoured termination of foetuses with spina-bifida, anencephaly, Huntington's disease, Down's syndrome and Duchenne muscular dystrophy, and a large minority favoured termination of foetuses with cystic fibrosis, sickle cell anaemia, achondroplasia, PKU and haemophilia"* (Shakespeare, 1998 p. 668).

In summary, whether the practice of prenatal testing is eugenic or not is a complex and contentious issue. Even those who advocate that the practice as not eugenic, recognise that eugenic outcomes can be promoted by the medical profession influence on reproductive decisions that often undermine the individual's free choice. Others more specifically proposed that obstetricians are the main profession to hold eugenic attitudes and are more directive in their advice, concerning termination of an affected fetus, to pregnant women. The literature reports that the attitudes towards prenatal testing of medical professionals and counsellors have a strong influence on parent's decision-making concerning prenatal testing and termination of pregnancy. The mechanism by which attitudes are expressed through influence or behaviour is not straightforward. Attitudes are hypothetical constructs therefore, not observable, making attitude research notoriously difficult to conduct and interpret. It is therefore important to consider the theory on attitudes and what assumptions about attitudes are adopted for the present study.

2.2 Attitudes.

The most basic structural question about attitudes concerns the nature of the concept itself. Despite the long history of research on attitudes, there is no universal agreed upon definition. Influential theorists variously define attitudes primarily in terms of evaluation (e.g. “a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour,” Eagly & Chaiken, 1993), affect (e.g. “the affect associated with a mental object,” Greenwald, 1989), cognition (e.g. “a special type of knowledge, notably knowledge of which content is evaluative or affective,” Kruglanski, 1989) and behavioural predisposition (e.g. “a state of a person that predisposes a favourable or unfavourable response to an object, person, or idea,” Triandis, 1991). In recent years this definition has been criticised particularly regarding the inclusion of behaviour as an inherent component of attitudes (Greenwald 1989). Nevertheless, the idea that attitudes are informed by beliefs, emotions and behaviour continues to provide a useful way of in which to examine social objects (Eagly and Chaiken, 1993).

Attitude towards objects can be broadly divided into two categories: ‘target’ and ‘behaviours’. For example a person might hold a favourable attitude towards people with a severe learning disability, and they might also hold a favourable or unfavourable attitude towards terminating a pregnancy for severe learning disability. While the two attitudes may well be linked they are conceptually distinct. The former would be an attitude towards a target, and the latter would be an attitude towards behaviour directed at a target. Intuitively, it might be expected that the two attitudes would be relatively consistent: that someone with an unfavourable attitude towards people with severe learning disability might be expected to use prenatal tests for the condition and to terminate an affected pregnancy. However, it has been demonstrated that this intuitive consistency is not always apparent in real life and that attitudes towards objects do not always accurately predict seemingly related behaviours (Sutton, 1998).

The present study however, was not investigating the behaviour-attitude link per se, but rather the attitudes towards the ‘target’, which in this case is the particular foetal condition or abnormality. One would expect that attitudes towards people with disability would have some influence on prenatal testing and termination intentions. A number of assumptions within the framework of attitude theory (Ajzen & Fishbein, 1988; Eagly & Chaiken, 1993) had influenced the use of the attitude measure and interpretation and discussion of results of the data collected. The assumptions are given below:

- Attitudes are thought to be evaluations of objects based on multiple sources of information, for example, beliefs, emotions, and experiences associated with the attitude object.
- It is assumed that although behaviour may influence attitudes, behaviour is a distinctly separate construct and not necessarily a constituent of the attitude construct as such.
- It is assumed that attitudes towards targets are conceptually different to attitudes towards behaviour. Thus the main focus of this study is to investigate attitudes towards the target, for example attitudes to disability.

It is acknowledged that Psychology has been criticised for neglecting the social and contextual aspects of attitudes and have focused more on the individual aspects of attitudes (Greenwald, 1989). This study measures aspects of attitudes at an individual and group level and it is assumed that attitudes are social, interpersonal constructions as well as intra-personal ones. It is acknowledged that attitudes are developed and acted upon in a particular social context, and as such have social consequences and that attitudes are hypothetical constructs that cannot be directly observed but only inferred from other responses (Ajzen, 1988). It is therefore acknowledged, that the responses made to the Attitude to Prenatal Testing (ATP) questionnaire used in the study can only infer the participants attitudes towards the conditions/disabilities being tested for. The following section outlines several studies on the subject of attitudes to disability.

2.2.1 Attitudes to disability

Researchers have argued that the decision about whether or not to carry an affected fetus to term may be influenced by the person's attitudes towards people with disabilities (Pueschel, 1991; Rapp, 1984; 1988; Richards, 1989). Other researchers go further and argue that, the process of obtaining a prenatal diagnosis both reflects and strengthens the attitudes of our society towards those with disabilities (Stacey, 1988).

Findings from other studies suggest that despite there being a positive shift in attitude towards individuals with disabilities, the change is happening very slowly and the general attitude remains negative (e.g., Duvdevany, 1995; Papadopoulos & Mulcahy, 1995). A study conducted in Sweden found that pregnant women eligible for prenatal testing had quite negative attitudes, they tended to perceive children with disabilities and their families as experiencing suffering and distress (Sjogren and Uddenberg, 1987).

A study carried out in Germany, Portugal and the UK, compared attitudes towards termination across lay populations and health professionals. It was reported that between 55% and 70% of the 'lay sample' (university employees) would terminate for Down's syndrome (Drake, Reid and Marteau, 1996). This was just slightly more than the number who said they would terminate for spina bifida and cystic fibrosis and lower than 80% who said they would terminate for anencephaly. Between countries a significant difference was found, with German people being the least likely, and Portuguese people the most likely to indicate they would terminate for disabling conditions.

In a survey of the British general public, 65% agreed with the routine availability of testing and termination for Down's syndrome, compared to 41% who said they themselves would use diagnostic testing with the aim of possible termination (Marteau, Michie, Drake and Bobrow, 1995). More people here said they would terminate for anencephaly (63%), and a lower proportion for cystic fibrosis (32%).

A study carried out in Belgium, reported that 67% of their sample would want to use prenatal diagnosis for Down's syndrome compared with 38% who would terminate an affected pregnancy (Evers-Kieboom, Denayer, Decruyenaere and Van den Berghe, 1993). This was a similar proportion to the number who would abort for a condition where the child would die soon after birth, but greater than for a condition which was related to physical disability only (17%). In an American survey there were similar findings, 65% of both women and men said they would want to use prenatal testing for serious genetic defects of which 41% said they would terminate an affected pregnancy (Singer, 1993).

In the study by Singer (1993), 71% of respondents indicated Down's syndrome in response to an item asking for definition of 'serious genetic defect'. However, those respondents, who indicated Down's syndrome specifically, were also more likely to say that genetic screening would do 'more harm than good'. Singer (1993) also reported that awareness of Down's syndrome did not necessarily equate to a willingness to test and terminate for it. Interestingly, one might assume that women who are opposed to abortion would not undergo prenatal testing because they would not terminate the pregnancy regardless of the test outcome. Research has shown, however, that generally women who oppose abortion would have prenatal testing and would terminate an affected pregnancy (Kyle, Cummings, & Evans, 1988). Nonetheless, in general, attitudes towards abortion constitute one of the strongest predictors of the decision to terminate the pregnancy or continue to carry an affected foetus to term (Breslau, 1987).

Approval of abortion depends on the circumstances of the pregnancy. Several researchers (Balakrishnan & Chen, 1990; Szafran & Clagett, 1988) have separated the reasons for abortion into two categories: physical and social. The physical category reason is danger to health or life of the mother or physical or mental disability of the foetus. The social category reasons are being single, lacking financial recourses, and perceiving a valid reason for an abortion (e.g. for rape etc). There is overwhelming approval for abortion for physical purposes, but persons are less likely to approve for social reasons. Even individuals who do not approve of abortion may be more accepting of pregnancy termination if there is a physical circumstance, which includes a foetal abnormality.

In summary, most of these general public samples reported favourable attitudes towards prenatal testing with a view to terminating a pregnancy for more severe conditions. Despite some differences across the studies, some general conclusions can be drawn. Firstly, people hold more favourable attitudes towards the availability of these prenatal testing technologies than they do towards using them themselves. Secondly, people hold more favourable attitudes towards using prenatal testing than they do towards terminating an affected pregnancy. Lastly, regarding peoples attitudes towards appropriateness for termination, Down’s syndrome tends to fall above physical disability of chronic illness, but below lethal conditions such as anencephaly.

There are a number of other factors that researchers have identified as predicting general attitudes toward prenatal testing and termination of pregnancy and they include, religious affiliation, church attendance, education and gender (Balakrishnan & Chen, 1990; Szafran & Clagett, 1988). However, there has been very little research on gender in relation to attitudes to prenatal testing and termination. Research on prenatal issues generally excludes men and the dominant assumption continues to be that the unborn child is the sole concern of women.

2.3 Men and the unborn child

Despite the recent interest in the male as a procreative being (Marsiglio, 1998), male partners have rarely been studied in research on prenatal genetic counselling, prenatal testing, or birth anomalies (Browner and Preloran, 1999; Hobdell and Deatrick, 1996; Sjogren and Uddenberg, 1987). An influential factor is, of course, that women are considered to be the primary caregiver. However, another contributory factor influencing this research bias, is that there seems to be a widespread belief that male partners tend only to bond with their offspring at the very late stages of pregnancy or after the birth, and that pregnancy is commonly believed to be a "women's business" (Stacey, 1996). Consequently, the person who is most often forgotten in the family bereaved by a miscarriage is the father' (Wilkinson, 1987). This is supported by Duncan's (1995) observation that after miscarriage the father's feelings are rarely given much consideration, as there is an assumption that the fathers really do not bond with the unborn child.

However, Johnson & Puddyfoot (1996) have recently reviewed the research concerning the psychological and emotional impact of miscarriage on men and their findings bring into question these commonly held beliefs. In the event of miscarriage the man's role has been almost exclusively one of support for his partner. Thus, there is sometimes the belief that these men would not feel a real sense of loss of the baby unless they were able to see and recognise the dead fetus as 'baby-like' (Allen and Marks, 1993).

Interviews carried out by Johnson and Puddifoot (1996), revealed that following their partner's miscarriage men did experience deeply-felt loss, comparable to the feelings of loss the women experienced, but the men were unable to express these feelings to either friends and family or indeed publicly. Thus, the presence of strangers in the form of medical staff and the fact that men are not supposed to show emotion mean that their feelings are often hidden (Ducan, 1995).

These findings bring into question the belief that in early to mid-pregnancy many men do not have a developed sense of a baby as an individual, a separate salient being, and consequently, in the event of a miscarriage be at low risk of negative impact (Johnson & Puddifoot, 1996). Johnson and Puddifoot (1996), found that men whose partners miscarried before the 25th week gestation, reported that they experienced raised levels of grief and stress, particularly those men who had seen an ultrasound scan of their unborn child. Consequently, one could argue that some of the psychological processes that are generally associated with birth may have shifted to an earlier point in pregnancy (see Beeson, 1984; Fletcher, 1972).

If miscarriage is distressing for mothers and their partners causing both grief and stress reactions, one would suspect that it would be just as distressing, if not more so, when mothers and fathers experience the termination of a wanted child in the case of foetal abnormality. Foetal diagnosis of genetic disease and malformation, with but a few exceptions, cannot lead to any treatment of the foetus, or modification in the medical care of the mother (Richards, 1998). Thus, the purpose of prenatal testing is threefold, to permit termination of pregnancy, to prepare a mother, partner and her family for the birth of a disabled child or, to rule out any of the disorders for which diagnosis is possible and so provide reassurance. Parents can suffer loss when they receive prenatal diagnosis about their foetus the loss is often of the foetus the parents had hoped they carried (Biesecker et al, 2000).

However, this grief reaction does not always result in parents choosing termination and they can welcome an affected foetus into the world.

Termination of any foetus is very distressing for parents and termination is particularly distressing when carried out on the grounds of foetal abnormality because they are wanted pregnancies and the grief reaction that follows is comparable to that experienced by mothers and fathers after miscarriage (Lloyd and Laurence, 1985; Keefe-Cooperman et al., 2000; Johnson & Puddifoot, 1996). Prenatal testing and termination of pregnancy involves the unborn child of two parents. The question is, how involved are men in the decision-making process concerning prenatal testing and/or termination of an affected foetus?

Browner et al., (1999) commented that there has been relatively little research on men's experiences with foetal diagnosis or their role in their female partners' decisions about whether to be tested. The authors focused on the role male partners played in the women's decision making whether to have amniocentesis; the couples in the study were of Mexican-origin. Browner et al., (1999) found that most women made the decision whether or not to use prenatal diagnosis by themselves or in combination with their partners

In a study by Sjogren (1992), twenty men were interviewed between six and seven weeks after their partners had received normal prenatal diagnostic (PND) test results. All men said that they and their wife had decided about PND without pressure from others or from the society in general. Nevertheless, eleven of the men considered that there was a risk of influence from medical staff in the decision making. The majority of the men considered that they themselves and their partner were equally motivated for PND. However, half of the men spontaneously stated that their wife had the final decision. About half of the men were quite certain that they would have wished for a legal abortion if the test had shown that the child was they would have wished for a legal abortion if the test had shown that the child was disabled. However the study reported that a great proportion of them had not reached a final decision at the moment when the test result was given.

In summary, although men generally adopt a supportive role with their partners after miscarriage, the strong and supportive role often masks the reality of man's own grief. Furthermore, the assumption that men do not bond with their unborn child implies that men are not as affected as women after a miscarriage. However, recent research reported that men do bond to their unborn child and suffer distress and experience grief reactions at the loss of a baby through miscarriage and that this loss is comparable to experiencing the loss of a baby through termination of an affected foetus.

The role of men in the decision-making process of choosing prenatal testing or/and termination of pregnancy is under researched and therefore poorly understood. One can only tentatively conclude from the few studies reviewed that couples were either equally motivated for PND or women tended to make the final decisions concerning using prenatal testing and/or choosing termination of pregnancy. The decision making process concerning whether to have prenatal testing and/or termination is complex and there are many factors that have been identified as having an influence on the process such as, religion, age, ethnicity, etc.

One factor identified has been the burden of caring for a child with disability on individual family members or the family as a whole. There has been some change over recent years and generally fathers take a more active role in the care of their children. However, women continue to be considered the primary caregiver in the family and the burden of caring for a disabled child would generally be the women's responsibility.

2.4 Burden of care

What is meant by 'burden' in many studies has not been clearly defined, nor has it been investigated within the prenatal context, why some people perceive parenting a disabled child as burdensome while others do not. A few studies have reported that the perceived burden of caring for a disabled individual and the belief that an affected child would impact negatively on partner and other children are factors associated with a favourable attitude towards prenatal testing (Jorgensen, 1995; Marteaul, 1991).

Other studies have reported a significant relationship between the perceived burden of caring for a child with Down's syndrome and attitudes towards diagnostic testing (Bryant, 1998; Marteau, 1992; Evers-Kiebooms et al., 1993). It is reported in the literature that generally women who undergo diagnostic testing and learn that their foetus carries severe abnormality do decide to terminate the pregnancy (Green et al., 1993; Rapp, 1988. Evers-Kiebooms and colleagues, 1993) reported that expected burden of caring for an affected child, the value placed on a successful life, and pleasure and relaxation were related to attitudes towards disability.

A review, by Milner (1993), of views critical of prenatal diagnosis and its impact on attitudes towards persons with disabilities, reported the following. "*The assumptions underlying prenatal diagnostic testing and termination appear to be that disability can reduce quality of life to an extent that non-existence is preferable to living with disability, and/or that the burdens of parenting a disabled child outweighs the joys*' (Milner, 1993 p.45). Lawson (2001) conducted a survey examining the perceptions of raising a child with serious disability and attitudes toward prenatal diagnostic testing on a sample of a 165 women. The results indicated that the net appraisal of mothering a child with disability is predominantly negative, especially with regards to the burden of caring for a child with disability such as, the time commitment, financial expense and emotional toll.

Because women rather than men have been the main focus of research, men's ideas, opinions and attitudes about families and their reproductive decisions are largely unknown. However, in recent years there has been an increase in research and literature on the changing identity of fatherhood (Belsky et al., 1994; Burgress, 1998 Cabrera, 2000). Belsky and Kelly (1994) argued that the experience of fatherhood has dramatically changed in the past few decades and that men no longer rely solely on the workplace to define them selves. They argue that, in addition to medical and technological advances that give parents earlier information and choices, the economy and society has changed. Wages for men have remained relatively static and record numbers of mothers of young children have joined the work force (Kimmel, 1996; Cabrera et al., 2000).

These trends conflict with traditional gender roles, the trend of many more women working requires many couples to postpone having children. Although delayed parenting has been associated with greater paternal readiness and involvement in child rearing (Coltrane, 1990), advanced paternal age is also associated with an increased chance of having children with anomalies (Savitz, Schwingl, and Keels, 1991).

However, although some investigators report that some fathers are becoming more involved in the relational aspect of fathering (Hearman, 1995), others disagree. Stern (1991) said there has always been a "variety and tension in fatherhood." In his view there is less investment in the paternal role and less paternal satisfaction than there was during pre-industrial and industrial periods. The increase of presence of mothers in the workplace generally has not been accompanied by an increased involvement of fathers in childcare.

A research project carried out in Leeds (Hewison & Dowswell, 1994), found little evidence that fathers took an 'equal share' in carrying out many of the caring tasks necessary during an episode of child illness. They commented that, taking the child to the doctor's and providing care during school absence, particularly if it involved taking time off work were, predominantly carried out by the mother or other female relatives. Hewison et al., (1994), concluded from their study, that it was clear most tasks associated with child health care were carried out by women, mostly by the child's mother and that most help was provided by female relatives or friends. They found that fathers very occasionally took off time to care for their sick child and that the contribution of fathers, male relatives and other men to child health in the home was limited.

There are few studies that have considered the relationship between fathers and their learning disabled children. Some studies that have considered this relationship, involved no direct observation of fathers and children and at best they have involved interviews with fathers, and in many cases the researchers impressions are from clinicians or professionals on which to base their conclusions. The general consensus from these studies is that mothers and fathers initially respond differently to the news that their child has a learning disability. It is reported that fathers tend to respond less emotionally and to focus on possible long-term problems (particularly financial ones) in contrast mothers respond more emotionally and express concerns about their ability to cope with the burden of child care which includes concerns about financial expense, time commitment and emotional toll (Evers-Kieboom et al, 1993; Lawson, 2001).

2.4.1 Burden of care summary

In summary, there is evidence to suggest that there is a significant relationship between perceived burden of care of a disabled child and favourable attitudes towards using prenatal diagnostic testing and termination of an affected foetus. The perceived burden of care of a disabled child will have on family members is an important factor in the decision-making process concerning the use of prenatal testing and whether to terminate an affected pregnancy or not. The family members that are most affected by the decision–making process are those who have more of the responsibility for caring for the child.

Traditionally the care of children has generally been the role of the mother. Despite the conflicting views on how much child care fathers are involved in, one can draw the conclusion from the literature and research, that caring for children predominantly continues to be the domain of women. Furthermore, certain studies revealed that majority of tasks associated with child health care were carried out by women. One would predict therefore, that as the primary carer of children, women would be more interested than men in finding out the condition of their foetus by way of prenatal testing particularly for the more severe, high burden conditions.

2.4.2 High-burden of care

High-burden conditions in the present study are disabilities that require a lot of care. The high-burden of care conditions are the following, severe learning disabilities, quadriplegia, trisomy 18 (Edwards syndrome), moderate learning disability and fragile X. Furthermore, one would predict that because women are more likely to be the primary carer of a disabled child, women more than men would choose to terminate for high burden conditions. Therefore the hypotheses are as follows:

1. The greater the level of burden of care required for the particular abnormality the more likely women are to choose prenatal testing than are men.
2. The greater the level of the burden of care for the particular abnormality the more likely women are to choose termination of the affected foetus than are men.

CHAPTER 3: METHODOLOGY

3.1 Design

A matched design was used to compare differences of attitudes to prenatal testing between members of couples who had recently experienced the pregnancy and birth of their baby.

3.2 Participants

Participants were drawn from antenatal clinics in Leeds. The people who attended the clinics are drawn from wide social backgrounds. Participants included white indigenous women, in the third trimester of pregnancy and their male partners also white indigenous. Participants were recruited pre-natally and data, from the Attitudes to Prenatal Testing (ATP) questionnaire, was collected post-natally. This particular method was used because of the ethical issues involved in asking women in late pregnancy questions about testing for foetal abnormalities and attitudes to termination and was therefore, considered more appropriate to collect the data from couples who had had their babies. Researchers from the Social and Ethnic Differences and Consent to Prenatal Testing (SEDPT) study piloted the method of recruiting participants (Hewison, et al., 2000) and in order to familiarise myself with the method I shadowed and observed one of the researchers during recruitment. Details of the recruitment method are given in the procedure.

3.2.1 Consent

Professor Jenny Hewison and her colleagues had established good relationships with maternity service providers throughout West Yorkshire, which made the access to potential participants unproblematic. A letter was sent to the Clinical Services Manager/Head of Midwifery at St James University Hospital requesting permission to access participants using the same recruitment method as the SEDPT study and permission was granted. Recruitment of participants began after receiving ethical clearance from the Chairman, DR P. R. F., Dear of the Leeds Health Authority/ St James's and Seacroft University Hospitals Clinical Research (Ethics) Committee on 15th of April 2002 (Appendix 1). The study was approved by the committee, on the basis that, it was a sub-study to the project, Social and Ethnic Differences and Consent to Prenatal Testing (Hewison et al, 2000), already approved by the committee. The committee accepted that my study would involve contacting partners of the mothers taking part in the main study, and that I would obtain consent from the mothers to do so. I also obtained consent from the Divisional Head of Midwifery to visit antenatal clinics in Leeds (Appendix 2)

3.2.2 Recruitment

The recruitment criteria were as follows: mothers recruited were 30+ weeks gestation and indigenous white UK. The mothers who were single or did not give consent to contact their partners, were recruited into the SEDPT study. The mothers who consented for their partners to be contacted were recruited into the SEDPT study as well as the present study. Fathers also had to be indigenous white UK. Between the dates of June the 11th 2002 and February 26th 2003, 75 pregnant women were recruited through community midwives, consent to contact men was given by the women. The midwives introduced the study by way of giving very brief information. If the women were interested they then saw a researcher who gave more detail about the research. Having the midwife as the first person to introduce the women to the study was obligatory, this was important ethically for the following reasons. Firstly, the woman could refuse to take part in the study, whilst remaining anonymous to the researcher, and thus maintain the privacy of her visit to the midwife. Secondly, midwives generally have prior knowledge of a woman's antenatal and postnatal history. Therefore, midwives are in a more informed position to discriminate between those women who would find the anticipation of completing a questionnaire on issues of prenatal testing too distressing and those who would not. However, having midwives as the person who introduced the study was sometimes problematic. For example, occasionally in some clinics the midwives were too busy, or simply forgot, to inform some women about the study and so some potential participants were lost although the exact number of losses was impossible to monitor and record.

In all 75 women, who were attending antenatal clinics for their routine appointments, were given brief information by the midwives about the study. Of the 75 women, 6 declined the offer to see me to find out more about the study. Therefore, I discussed the study with 69 women, 2 of who were single but were recruited into SEDPT study. Of the 69 women recruited 6 did not consent to contacting their partners. Thus, 63 women consented for me to contact their partners, however, 2 women became single during the course of the study, giving a total of 61 women recruited and their partners (n=61) to contact. See table 1 below for numbers of women recruited at antenatal clinics and number of male partners to contact.

Table 1. Numbers of women approached and recruited at antenatal clinics and number of women who consented to contact their partners.

Antenatal clinic	**Women approached by midwife**	**Women refused**	**Single women**	**Women recruited**	**Refused contact of men**	**Consent to contact men**	**Total women recruited**	**Total men to contact**
Manor Park	11	2	0	9	1	8	9	**8**
Silver Lane	5	0	0	5	1	4	**5**	**4**
Robin Lane	10	3	0	7	1	6	**7**	**6**
Lingwell	19	0	2	19	3	16	**19**	**13**
Burton Croft	18	1	0	17	0	17	**17**	**17**
The Croft Golden Bank	12	0	0	12	0	12	**12**	**12**
Total	**75**	**6**	**2**	**69**	**6**	**63**	**69**	**61**

Of the 61 women, 36 participated in the study and returned their questionnaires completed. Of the 61 men, 20 men returned their questionnaires. I phoned all the men and women who did not return their questionnaires within two to three weeks of them being posted. The purpose of the phone calls were to find out, if they had received the ATP questionnaire, or mislaid it and would like another, or/and if they needed assistance over the phone with completing it. The ATP questionnaires returned by the 36 women and 20 men were generally complete with only a few questions with missing data. However, from the same participants, there were fewer responses to the qualitative sections of the APT questionnaire, 17 of the women and 6 of the men gave some qualitative information. When pairing the data into couples that participated, of the 36 women and 20 men, there were 19 male-female couples that had returned completed questionnaires.

3.3 Measures

3.3.1 Demographic information

A brief demographic questionnaire for men (Appendix 3) and a recruitment questionnaire for women (Appendix 4) was used to obtain information regarding, age, education, professional qualification, place of birth, religion, prenatal history etc.

3.3.2 Questionnaire design

A postal questionnaire (Attitudes to Prenatal Testing questionnaire (ATP)) was used to obtain men (Appendix 5) and women's (Appendix 6) attitudes to prenatal testing and termination of pregnancy. For the larger scale study looking at social and ethnic differences to prenatal testing Professor Jenny Hewison and colleagues (2000) had designed a questionnaire that was closely based on previous work by Wertz and colleagues (1992), Hietala and colleagues (1995). The ATP questionnaire was piloted by the researchers on the main study and has been found to be a reliable and valid measure of attitudes to prenatal testing for a wide range of disorders. The measure has been designed as a postal questionnaire appropriate for self-completion.

The questionnaire consists of a list of conditions for which testing in pregnancy is either already available, or could become available in the future. The questionnaire presents the respondents with a hypothetical testing situation by asking them, whilst completing the questionnaire, to keep the following assumptions in mind. Firstly, that the conditions mentioned are rare. Secondly, to assume that the results from the prenatal test would tell them whether the baby definitely does or does not have the condition and thirdly, to assume that the prenatal tests would be carried out in early pregnancy using routinely collected bloods.

The rationale for presenting these assumptions was to attempt to eliminate as many factors, as possible, which may influence the respondent's decision-making processes whilst completing the questionnaire. For example, uncertainty that a prenatal test may not produce accurate results is likely to influence the individual's decision whether to have the test or not. Therefore, the respondent may answer the question, by thinking more about the quality of the test, rather than answering the question by thinking about the test showing their baby definitely does or does not have a disabling condition. For example, a prenatal test that presents the expectant couple with only a possible indication of a disabling condition may leave a couple, who would consider termination for that particular disability, in a very difficult decision making position. The couple's dilemma would be one whereby they consider termination, thus taking the risk of aborting an unaffected foetus, or they consider going ahead with the pregnancy and risk having a child with a disability.

After information about the hypothetical testing situation the questionnaire then presents the respondents with a tick box format and they are asked to consider each condition and tick either 'No', 'Yes' or 'Not sure' in answer to the two following questions. These are, a) would you want a prenatal test? And, b) would you consider a termination if the test showed that the baby has the condition? The men's version of the questionnaire phrases the first question slightly differently and is as follows, a) would you want your partner to have a prenatal test? Hewison et al (2000), considered a Likert scale format, but decided that since responses were likely to be bimodal, a simple categorical format was thought more suitable.

The questionnaire describes thirty conditions to be detected in early pregnancy, and has followed previous practice such as, Wertz and colleagues (1992) and Hietala and colleagues (1995) in which the list would not give the name of specific disorders, but instead give a brief description of each, e.g. instead of trisomy 18, "severe learning difficulties/mental handicap, child unable to speak or understand" and instead of Huntington's disease, severe painful disorder starting at age 40, incurable". Cystic Fibrosis, Duchenne muscular dystrophy, Fragile-X, thalassaemia and deafness were amongst other conditions listed.

The precise content of the label for each condition was determined through pilot work (see table 2) and particular attention was paid to the wording and ordering of the descriptions of foetal conditions. For example, in order to avoid any value judgement about the condition/disability, the word 'and' was used instead of 'but'. For example, condition 3 on the questionnaire describes that a, "Child would be unable to move from the neck down require a lot of looking after and have a normal life span". The use of the word 'and' in this description is used deliberately to give a neutral meaning the to the words 'normal life span'. If however, the word 'but' was used to say, 'but have a normal life span' this could imply that 'despite' the disabling condition, the child does have a normal life span, therefore making a value judgement about the disability.

In order to obtain qualitative information concerning possible influences that may have affected the respondents' responses to the prenatal testing and termination questions, two final questions were presented as follows after some explanatory material: " Is there anything you would like to say about how your religious beliefs have influenced your decisions about prenatal testing" and "Is there anything you would like to say about other factors that influenced the decisions that you have made about prenatal testing in this questionnaire"

Table 2: Descriptions and corresponding names/definitions of the conditions given on the Attitudes to Prenatal Testing (ATP) questionnaire.

Description of the condition given on the questionnaire	Name/definition of condition
1. Child would have severe learning difficulties/mental handicap, unable to speak or understand, require a lot of looking after and have a normal life span.	Severe learning disabilities/mental handicap
2. Child would be unable to move from the neck down require a lot of looking after and have a normal life span.	Quadriplegia + normal lifespan
3. Child would have normal lifespan and be extremely short.	Dwarf
4. Child would have a treatable cleft lip or palate, require medical interventions throughout childhood and have a normal lifespan.	Treatable cleft lip and palate + normal life span
5. Child would develop a degenerative mental condition by age 60, require a lot of looking after and possibly have a shortened life span.	Alzheimer's and early death
6. Child would be very short female who might have some medical problems, a normal lifespan and would not be able to have children.	Turner's syndrome (chromosome 45X) + normal life span
7. Child would have severe learning disabilities /mental handicap, require lots of looking after and die within first few months of life.	Trisomy 18 (Edwards syndrome)
8. Child would have mild learning disabilities/mental handicap, able to work and live independently and have a normal lifespan.	Mild learning disabilities/mental handicap + normal life span.
9. Child born without a brain and die before of soon after birth.	Anencephaly or Perinatal death.
10. Child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan.	Thalassaemia + shortened lifespan.
11. Child would be at high risk of heart attack (before age 50).	Coronary heart disease before age of 50.
12. Child would have problems with lungs and digestive systems, require a lot of medical care throughout life and have a shortened lifespan (death probably before 40 years of age).	Cystic fibrosis + shortened lifespan before age of 40.
13. Child would be at high risk of becoming alcoholic and have a potentially shortened lifespan.	High risk of alcoholism + shortened lifespan.
14. Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after.	Moderate learning disability/mental handicap + normal lifespan.
15. A male child would have mild learning disabilities/mental handicap or behaviour problems, usually tall and not very masculine appearing, need some looking after, be unable to father a child and have a normal lifespan.	Klinefelter's syndrome (chromosome 47 XXY).
16. Child might have disfiguring large lumps on head and face, which are noticeable from a	Neurofybromytosis + normal lifespan.

distance, have a normal lifespan and might need medical care in childhood.	
17. Child would be grossly overweight and have a potentially shortened lifespan.	Grossly overweight and have a potentially shortened lifespan.
18. Child would have a blood condition that could cause mental problems if left untreated, have a normal lifespan and have strict diet restrictions throughout life.	Phenyketonuria + normal lifespan.
19. Child would be deaf from birth and have a normal lifespan.	Deaf + normal lifespan.
20. Child would have a normal lifespan and a high risk of developing mental illness in adulthood, need some looking after and long-term medication, be unable to work or relate to others.	Schizophrenia
21. Child would develop an incurable condition by age 40, which has both severe mental and physical deterioration, require constant looking after and medical help and have a shortened lifespan.	Huntington's disease + shortened lifespan.
22. Child would have severe behavioural and communication problems.	Autism + normal lifespan.
23. Child would have progressive muscle-wasting disease, be wheelchair bound by 11 or 12 years and have a much shortened lifespan (death probably before the 20 of age).	Duchenne muscular dystrophy + much shortened lifespan.
24. Child would have normal lifespan, behavioural and communication problems, have moderate learning disabilities/mental handicap and require looking after.	Fragile X.
25. Child would be blind from birth and have a normal lifespan.	Blindness + normal lifespan.
26. Child would develop bowel cancer in early adulthood, require surgery and medication and have a potentially shortened lifespan.	Cancer (bowel) + potentially shortened lifespan.
27. Child would have a neurological condition that causes fits/convulsions from an early life, have a normal lifespan and require long-term medication.	Epilepsy + normal lifespan.
28. Child would have a physical illness requiring daily injections, there might be possible complications such as heart and kidney disease, blindness, would have limitations on diet throughout life and have a potentially shortened lifespan.	Diabetes + potentially shortened lifespan.
29. Child would have a normal lifespan and be born without a limb, or have a limb that does not function.	Absent/dysfunctional limb+normal lifespan.
30. Child is not the sex desired by the parent.	Not the preferred gender.

3.3.3.High-burden of care, and low-burden of care conditions from the Attitudes to Prenatal Testing (ATP) questionnaire.

In order to test the hypotheses particular conditions on the ATP questionnaire were divided into high-burden (see table 3) and low-burden conditions (see table 4). This was operationalised by taking the conditions that made reference to "require a lot of looking after" as the high-burden of care items and the five low-burden of care conditions were those that would require no extra care than a child without a condition. The low-burden items were also chosen by considering the data obtained from the 400 women participants in the Social and Ethnic differences in Attitudes and Consent to Prenatal Testing (SEACP) study. The five conditions that women from the SEACP study were less likely to want testing for, or to choose termination for, were operationalised as low-burden of care conditions.

Table 3: Descriptions and corresponding definitions of high burden conditions taken from the Attitudes to Prenatal Testing (ATP) questionnaire.

High burden conditions by question number.	**Name/definition of condition**
1. Child would have severe learning difficulties/mental handicap, unable to speak or understand, require a lot of looking after and have a normal life span.	Severe learning disabilities/mental handicap
2. Child would be unable to move from the neck down require a lot of looking after and have a normal life span.	Quadriplegia + normal lifespan
7. Child would have severe learning disabilities /mental handicap, require a lot of looking after and die within first few months of life.	Trisomy 18 (Edwards syndrome)
14. Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after.	Moderate learning disability/mental handicap + normal lifespan.
24. Child would have normal lifespan, behavioural and communication problems, have moderate learning disabilities/mental handicap and require a lot looking after.	Fragile X.

Table 4: Descriptions and corresponding definitions of low burden conditions taken from the Attitudes to Prenatal Testing (ATP) questionnaire.

Low burden conditions by question number.	Name/definition of condition
3. Child would have normal lifespan and be extremely short.	Dwarf
4. Child would have a treatable cleft lip or palate, require medical interventions throughout childhood and have a normal lifespan.	Treatable cleft lip and palate + normal life span
6. Child would be very short female who might have some medical problems, a normal lifespan and would not be able to have children.	Turner's syndrome (chromosome 45X) + normal life span
11. Child would be at high risk of heart attack (before age 50).	Coronary heart disease before age of 50.
17. Child would be grossly overweight and have a potentially shortened lifespan.	Grossly overweight and have a potentially shortened lifespan.

3.4 Procedure

A high proportion of women attend antenatal clinics in the last few weeks of pregnancy and therefore the clinics in Leeds were an ideal recruitment environment. I was able to speak to a large number of women in a relatively short time, and because of the personal contact I hoped to achieve a satisfactory response rate.

Mindful that asking women, in the late stages of pregnancy, questions about testing for foetal abnormalities would pose serious ethical issues, participants were recruited pre-natally, but data, from the Attitudes to Prenatal Testing (ATP) questionnaire, was collected post-natally. The rationale for collecting data from women who had recently experienced pregnancy and, at least, experienced routine antenatal tests such as ultra sound scans and routine blood tests, was the women would have more recent memories of these experiences whilst completing the questionnaire. Likewise, the men would have the experience of being with their partners during these times thus, making their responses far more realistic and richer for the experience, say than men who had not been fathers, or the experience of becoming a father had been so long ago that the strength of feelings and memory of the experiences was weaker.

I arranged visits to the antenatal clinics by contacting the midwives on duty. At the clinic the midwife would ask the women who were 30 weeks or more gestation if they were interested in taking part in a prenatal testing study. To those women who were interested, I explained the study and provided them with an information sheet (Appendix 7). Furthermore, I explained that I was also interested in their partner's views with the purpose of investigating gender differences in attitudes to prenatal testing. To those women who thought that their partners might take part, a 'partner' information sheet (Appendix 8) was given to the woman to give to her partner. Women had an opportunity at this stage to ask any questions about the study. Those who consented to taking part in the study were asked to complete and sign two consent forms (appendix 9) one for her to keep and the other for my research records. The consent form included a statement asking the woman if she permitted me to contact her partner. Also the women's demographic information was collected at this time using a brief demographic questionnaire.

Consent was also sought for the mothers to be contacted about two weeks after their baby's birth (to enquire how the mother and baby were and if they wanted to continue with the study) and again at six weeks after the baby was born (requesting their permission to send the ATP questionnaire) giving a clear message that they were able to withdraw from the study at any time. A researcher from the SEACP project made most of the telephone calls to the women participants. The provision of address and telephone numbers (collected as part of the demographic information at recruitment) was taken as evidence of consent to be contacted at a later date. Subject to obtained consent a questionnaire was posted to the mother, a researcher then phoned to ask if she needed any assistance to complete the questionnaire.

3.4.1 Contacting male partners

Between a few days and a week after recruiting the women, I contacted the partners by phone to ask if they had received the information sheet and if they had any questions, or wanted further information, about the study. Demographic information was collected on the phone (or if they preferred, a demographic questionnaire was sent with the ATP questionnaire). I also requested consent for a questionnaire to be sent to him six weeks after the baby was born, making it clear that he could withdraw from the study at any stage. However, the men were not always available when I phoned (I generally phoned after 6 p.m. in hope that it was after working hours) for several reasons, he was either working shifts and would be late home or working away. The most common reason was that the man was otherwise engaged after a long day at work. In these cases the mother often requested that the questionnaire was posted to him.

Towards the end of my recruitment the SEDPT study had reached their target number of mothers. Therefore, I recruited the last 17 mothers and made all the phone calls. For example, I phoned the women and the men approximately two weeks postnatally, to enquire how the mother, father and baby were and if they wanted to continue with the study, and again six weeks postnatally, requesting their permission to send the ATP questionnaire, giving a clear message that they were able to withdraw from the study at any time.

3.4.2 Questionnaires

The self-completion Attitudes to Prenatal Testing (ATP) (Appendix 5 & 6) questionnaire was sent with a covering letter (Appendix 9) and a stamped self-addressed return envelope. In the covering letter the partner would be asked if he could please try not to confer with his partner when filling out the questionnaire. The request not to confer was also made at recruitment, and to the partner in the

Partner Information Sheet (Appendix 8). The mother's (Appendix 7) and partner's Information Sheets also informed the participants that their questionnaire responses would be treated as confidential information to be used anonymously for research purposes only.

To follow up non-responders, I sent reminders and in some cases offered assistance to complete the questionnaire by telephone. As mentioned above the mother's consent would be obtained at recruitment, the partner's consent would be obtained by phone or/and by his completing the ATP questionnaire, which is considered to be implied consent.

3.4.3 Pilot study

Researchers from the SEDPT study (Hewison et al, 2000) conducted a pilot study of both the ATP questionnaire and recruitment method. A few minor changes had to be made to the questionnaire and the final version is considered to be reliable and valid. The researchers found that the recruitment, and data collecting methods produced a satisfactory response rate. For example, from a researcher approaching twenty-two women at antenatal clinics, 10 white indigenous and 12 Pakistani women, a total of 21 women participated in the study and returned their ATP questionnaires.

3.4.4 Analysis

The data was taken directly from the demographic questionnaire and the Attitudes to Prenatal Testing (ATP) questionnaire and put directly onto the SPSS data-base for analysis. See the results section for demographic information and results of the analyses of the ATP questionnaire data.

CHAPTER 4: RESULTS

4:1 Demographic information

4.1.1 Age

Twenty men and 36 women participated in the present study and all were white British. The men had a mean age of 33.6 years (s.d 6.6) and the range was 19 years to 44 years old. The women had a mean age of 29.9 years (s.d 5.9) and the range was 16 years to 42 years old. All participants were living with a partner or wife/husband, a distinction was not made in the study between those who cohabited and those who were married. Half of the women 18 (50%), and just over half of the men 11 (58%) had another child or children living with them. The mean age of the baby at the time of returning the Attitude to Prenatal Testing (ATP) questionnaire was 46.6 days (S.D. 7.0) and the range was 35 to 56 days old.

4.1.2. Education

Educational level was classified using qualification attainment; The sample were matched for educational level 44% of women and 42% of men attained GCSE or less and 53% of women and 45% of men attained A' level or more. One (3%) woman and 2 (10%) men did not give this information. As regards religious affiliation 25 (69%) women and 8 (42%) men classed themselves as Christians of various denominations (e.g. Church of England), 5 (13%) women and 1(5%) man considered themselves Christian Catholic and 6 (17%) women and 8 (42%) men reported they had no religious affiliation. Two women and no men reported that their religious beliefs had influenced their decisions about prenatal testing.

4.1.3 Prenatal testing history

Details of women's prenatal testing history were obtained. All 36 women participants had had screening/diagnostic tests in this pregnancy. All women had the routine antenatal tests, such as, routine blood tests and ultrasound scan. Six (18%) of these women also had had the nuchal translucency test. Twenty of the 36 women had had a previous pregnancy during which they had routine blood test and ultrasound scan but no other tests.

4:2 Attitudes to Prenatal Testing Questionnaire (ATP): The overall level of interest in prenatal testing and termination of pregnancy across all conditions for couples.

The data from the ATP questionnaire from all male (n=20) and female (n=36) participants was numerically coded directly from the questionnaire as, 'No'=1, 'Yes'=2 and 'Not Sure'=3 and put onto to the statistical database (SPSS). Of the 20 men and 36 women there were 19 couples. The data was analysed for frequencies see table 5 below for numbers and percentages of men (n=19) and women's (n=19) scores for interest in wanting prenatal testing across conditions (n=30). In figure I (see pp 43) the frequencies of men and women wanting prenatal testing across conditions are graphically illustrated. Also see table 6 below for numbers and percentages of men (n=19) and women's (n=19) scores for interest in termination of pregnancy across conditions (n=30). In figure II (see pp 46) the frequencies of men and women wanting termination across conditions are graphical illustrated.

Table 5: Gender x Prenatal Diagnosis

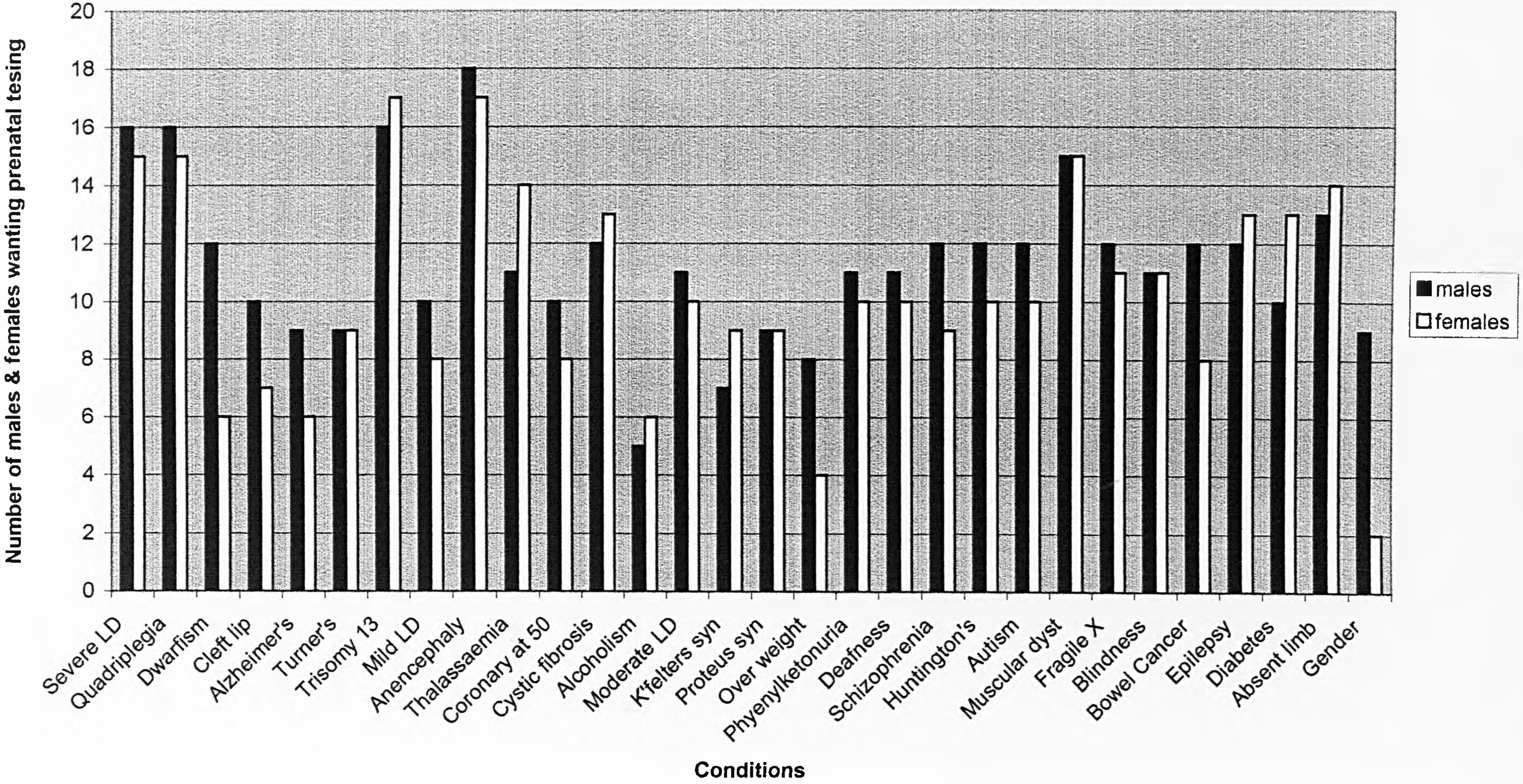
"Would you want a prenatal test?"

	YES		NOT SURE		NO	
Condition	**Males (n=19)**	**Females (n=19)**	**Males (n=19)**	**Females (n=19)**	**Males (n=19)**	**Females (n=19)**
1. Severe learning dis	16 (84%)	15 (79%)	0	2 (10%)	3 (16%)	2 (10%)
2. Quadriplegia	!6 (84%)	15 (79%)	2 (10%)	2 (10%)	1 (5%)	2 (10%)
3. Dwarf	12 (63%)	6 (31%)	3 (16%)	2 (10%)	4 (21%)	11 (58%)
4. Cleft lip and palate	10 (53%)	7 (37%)	4 (21%)	1 (5%)	5 (26%)	11 (58%)
5. Alzheimer's	9 (47%)	6 (31%)	0	3 (16%)	10 (53%)	10 (53%)
6. Turner's syndrome	9 (47%)	9 (47%)	2 (10%)	2 (10%)	8 (42%)	8 (42%)
7. Trisomy 13	16 (84 %)	17 (89%)	0	1 (5%)	3 (16%)	1 (5%)
8. Mild learning dis	10 (53%)	8 (42%)	2 (10%)	1 (5%)	7 (37%)	19 (53%)
9. Anencephaly	18 (95%)	17 (89%)	1 (5%)	1 (5%)	0	1 (5%)
10. Thalassaemia	11 (58%)	14 (74%)	3 (16%)	1 (5%)	5 (26%)	4 (21%)
11. Coronary at 50	10 (53%)	8 (42%)	1 (5%)	1 (5%)	8 (42%)	10 (53%)
12. Cystic fibrosis	12 (63%)	13 (68%)	3 (16%)	1 (5%)	4 (21%)	5 (26%)
13. Alcoholism	5 (26%)	6 (31%)	1 (5%)	0	13 (68%)	13 (68%)
14. Mod learning dis	11 (58%)	10 (53%)	4 (21%)	3 (16%)	4 (21%)	6 (31%)
15. K'felter's synd	7 (37%)	9 (47%)	3 (16%)	3 (16%)	9 (47%)	7 (37%)
16. Proteus syndrome	9 (47%)	9 (47%)	3 (16%)	2 (10%)	7 (37%)	8 (42%)
17. Grossly o' weight	8 (42 %)	4 (21%)	2 (10%)	4 (21%)	9 (47%)	11 (58%)
18. Phyenylketonuria	11 (58%)	10 (53%)	0	1 (5%)	8 (42%)	8 (42%)
19. Deafness	11 (58%)	10 (53%)	0	2 (10%)	8 (42%)	7 (37%)
20. Schizophrenia	12 (63%)	9 (47%)	2 (10%)	3 (16%)	5 (26%)	6 (31%)
21. Huntington's	12 (63%)	10 (53%)	3 (16%)	2 (10%)	4 (21%)	6 (31%)*
22. Autism	12 (63%)	10 (53%)	4 (21 %)	4 (21%)	3 (16%)	5 (26%)
23. Muscular Dyst	15 (79%)	15 (79%)	2 (10%)	1 (5%)	2 (10%)	3 (16%)
24. Fragile X syn	12 (63%)	11 (58%)	3 (16%)	4 (21%)	4 (21%)	4 (21%)
25. Blindness	11 (58%)	11 (58%)	2 (10%)	1 (5%)	5 (26%)*	6 (31%)*
26. Bowel Cancer	12 (63%)	8 (42%)	2 (10%)	3 (16%)	5 (26%)	8 (42%)
27. Epilepsy	12 (63%)	13 (68%)	0	0	7 (37%)	6 (31%)
28. Diabetes	10 (53%)	13 (68%)	0	1 (5%)	9 (47%)	5 (26%)
29. Absent limb	13 (68%)	14 (74%)	1 (5%)	1 (5%)	5 (26%)	4 (21%)
30. Not prefer gender	9 (47%)	2 (10%)	0	0	10 (53%)	17 (89%)

Key
1 =Severe learning disability
8 =Mild learning disability
14 = Moderate learning disability
15 = Klinefelter's syndrome
17 = Grossly over weight
21 = Huntington's disease
23 =Duchenne muscular dystrophy
29 = Absent/ dysfunctional limb
30 = Not preferred gender

syn=syndrome
dis=disability

Figure I: A bar chart showing number of males (n=19) and females (n=19) wanting prenatal testing across conditons.



To compare attitudes of the two groups to prenatal testing, the paired data scores above of men (n=19) and women (n=19) were given numeric values as follows; ‘yes’=2, ‘not sure’=1 or ‘no’=0 for interest in prenatal testing for each condition (n=30) on the ATP questionnaire. The total scores, for the men and women, were analysed for skewness and were found to be reasonably normally distributed. Therefore, the data conformed to parametric status and a paired samples t-test was used to test for any significant differences between the men’s and women’ mean scores for prenatal testing. There was no significant difference between the mean scores (t-value=1.015, df=18, 2-tailed sig = 0.324) at the 5% level of probability. However, observation of the frequencies of men and women who want prenatal testing there is a trend that more men than women chose prenatal testing across conditions in particular, for the conditions dwafism, being grossly overweight and gender (see figure I, pp 43).

4.2.1 The overall level of interest in termination of pregnancy across all conditions for couples

See table 6 below for numbers and percentages of men (n==19) and women's (n=19) scores for interest in termination of pregnancy across conditions (n=30).

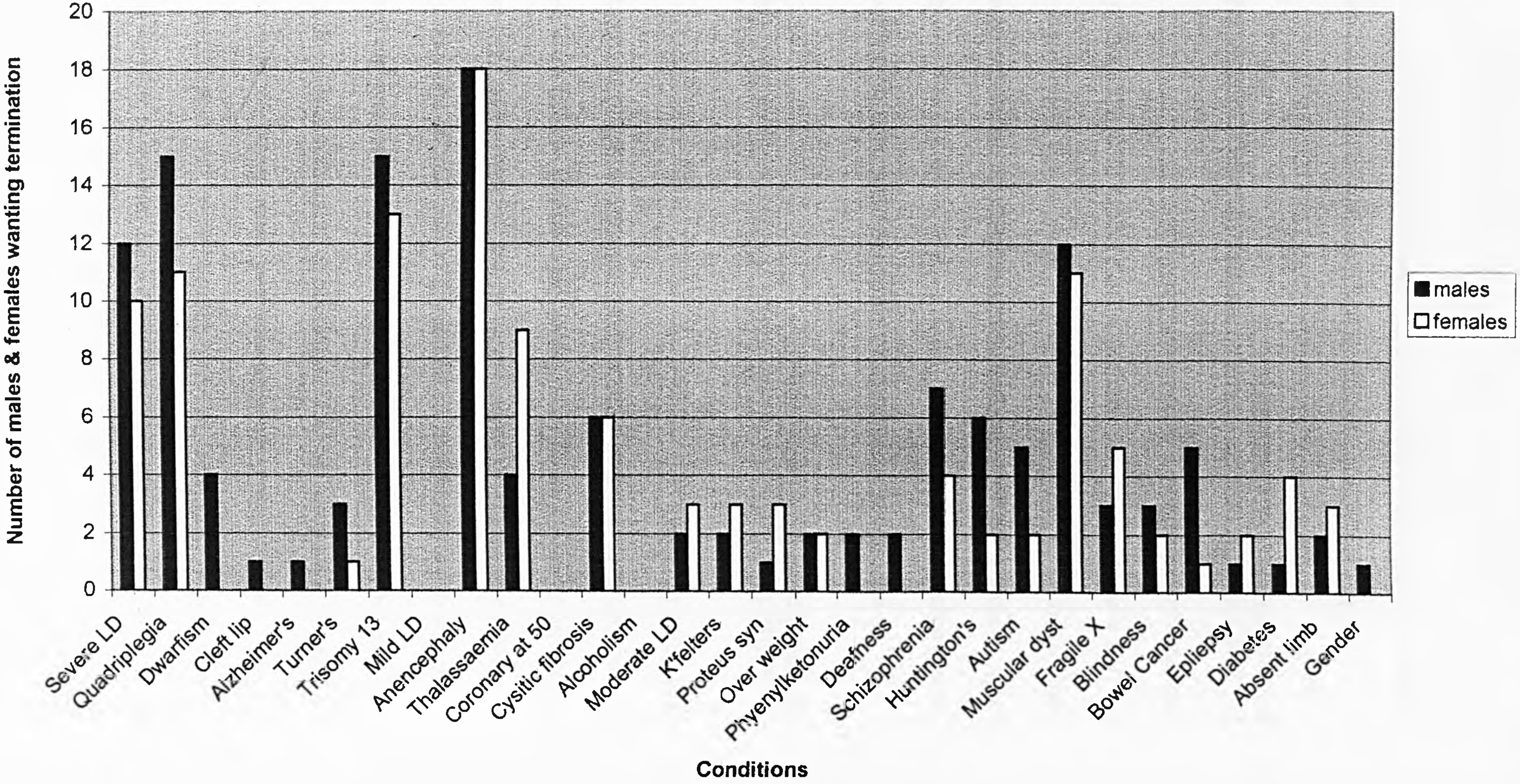
Table 6: Gender x Termination of Pregnancy.

"Would you consider termination if the test showed the baby had this condition?"

	YES		**NOT SURE**		**NO**	
Condition	**Males (n=19)**	**Females (n=19)**	**Males (n=19)**	**Females (n=19)**	**Males (n=19)**	**Females (n=19)**
1. Severe learning dis	12 (63%)	10 (53%)	6 (31%)	6 (31%)	1 (5%)	3 (16%)
2. Quadriplegia	15 (79%)	11 (58%)	3 (16%)	6 (31%)	1 (5%)	2 (10%)
3. Dwarf	4 (21 %)	0	4 (21 %)	4 (21%)	11 (58%)	15 (79%)
4. Cleft lip and palate	1 (5%)	0	5 (26%)	2 (10%)	13 (68%)	17 (89%)
5. Alzheimer's	1 (5%)	0	4 (21%)	7 (37%)	14 (74%)	12 (63%)
6. Turner's syndrome	3 (16%)	1 (5%)	7 (37%)	7 (37%)	9 (47%)	11 (58%)
7. Trisomy 13	15 (79%)	13 (68%)	2 (10%)	3 (16%)	2 (10%)	3 (16%)
8. Mild learning dis	0	0	3 (16%)	5 (26%)	16 (84%)	14 (74%)
9. Anencephaly	18 (95%)	18 (95%)	1 (5%)	1 (5%)	0	0
10. Thalassaemia	4 (21%)	9 (47%)	9 (47%)	2 (10%)	6 (31%)	8 (42%)
11. Coronary at 50	0	0	4 (21%)	5 (16%)	15 (79%)	14 (74%)
12. Cystic fibrosis	6 (32%)	6 (31%)	6 (32%)	8 (42%)	7 (37%)	5 (26%)
13. Alcoholism	0	0	3 (16%)	4 (21%)	16 (84%)	15 (79%)
14. Mod learning dis	2 (10%)	3 (16%)	9 (47%)	9 (47%)	8 (42%)	7 (37%)
15. K'felter's synd	2 (10%)	3 (16%)	8 (42%)	9 (47%)	9 (47%)	7 (37%)
16. Proteus syndrome	1 (5%)	3 (16%)	8 (42%)	6 (31%)	10 (53%)	10 (53%)
17. Grossly o' weight	2 (10%)	2 (10%)	7 (37%)	5 (26%)	10 (53%)	12 (63%)
18. Phyenylketonuria	2 (10%)	0	2 (10%)	5 (26%)	15 (79%)	14 (74%)
19. Deafness	2 (10%)	0	3 (16%)	5 (26%)	14 (74%)	14 (74%)
20. Schizophrenia	7 (37%)	4 (21%)	6 (31%)	8 (42%)	6 (31%)	7 (37%)
21. Huntington's	6 (31%)	2 (10%)	6 (31%)	11 (58%)	7 (37%)	6 (31%)
22. Autism	5 (26%)	2 (10%)	8 (42%)	10 (53%)	6 (31%)	7 (37%)
23. Muscular Dyst	12 (63%)	11 (58%)	6 (31%)	5 (16%)	1 (5%)	3 (16%)
24. Fragile X syn	3 (16%)	5 (26%)	8 (43%)	10 (52%)	8 (42%)	4 (21%)
25. Blindness	3 (16%)	2 (10%)	3 (16%)	3 (16%)	13 (68%)	13 (68%)*
26. Bowel Cancer	5 (26%)	1 (5%)	9 (47%)	6 (31%)	5 (26%)	12 (63%)
27. Epilepsy	1 (5%)	2 (10%)	3 (16%)	2 (10%)	15 (79%)	15 (79%)
28. Diabetes	1 (5%)	4 (21%)	5 (26%)	6 (31%)	13 (68%)	9 (47%)
29. Absent limb	2 (10%)	3 (16%)	7 (37%)	7 (37%)	10 (53%)	9 (47%)
30. Not prefer gender	1 (5%)	0	0	0	18 (95%)	19 (100%)

Use same key table

Figure II: A bar chart showing number of males (n=19) and females (n=19) wanting termination across conditions.



To compare the attitudes of the two groups to termination of pregnancy, the paired data scores above of men (n=19) and women (n=19) were given numeric values as follows; ‘yes’=2, ‘not sure’=1 or ‘no’=0 for interest in wanting prenatal testing for each condition (n=30) on the APT questionnaire. The total scores, for the men and women, were analysed for skewness and were found to be reasonably normally distributed. Therefore, the data conformed to parametric status and a paired samples t-test was used to test for any significant differences between the men’s and women’s mean scores for termination of pregnancy. There was no significant difference found between mean scores (t-value=0.551, df=18, 2-tailed sig=0.589) at the 5% level of probability. Observation of frequencies that men and women want termination there is a trend that more men than women chose termination across the majority of conditions (see figure II, pp 46).

4.2.2 High-burden of care and low-burden of care conditions from the Attitudes to Prenatal Testing (ATP) questionnaire.

In order to test the hypotheses particular conditions on the questionnaire (ATP) were designated as high-burden (refer to table 3, pp 35) and low-burden conditions (refer to table 4, pp 36). This was operationalised by taking the conditions (n=5) that made reference to “require a lot of looking after” as the high-burden of care items and the five low-burden of care conditions (n=5) were those that would require no extra care than a child without a condition/disability.

4.2.3 Gender differences in interest in wanting prenatal testing for high-burden of care and low-burden of care conditions

Table 7 displays the means, standard deviations and paired-sample t.test results of men’s (n=19) and women’s (n=19) scores for high-burden (n=5 with a maximum value of 10) and low-burden (n=5 with a maximum value of 10) conditions for interest in wanting prenatal testing.

Table 7: Means, standard deviations and paired sample t-tests for interest in wanting prenatal testing scores for high-burden (n=5) and low-burden (n=5) conditions by gender.

Conditions	Men Mean (Max value of 10) Std deviation	Women Mean (Max value of 10) Std deviation	t.value	Sig (2-tailed)
High-burden	7.84 (2.92)	7.78 (3.08)	.129	.89
Low-burden	5.78 (4.03)	4.10 (4.05)	1.97	.07

The scores for wanting prenatal testing for high-burden of care conditions had already been given the numeric values of 'No'=0, 'Not Sure'=1 and 'Yes'=2 as described above. The total sores were analysed for skewness and were found to be reasonably normally distributed. Therefore, the data conformed to parametric status and so a paired samples t-test was used to ascertain if there was a significant difference between the men and women's mean scores. The result was not significant (t-value=0.129, df=18, 2-tailed sig =0.89) at the 5% level of probability (see table 7 above). Therefore, hypothesis 1, 'The greater the level of the burden of care required for the particular abnormality the more likely that women would choose prenatal testing than would men', was not supported. There was no significant difference between men and women's interest in wanting prenatal testing for high burden conditions.

Although there was no specific hypothesis relating to low-burden of care conditions the results were analysed to see if there was a difference between men and women's mean scores for wanting prenatal testing for low-burden of care conditions. The scores for wanting prenatal testing for low-burden of care conditions had already been given the numeric values of 'No'=0, 'Not Sure'=1 and 'Yes'=2 as described above. The total scores were analysed for skewness and found to be reasonably normally distributed. Therefore, the data conformed to parametric status and so a paired samples t-test was used to ascertain if there was a significant difference between the men and women's mean scores. The result was not significant (t-value=1.97, df=18, 2-tailed sig =0.071) at the 5% level of probability (see table 7 above). Therefore, there was no significant difference between women and men for interest in wanting prenatal testing fore low-burden conditions. However, there appears to a trend in the direction that men's mean scores are higher than the women's mean scores.

4.2.4. Gender differences in wanting a termination of pregnancy for high-burden and low-burden of care conditions.

Table 8 displays the means, standard deviations and paired-sample t.test results of men's (n=19) and women's (n=19) scores for high-burden (n=5, maximum value of 10) and low-burden (n=5, maximum value of 10) conditions for interest in wanting termination.

Table 8: Means, standard deviations and paired sample t-tests for interest in wanting termination scores for high-burden (n=5) and low-burden (n=5) conditions by gender.

Condition	**Men** (n=19) Mean (Max value of 10) Std deviation	**Women** (n=19) Mean (Max value of 10) Std deviation	**t.value**	**Sig (2-tailed)**
High-burden	6.24 (2.34)	6.15 (3.08)	.44	.65
Low-burden	2.47 (1.77)	1.52 (2.06)	1.48	.15

The scores for wanting termination for high-burden of care conditions had already been given the numeric values of 'No'=0, 'Not Sure'=1 and 'Yes'=2 as described above. The total scores were analysed for skewness and were found to be reasonably normally distributed. The data conformed to parametric status therefore, a paired samples t-test was used to ascertain if there was a significant difference between the men and women's mean scores. The result was not significant (t-value=0.44, df=18, 2-tailed sig =0.65) at the 5% level of probability (see table 8 above). Therefore, hypothesis 1, 'The greater the level of the burden of care required for the particular abnormality the more likely that women would choose termination than would men', was not supported. There is no significant difference between men's and women's interest in termination for high burden conditions.

Although there was no specific hypothesis relating to low-burden of care conditions the results were analysed to see if there was a difference between men's and women's mean scores for wanting termination for low-burden of care conditions. The scores for wanting termination for low-burden of care conditions had already been given the numeric values of 'No'=0, 'Not Sure'=1 and 'Yes'=2 as described above. The data was analysed for skewness and found to be reasonably normally distributed. Therefore, the data conformed to parametric status and so a paired samples t-test was used to ascertain if there was a significant difference between the men and women's mean scores. The result was not significant (t-value=1.48, df=18, 2-tailed sig =0.155) at the 5% level of probability (see table 8 above). Therefore, there was no significant difference between women and men for interest in termination for low-burden conditions. From observation of the percentages there seemed to be some trends and patterns of observed differences between groups for interest in prenatal testing and termination for low burden conditions and are therefore explored in the next section.

4.3. Exploratory analysis

As the results indicate above the hypotheses were not supported. On inspection of the means for high-burden conditions for interest in prenatal testing and termination there appeared to be no significant difference between paired men (n=19) and women (n=19). However, on inspection of the means for low-burden conditions for interest in prenatal testing and termination the men's scores were higher than women's scores which is in the opposite direction to what one would have predicted, given that the hypotheses was predicting that for high-burden conditions women would consider prenatal testing and termination more than men.

In order to inspect the patterns of scores for high-burden and low-burden conditions men and women's scores were recoded. 'No' and 'Not Sure' were both given the value of 1 and 'Yes' the value of 2. For certain conditions crosstabulations were performed to observe the patterns of difference and McNemar tests were conducted to ascertain if differences between the correlated proportions of men and women were significant. Where crosstabulations could not be performed percentages were obtained and presented in tables.

4.3.1 Interest in prenatal testing for high-burden conditions.

Table 9: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for severe learning disability.

			Women's prenatal testing for severe LD		
			NO	YES	TOTAL
Men's prenatal testing for severe LD	**NO**	**Count** **% of total**	3 (15.8%)		3 (15.8%)
	YES	**Count** **% of total**	1 (5.3%)	15 (78.9%)	16 (84.2%)
Total		**Count** **% of total**	4 (21.1%)	15 (78.9%)	19 100%

The marginal totals in table 9 show 15 (78%) women and 16 (84%) men wanted prenatal testing for severe learning disability. A McNamar test was performed to see if there was a significant difference in the proportions of men and women wanting prenatal testing for severe learning disability. The test was not significant (exact sig=1.00) at the 5% level of significance. Observation of the crosstabulations revealed that of the 19 couples, 3 (15.8%) couples agreed that they would not want prenatal testing, 15 (78.9%) couples agreed that they would want prenatal testing and only 1

(5.3%) couple disagreed on whether or not they wanted prenatal testing for severe learning disability. See figure III, pp 55 for graphical representation of agreement and disagreement within couples for choosing prenatal testing for high-burden conditions.

Table 10: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for quadriplegia.

			Women's prenatal testing for quadriplegia		
			NO	**YES**	**TOTAL**
Men's prenatal testing for quadriplegia	**NO**	**Count**	3		3
		% of total	(15.8%)		(15.8%)
	YES	**Count**	1	15	16
		% of total	(5.3%)	(78.9%)	(84.2%)
Total		**Count**	4	15	19
		% of total	(21.1%)	(78.9%)	100%

The marginal totals, the McNamar test result and the agreement/disagreement results within couples represented in table 10 for interest in prenatal testing for quadriplegia are the same as the results reported above for prenatal testing for severe learning disability.

Table 11: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for trisomy 18.

			Women's prenatal testing for trisomy 18		
			NO	**YES**	**TOTAL**
Men's prenatal testing for trisomy 18	**NO**	**Count**	1	2	3
		% of total	(5.3%)	(10.5%)	(15.8%)
	YES	**Count**	1	15	16
		% of total	(5.3%)	(78.9%)	(84.2%)
Total		**Count**	4	15	19
		% of total	(21.1%)	(78.9%)	100%

Results in table 11 show 15 (78.9%) women and 16 (84.2%) men wanted prenatal testing for trisomy 18. The McNamar test was not significant (exact 1.00) at the 5 % level therefore there was no significant difference between the men and women wanting prenatal testing for trisomy 18. Within the couples (n=19), 15 (78.9%) couples agreed to prenatal testing, one couple a greed they would not want prenatal testing and

3 (15.8%) couples disagreed whether or not they wanted prenatal testing for trisomy 18 (see **figure III pp?** for graphical representation of agreement/disagreement within couples).

Table 12: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for moderate learning disability.

			Women's prenatal testing for moderate LD		
			NO	YES	TOTAL
Men's prenatal testing for moderate LD	NO	Count % of total	6 (31.6%)	2 (10.5%)	8 (42.1%)
	YES	Count % of total	3 (15.8%)	8 (42.1%)	11 (57.9%)
Total		Count % of total	9 (47.4%)	10 (52.6%)	19 100%

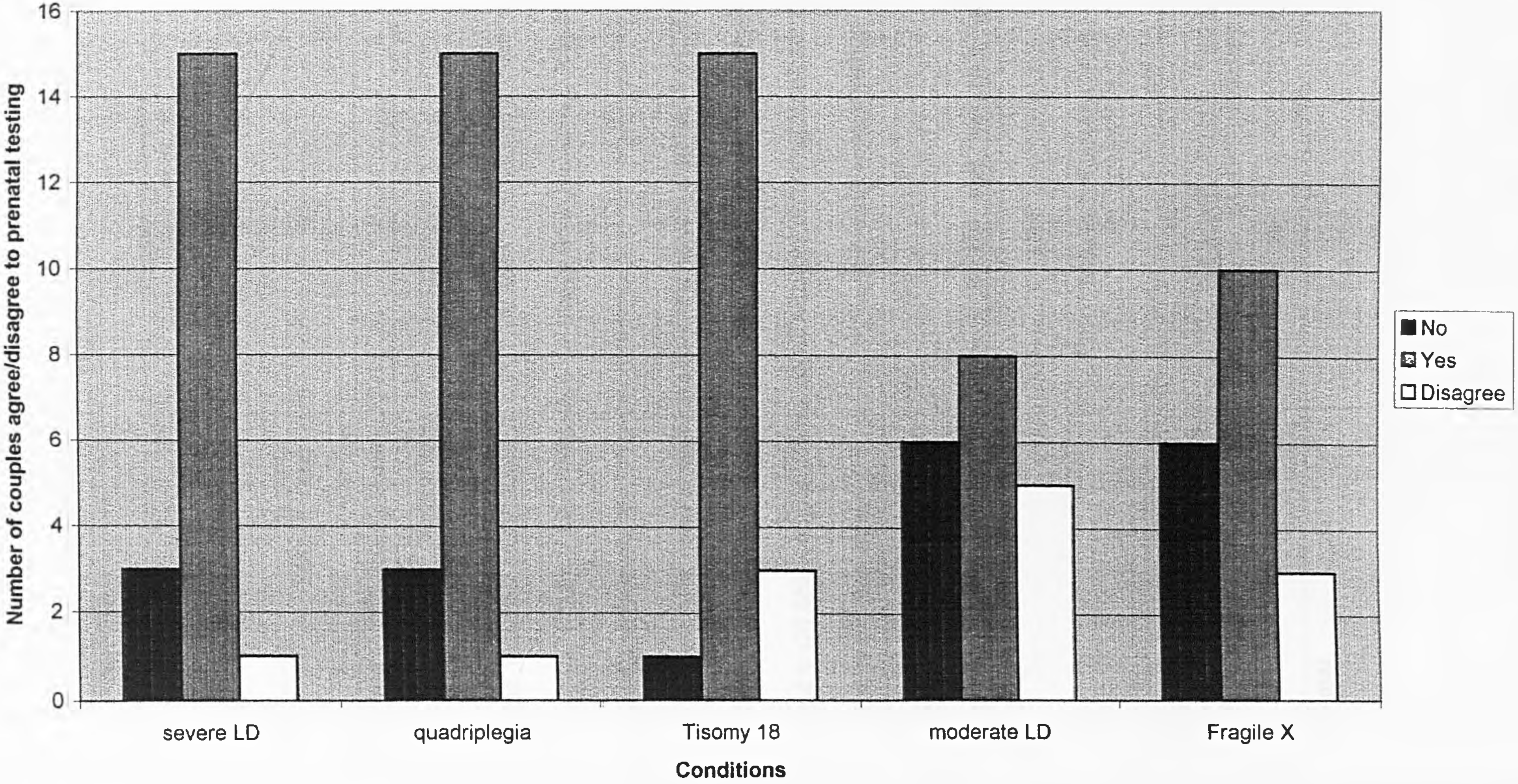
The marginal totals in table 12 show that 11 (57.9%) men and 10 (52.6%) women wanted prenatal testing for moderate learning disability, however, the McNamar test revealed no significant difference between men and women at the 5% level of significance. The crosstabulations show within couples (n=19), 8 (42%) couples agreed they would want prenatal testing, 6 (31.6%) couples agreed that they would not want prenatal testing and 5 (23%) couples disagreed whether or not they wanted prenatal testing for moderate learning disability (see figure III, pp 55).

Table 13: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for fragile X.

			Women's prenatal testing for fragile X		
			NO	YES	TOTAL
Men's prenatal testing for fragile X	NO	Count % of total	6 (31.6%)	1 (10.5%)	8 (42.1%)
	YES	Count % of total	2 (10.5%)	10 (42.1%)	11 (57.9%)
Total		Count % of total	8 (42.1%)	11 (57.9%)	19 100%

For prenatal testing for fragile X, the marginal totals in table 13 show that equal numbers of men (n=11) and women (n=11) wanted prenatal testing. Observation of the crosstabulations show that within the couples, 10 (42%) couples agreed they would want prenatal testing, 6 couples agreed they would not want prenatal testing and 3 (15.8%) couples disagreed whether or not they would want prenatal testing for fragile X (see figure III, pp 55).

Figure III: A bar chart showing number of couples (max n=19) who choose 'yes', 'no' or 'disagree' to prenatal testing for high-burden conditions.



4.3.2 Interest in termination for high-burden conditions.

Table 14: Crosstabulation of men (n=19) and women's (n=19) interest in termination for severe learning disability.

			Women's termination for severe LD		
			NO	YES	TOTAL
Men's termination for severe LD	**NO**	**Count**	5	2	7
		% of total	(26.3%)	(10.5%)	(42.1%)
	YES	**Count**	4	8	12
		% of total	(21.1%)	(42.1%)	(63.2%)
Total		**Count**	9	10	19
		% of total	(47.4%)	(52.6%)	100%

The marginal percentages in table 14 show that slightly more men (63.2%) than women (52.6%) were interested in termination for severe learning disability. The McNamar test revealed that this difference was not significant (exact sig 0.68) at the 5% level. The crosstabulations show that within couples, 8 (42.1%) couples agreed they would choose termination, 5 (26.3) agreed they would not choose to terminate and 6 (31.6%) couples did not agree whether or not to terminate for severe learning disability. See figure IIII, pp 60 for a graphical representation of agreement and disagreement within couples.

Table 15: Crosstabulation of men (n=19) and women's (n=19) interest in termination for quadriplegia.

			Women's termination for quadriplegia		
			NO	YES	TOTAL
Men's termination for quadriplegia	**NO**	**Count**	3	1	4
		% of total	(15.8%)	(5.3%)	(21.1%)
	YES	**Count**	5	10	15
		% of total	(26.3%)	(52.6%)	(78.9%)
Total		**Count**	8	11	19
		% of total	(42.1%)	(57.9%)	100%

The marginal totals in table 15 show that more men, 15 (78.9%), than women, 11 (57.9%), wanted termination for quadriplegia. However, the McNamar test revealed that the difference was not significant (exact sig=0.21) at the 5% level of significance. Within couples (n=19), 10 (53.6%) couples agreed they would want termination, 3 (15.8%) agreed they would not want to terminate and 6 (31.6%) disagreed concerning whether or not to terminate for quadriplegia (see figure IIII, pp 60 for graphical representation).

Table 16: Crosstabulation of men (n=19) and women's (n=19) interest in termination for trisomy 18.

			Women's termination for trisomy 18		TOTAL
			NO	YES	
Men's termination for trisomy 18	**NO**	**Count** **% of total**	2 (10.5%)	2 (10.5%)	4 (21.1%)
	YES	**Count** **% of total**	4 (21.1%)	11 (57.9%)	15 (78.9%)
Total		**Count** **% of total**	6 (31.6%)	13 (65.4%)	19 100%

The results in table 16 show that 15 (78.9%) men and 13 (65.4%) women would choose termination for trisomy 18, the McNamar test however, revealed the difference was not significant at the 5% level of significance. Eleven (57.9%) couples agreed they would choose termination for trisomy 18, 2 (10.5%) couples agreed they would not want to terminate and disagreement was found within 6 (31.6) couples as whether or not to terminate for trisomy 18 (see figure IIII, pp 60).

Table 17: Crosstabulation of men (n=19) and women's (n=19) interest in termination for moderate learning disability.

			Women's termination for moderate LD		
			NO	YES	TOTAL
Men's termination for moderate LD	NO	Count	15	2	17
		% of total	(78.9%)	(10.5)	(89.5%)
	YES	Count	1	1	2
		% of total	(5.3%)	(5.3%)	(10.5%)
Total		Count	16	3	19
		% of total	(82.2%)	(15.8%)	100%

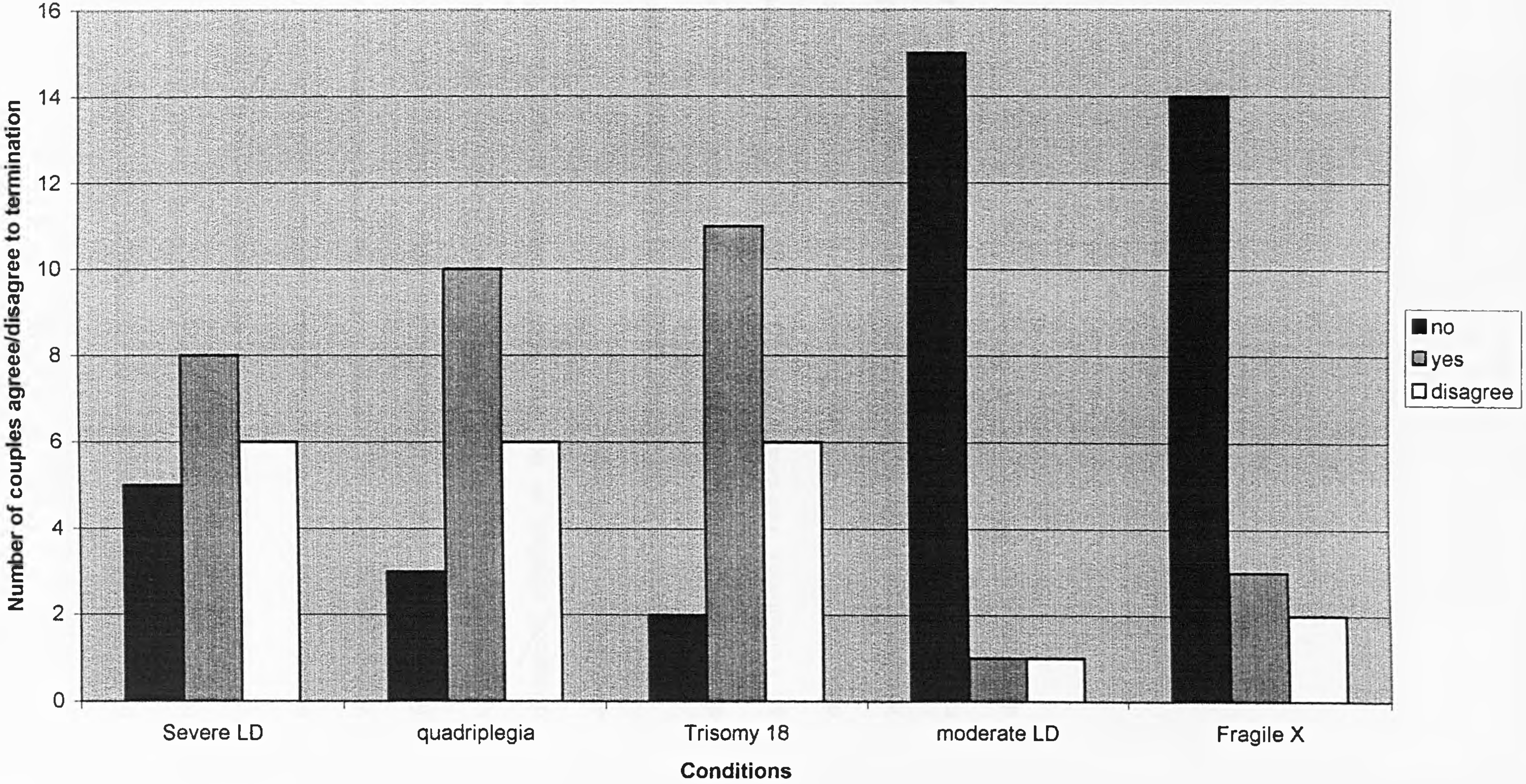
The marginal totals in table 17 show that a small number of men (n=2) and women (n=3) would choose to terminate for moderate learning disability. The McNamar test revealed no significant difference between the men and women at the 5% level of significance. The majority of couples (n=15) agreed that they would not terminate compared to only one couple who agreed they would choose to terminate and 3 (15.8%) couples did not agree whether to choose termination or not for moderate learning disability (see figure IIII, pp 60).

Table 18: Crosstabulation of men (n=19) and women's (n=19) interest in termination for fragile X.

			Women's termination for fragile X		
			NO	YES	TOTAL
Men's termination for fragile X	NO	Count	14	2	16
		% of total	(73.7%)	(10.5%)	(84.2%)
	YES	Count		3	3
		% of total		(15.8%)	(15.8%)
Total		Count	14	5	19
		% of total	(73.7%)	(26.3%)	100%

The results in table 17 revealed that 5 (26.3%) women 3 men (15.8%) were interested in termination for fragile X. A McNamar test revealed that the difference between men and women was not significant at the 5% level of significance. The crosstabulations show that within couples (n=19), 3 (15.8%) couples agreed they would choose termination, 14 (73.7%) agreed they would not choose termination and 2 (10.5%) couples disagreed whether or not to terminate for fragile X (see figure IIII, pp 60).

Figure IIII: A bar chart showing number of couples (max n=19) who choose 'yes', 'no' or 'disagree' to termination for high-burden conditions.



In summary, 10 different comparisons (5 for interest in prenatal testing and 5 for interest in termination) of men and women's paired data for interest in wanting prenatal testing/termination were inspected for high-burden conditions (n=5). The inspection of the data for interest in prenatal testing for all five high-burden conditions showed a trend that there was no difference between the proportions of men and women. Inspection of the crosstabulations revealed that there was more disagreement within couples (n=5) for prenatal testing for moderate learning disability than was found for the other 4 high-burden conditions. Disagreement was found within 3 couples for interest in prenatal testing for both Trisomy 18 and fragile X and 2 couples disagreed whether or not they wanted prenatal testing for both severe learning disability and quadriplegia.

Inspection of the data for termination of high-burden conditions revealed that there was no significant difference between the proportions of men and women across all 5 conditions. The crosstabulations revealed that for the conditions severe learning disability, trisomy 18 and quadriplegia the same number of couples (n=5) disagreed whether or not to choose termination, two couples disagreed for fragile X and only one couple disagreed whether or not to terminate for the condition moderate learning disability.

4.3.3 Interest in prenatal testing for low-burden conditions.

Table 19: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for dwarfism.

			Women's testing for Prenatal dwarfism		
			NO	YES	TOTAL
Men's prenatal testing for dwarfism	**NO**	**Count**	7		7
		% of total	36.8%		38.8%
	YES	**Count**	6	6	12
		% of total	31.6%	31.6%	63.2%
Total		**Count**	13	6	19
		% of total	65.4%	31.6%	100%

The results in table 19 show that a total of 12 (63%) men compared to 6 (31%) women wanted prenatal testing for dwarfism. A McNemar test was performed to see if there was a significant difference in the proportions of men and women wanting prenatal. The test revealed a significant difference between the proportions of men and women (exact sig 0.031) at the 5% level of significance. Observation of the percentages show significant difference between the proportions of men and women was in the direction that more men were interested in prenatal testing for dwarfism than were women. The crosstabulations show that within the 19 couples, 6 (31.6%) couples agreed they would choose prenatal testing, 7 (36.8%) agreed they would not choose prenatal testing and 6 (31.6%) couples disagreed whether or not they would choose prenatal testing for dwarfism See figure V, pp 66 for graphical representation of agreement and disagreement within couples for choosing prenatal testing for low-burden conditions.

Table 20: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for cleft lip + palate.

			Women's prenatal testing for cleft lip +palate		
			NO	YES	TOTAL
Men's prenatal testing for cleft lip+ palate	**NO**	**Count**	9		9
		% of total	47.4%		47.4%
	YES	**Count**	3	7	10
		% of total	15.8%	36.8%	52.6%
Total		**Count**	12	7	19
		% of total	63.2%	36.8%	100%

The results in table 20 show that more men (52%) than women (36%) were interested prenatal testing for cleft lip + palate. However, the McNemar test was not significant (exact sig 0.25) at the 5% level. Therefore, there was no significant difference between the correlated proportions of men and women for interest in prenatal testing for cleft lip + palate. Within couples (n=19) the crosstabulations revealed that 7 (36.8%) couples agreed they were interested in prenatal testing, 9 (47.4%) agreed they were not interested in prenatal testing and there was disagreement within 3 couples whether or not they wanted prenatal testing for cleft lip and palate (see figure V, pp 66)

Table 21: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for Turner's syndrome.

			Women's prenatal testing for turner's syndrome		
			NO	YES	TOTAL
Men's prenatal testing for Turner's syndrome	**NO**	**Count**	8	2	10
		% of total	42.1%	10.5%	52.6%
	YES	**Count**	2	7	9
		% of total	10.5%	36.8%	47.4%
Total		**Count**	10	9	19
		% of total	52.6%	47.4%	100%

The marginal totals in table 21 show that equal number of men and women were interested in prenatal testing for Turner's syndrome. The McNemar test was not significant (exact sig=1.00) at the 5% level of significance. Within couples (n=19), 7 (36.8%) agreed they would choose prenatal testing, 8 (42.1%) couples agreed not to choose prenatal testing and 4 (21.1%) couples disagreed whether or not to choose prenatal testing for Turner's syndrome (see figure V pp 66).

Table 22: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for a coronary at 50 yrs old.

			Women's prenatal testing for coronary		
			NO	**YES**	**TOTAL**
Men's prenatal testing for coronary	**NO**	**Count**	7	2	9
		% of total	36.8%	10.5%	47.4%
	YES	**Count**	4	6	10
		% of total	21.1%	31.6%	52.6%
Total		**Count**	11	8	19
		% of total	57.9%	42.1%	100%

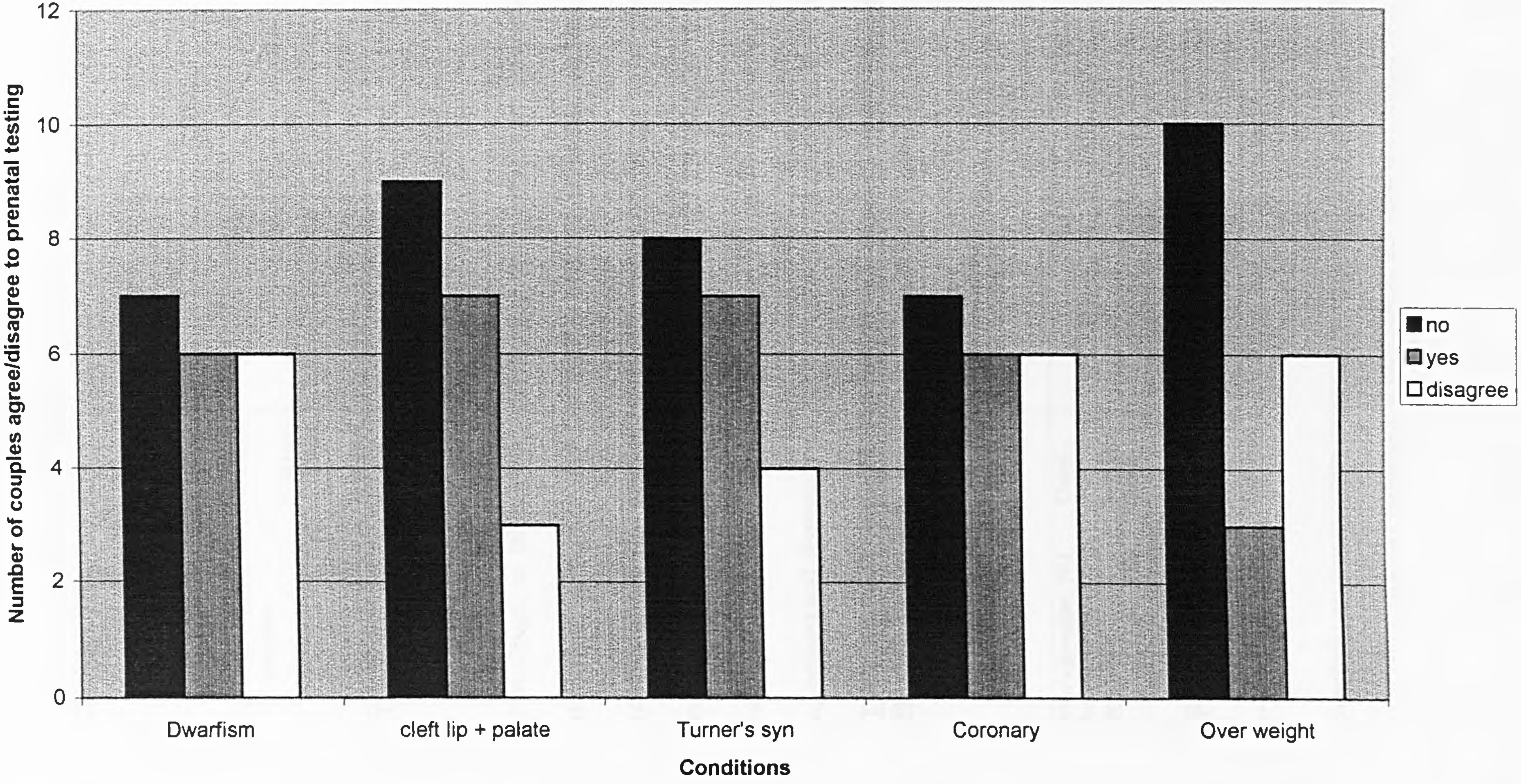
The percentages in table 22 show that slightly more men (52%) than women (42%) were interested in prenatal testing for coronary at 50yrs old. The McNemar test, however, was not significant (exact sig=0.68) at the 5% level. There was no significant difference between the proportions of men and women's interest in wanting prenatal testing for coronary at 50 yrs old. The crosstabulations revealed that 6 (31.6%) couples agreed 'yes' to prenatal testing, 7 (36.8%) couples agreed 'no' to prenatal testing and 6 (31.6%) couples disagreed between 'yes' and 'no' to prenatal testing for coronary at 50 yrs old (see figure V, pp 66 for graphical representation).

Table 23: Crosstabulation of men (n=19) and women's (n=19) interest in prenatal testing for grossly overweight.

			Women's Prenatal testing for overweight		
			NO	YES	TOTAL
Men's prenatal testing for overweight	**NO**	**Count**	10	1	11
		% of total	52.6%	5.3%	57.9%
	YES	**Count**	5	3	8
		% of total	26.3%	15.8%	42.1%
Total		**Count**	15	4	19
		% of total	78.9%	21.1%	100%

One can see from the percentages in table 23 above that more men (42%) than women (21%) were interested in prenatal testing for the condition of being grossly overweight. However, the McNemar test was not significant (exact sig=0.21) at the 5% level of significance. Therefore, there was no significant difference in the proportions of men and women interested in wanting prenatal testing for the condition of being grossly overweight. Within couples (n=19), 3 (15.8%) couples agreed 'yes' for prenatal testing, 10 (52.6%) couples agreed 'no' for prenatal testing and 6 (31.6%) couples disagreed between 'yes' and 'no' for prenatal testing (see figure V, pp 66)

Figure V: A bar chart showing number of couples (max n=19) who choose 'yes', 'no' or 'disagree' to prenatal testing for low-burden conditions.



4.3.4 Interest in termination for low-burden conditions.

Table 24: Percentages of men (n=19) and women's (n=19) interest in termination for dwarfism.

			Women's termination for dwarfism	TOTAL
			NO	
Men's termination for dwarfism	NO	Count	15	15
		% of total	78.9%	78.9%
	YES	Count	4	4
		% of total	21.1%	21.1%
Total		Count	19	19
		% of total	100%	100%

Percentages in table 24 show that more men (21%) were interested termination for dwarfism. No women were interested in termination for this condition. Within couples (n=19), 15 (78.9%) couples agreed they would not choose termination, there were no couples who chose 'yes' to termination and 4 (21.1%) couples disagreed whether or not to terminate for dwarfism. See figure VI, pp 70 for graphical representation of agreement and disagreement within couples for termination of low-burden conditions.

Table 25: Percentages of men (n=19) and women's (n=19) interest in termination for cleft lip + palate.

			Women's termination for cleft lip +palate	TOTAL
			NO	
Men's prenatal testing for cleft lip+ palate	NO	Count	18	18
		% of total	94.7%	94.7%
	YES	Count	1	1
		% of total	5.3%	5.3%
Total		Count	19	19
		% of total	100%	100%

Similarly, no women were interested in termination for cleft lip +palate table and one man (5%) who was interested in termination for cleft lip + palate (See table 25 above).

The majority of couples (n=18) agreed they would not choose termination and only one couple disagreed whether or not to terminate for cleft lip and palate (see figure VI, pp 70)

Table 26: Crosstabulation of men (n=19) and women's (n=19) interest in termination for Turner's syndrome.

			Women's termination for Turner's syndrome		
			NO	YES	TOTAL
Men's termination for Turner's syndrome	NO	Count	16		16
		% of total	84.2%		84.2%
	YES	Count	2	1	3
		% of total	10.5%	5.3%	15.8%
Total		Count	18	1	19
		% of total	94.7%	5.3%	100%

Observation of the data in table 26 shows there were more men (15%) than women (5.3%) who were interested in termination for Turner's syndrome. However, no significant difference was found, using the McNemar test, at the 5% level of significance. The crosstabulations revealed that there was agreement within 16 (84.2%) couples not to terminate, 1 (5.3%) couple agreed they would terminate and 2 (10.5%) couples disagreed whether to terminate or not for Turner's syndrome (see figure VI, pp 70).

Coronary at 50 yrs old

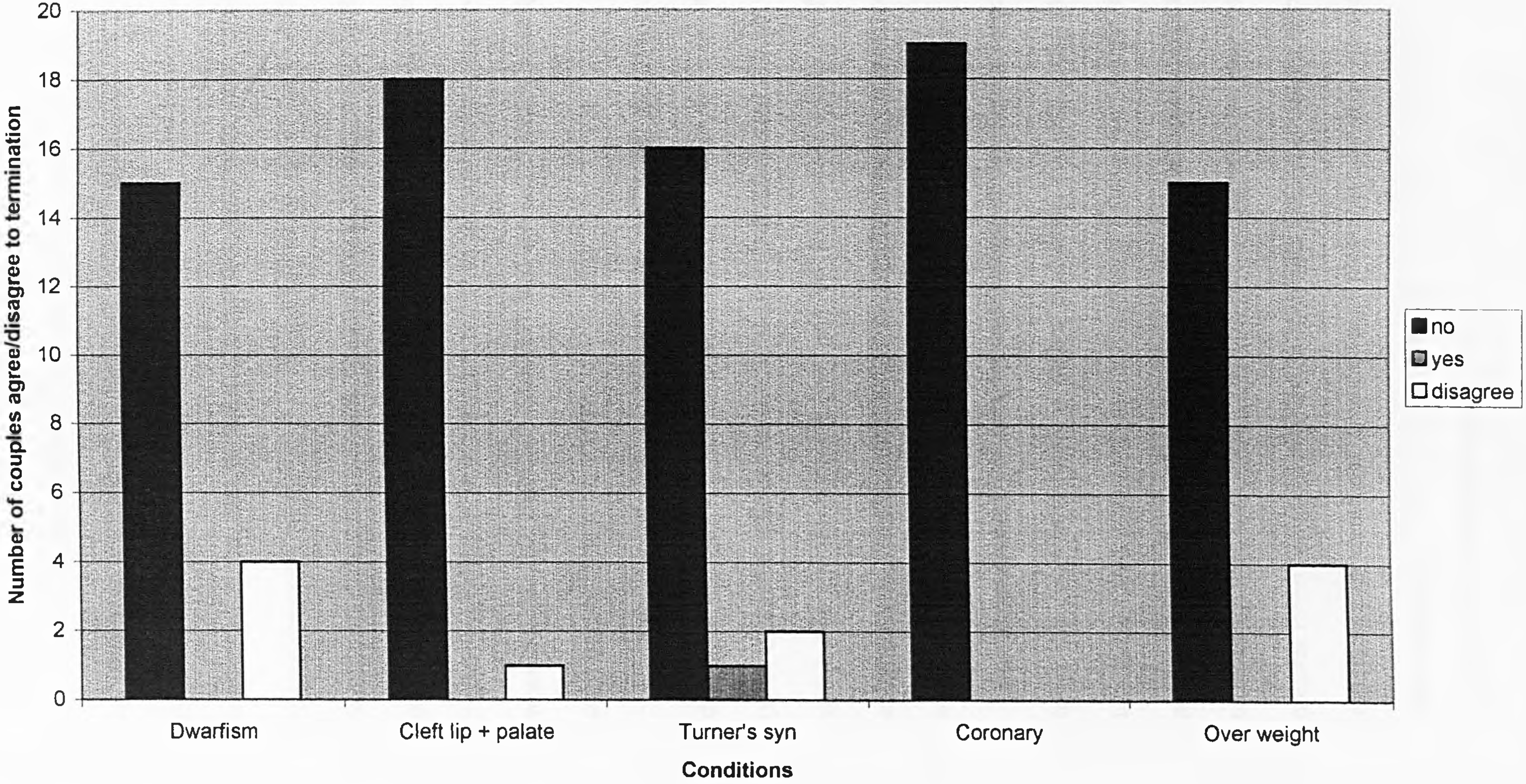
Of the 19 men and 19 women there was no one who was interested in termination for a coronary at 50 yrs old, therefore there was agreement within all couples (n=19) not to choose termination for coronary at 50yrs old (see figure VI, pp 70).

Table 27: Crosstabulation of men (n=19) and women's (n=19) interest in termination for grossly overweight.

			Women's testing for prenatal overweight		
			NO	YES	TOTAL
Men's prenatal testing for overweight	**NO**	**Count**	15	2	17
		% of total	78.9%	10.5%	89.5%
	YES	**Count**	2		2
		% of total	10.5%		10.5%
Total		**Count**	17	2	19
		% of total	89.5%	10.5%	100%

The marginal totals in table 27 show that equal number of men (n=2) and women (n=2) were interested in termination of pregnancy for the condition of being grossly overweight. The crosstabulations show that 15 (78.9%) couples agreed they would not choose termination and 4 (21.1%) couples disagreed whether or not to choose termination for the condition of being grossly over weight (see figure VI, pp 70).

Figure VI: A bar chart showing number of couples (max no=19) who choose 'yes', 'no' or 'disagree' to termination for low-burden conditions.



In summary, 10 different comparisons (5 for interest in prenatal testing and 5 for interest in termination) of men and women's paired data for interest in wanting prenatal testing/termination were inspected for low-burden conditions (n=5). Inspection of the data revealed a trend that men were more interested in prenatal testing than were women in 4 of the conditions. In one of the 4 conditions there was a significant difference between the proportions of men and women for interest in prenatal testing for dwarfism. And the observed difference was in the direction that a higher proportion of men were interested in prenatal testing for dwarfism than were women. For one condition both men and women's scores were equivalent for the condition of Turner's syndrome.

The crosstabulations revealed that for 3 of the low-burden conditions, dwarfism, coronary at 50 yrs old and grossly over weight, the same number of couples (n=6) disagreed whether or not to choose prenatal testing. There was disagreement within 4 couples for choosing 'yes' and 'no' for prenatal testing for Turner's syndrome and there was disagreement within 3 couples for choosing prenatal testing for cleft lip + palate.

Inspection of the data for termination of low-burden conditions revealed a trend that in 4 conditions a higher proportion of men were more interested in termination than were women. For the condition being over weight, men and women's scores were equivalent. There were no conditions that women were more interested in termination than were men. The crosstabulations revealed that the same number of couples (n=4) disagreed whether to terminate for the condition of being grossly over weight and for dwarfism. Disagreement within two couples was found for choosing termination for Turner's syndrome and one couple disagreed whether or not to terminate for cleft lip and palate.

4.3.5 Differences across conditions within groups of men and women.

The data was coded as described above, 'No' and 'Not Sure', were coded as 1, and 'Yes' was coded as 2. Analysis was conducted, using Cochran's Q, to ascertain whether there were differences in proportions of 'Yes' for interest in prenatal testing and termination across conditions within groups of men (n=19) and women (n=19). There was a significant difference in proportions of those interested in prenatal testing across conditions within the men's group (Cochran's Q= 103.295, df =29, $p<0.001$). The difference in proportions is significant at the 0.01 level. There was also a significant difference in proportions of those interested in termination across conditions within the men's group (Cochran's Q=229.356, df=29, $p<0.001$). The difference in proportions is significant at the 0.01 level.

The same analysis was conducted for the women's group. There was a significant difference in proportions of those interested in prenatal testing across conditions within the women's group (Cochran's Q=126.953, df=29, $p<0.001$). The difference in proportions is significant at the 0.001 level. Similarly, there was a significant difference in proportions of those interested in termination across conditions within the women's group (Cochran's Q=217.076, df=29, $p<0.001$). The difference in proportions is significant at the 0.001 level.

The results therefore, indicate that there is a high level of agreement within the group of men regarding which were more or less severe conditions when considering prenatal testing and termination. Similarly, within the group of women there is a high level of agreement regarding which were more or less severe conditions for both interest in prenatal testing and termination. Within both groups there was significant differences across conditions for both prenatal testing and termination. Conditions were not treated as homogenous within the male and female groups.

The results discussed so far have been on the paired data of men (n=19) and women (n-19). Therefore, in the next section, analysis of the whole sample of 20 men and 36 women has been explored, including analysis conducted on the paired and unpaired samples of women to ascertain if there were differences between the two samples.

4.3.3 Differences in paired-women (n=19) and unpaired-women's (n=17) interest in wanting prenatal testing and termination across conditions.

Represented in tables 28 & 29 (Appendix 11 & Appendix 12) the percentages of men (n=20) and women's (n=36) scores, for interest in prenatal testing and termination of pregnancy, on the ATP questionnaire across conditions. Nineteen of the men had a female partner, giving 19 paired men and women. No significant differences were found from any of the paired analysis, see above for results. The sample of unpaired men (n=1) was not large enough to compare paired and unpaired men. However, there were 36 female participants, 19 were paired women and 17 non-paired thus, the groups were large enough to analyse for differences. The analysis of differences between paired and non–paired women was conducted to find out if the results of the paired analyses were representative of the entire sample of women.

All the women's (n=36) scores on the ATP were given the numeric values of, 'yes'=2, 'not sure'=1 and 'no'=0, for considering prenatal testing and for considering termination for the each condition (n=30). The total scores were analysed for skewness and were found to be reasonably normally distributed thus conformed to parametric status. Therefore, independent samples t-tests were used to test any significant differences between the paired-women (19) and the unpaired- women's mean scores for prenatal testing and for termination, see table 30 below.

Table 30: Means, standard deviations and independent sample t-tests for interest in wanting prenatal testing and termination scores across conditions by paired and unpaired women.

	Paired women (n=19) Mean (Max value of 60) Std deviation	Unpaired Women (n=17) Mean (Max value of 60) Std deviation	t.value	Sig (2-tailed)
Prenatal testing	35.5 (18.03)	37.82 (19.45)	-.35	.72
Termination	20.31 (11.32)	13.70 (2.06)	1.99	.60

As represented in table 30 above, the independent samples t-test for interest in prenatal testing revealed no significant difference between the mean scores of the two groups (t-value=-.35, df=34, 2-tailed sig=.72, p>.05) at the 5% level of probability. Similarly, for interest in termination, no significant difference was found between the mean scores of the two groups (t-value=1.99, df=34, 2-tailed sig= 0.6 p>.05). There were no significant difference between the paired and non-paired women for interest in prenatal testing and termination therefore the 19 paired women were considered to be representative of the whole sample of women.

4.3.7 The overall level of interest in prenatal testing and termination of pregnancy, across all conditions, for the whole sample.

The data from the ATP questionnaire from all participants (n=56) was numerically coded directly form the questionnaire as; 'No'=1, 'Yes'=2, and 'Not Sure'=3 and put onto to the statistical data-base SPSS. The data was analysed for frequencies, see appendix 11 table18, for numbers and percentages of men (n=20) and women's (n=36) scores for interest in wanting prenatal testing across conditions. Also, see appendix 12 table 19, for numbers and percentages of men (n=20) and women's (n=36) scores for interest in termination of pregnancy across conditions (n=30).

4.3.8. Similarities of the severity judgment of condition within groups of men (n=20) and women (n=36)

Analyses was conducted to ascertain whether the severity of judgement of condition was similar within the two groups and whether there was agreement within the groups on high and low ranking conditions. The analysis was conducted on the whole sample's (n=36 women and n=20 men) data. The percentages of men and women who indicated 'yes' for interest in prenatal testing and termination were put on the SPSS data-base by condition. See table 31 for percentages and rank order of male and female frequencies for interest in prenatal testing by condition (n=30). See also table 32 for the percentages and rank order of male and female frequencies for interest in termination of pregnancy by condition (n=30).

Table 31: Percentages and rank order of men and women's frequencies of interest in prenatal testing by condition.

Condition	Men (n=20)	Rank Order	Women (n=36)	Rank Order
1. Severe learning dis	16 (80%)	28	29 (81%)	28
2. Quadriplegia	16 (80%)	28	28 (78%)	26
3. Dwarf	12 (60%)	21	12 (33%)	5
4. Cleft lip and palate	10 (50%)	10	15 (42%)	8
5. Alzheimer's	9 (45%)	6	15 (42%)	8
6. Turner's syndrome	9 (45%)	6	18 (50%)	11
7. Trisomy 13	16 (80%)	28	32 (88%)	29
8. Mild learning dis	10 (50%)	10	16 (44%)	9
9. Anencephaly	18 (90%)	30	33 (92%)	30
10. Thalassaemia	11 (55%)	14	23 (64%)	21
11. Coronary at 50	10 (50%)	10	12 (33%)	5
12. Cystic fibrosis	12 (60%)	21	21 (33%)	5
13. Alcoholism	5 (25%)	1	11 (30%)	3
14. Mod learning dis	11 (55%)	14	20 (55%)	15
15. K'felter's synd	7 (35%)	2	18 (50%)	11
16. Proteus syndrome	9 (45%)	6	19 (52%)	13
17. Grossly o' weight	8 (40%)	3	11 (30%)	3
18. Phyenylketonuria	11 (55%)	14	21 (58%)	17
19. Deafness	11 (55%)	14	20 (55%)	15
20. Schizophrenia	12 (60%)	21	20 (55%)	15
21. Huntington's	12 (60%)	21	23 (64%)	21
22. Autism	12 (60%)	21	22 (64%)	21
23. Muscular Dyst	15 (75%)	26	29 (80%)	27
24. Fragile X syn	12 (60%)	21	22 (61%)	19
25. Blindness	11 (55%)	14	22 (61%)	19
26. Bowel Cancer	12 (60%)	21	18 (50%)	11
27. Epilepsy	12 (60%)	21	24 (66%)	23
28. Diabetes	10 (50%)	10	26 (72%)	24
29. Absent limb	13 (65%)	25	27 (75%)	25
30. Not prefer gender	9 (45%)	5	5 (14%)	1

Abbreviations

1. dis = disability
2. syn= syndrome

Condition

1 =Severe learning disability
8 =Mild learning disability
14 = Moderate learning disability
15 = Klinefelter's syndrome
17 = Grossly over weight
21 = Huntington's disease
23 =Duchenne muscular dystrophy
29 = Absent/ dysfunctional limb
30 = Not preferred gender

Table 32: Percentages and rank order of man and women's frequencies of interest in termination by condition.

Condition	Men (n=20)	Rank Order	Women (n=36)	Rank Order
1. Severe learning dis	12 (60%)	27	19 (53%)	28
2. Quadriplegia	15 (75%)	29	14 (39%)	26
3. Dwarf	4 (20%)	20	0	4
4. Cleft lip and palate	1 (5%)	7	1 (3%)	9
5. Alzheimer's	1 (5%)	7	1 (3%)	9
6. Turner's syndrome	3 (15%)	17	1 (3%)	9
7. Trisomy 13	15 (75%)	29	25 (69%)	29
8. Mild learning dis	0	2	0	4
9. Anencephaly	18 (90%)	30	33 (92%)	30
10. Thalassaemia	4 (20%)	20	11(31%)	25
11. Coronary at 50	0	2	0	4
12. Cystic fibrosis	6 (30%)	24	8 (23%)	24
13. Alcoholism	0	2	0	4
14. Mod learning dis	2 (10%)	13	4 (11%)	17
15. K'felter's synd	2 (10%)	13	5 (14%)	20
16. Proteus syndrome	1 (5%)	7	4 (11%)	17
17. Grossly o' weight	2 (10%)	13	2 (6%)	12
18. Phyenylketonuria	2 (10%)	13	0	4
19. Deafness	2 (10%)	13	0	4
20. Schizophrenia	7 (35%)	25	6 (17%)	22
21. Huntington's	6 (30%)	24	6 (17%)	22
22. Autism	5 (25%)	22	4 (11%)	17
23. Muscular Dyst	12 (60%)	27	18 (50%)	27
24. Fragile X syn	3 (15%)	17	7 (20%)	23
25. Blindness	3 (15%)	17	2 (6%)	12
26. Bowel Cancer	5 (25%)	22	3 (8%)	14
27. Epilepsy	1 (5%)	7	4 (11%)	17
28. Diabetes	1 (5%)	7	5 (14%)	20
29. Absent limb	2 (10%)	13	3 (8%)	14
30. Not prefer gender	1 (5%)	7	0	4

Abbreviations

3. dis = disability
4. syn= syndrome

Condition

1 =Severe learning disability
8 =Mild learning disability
14 = Moderate learning disability
15 = Klinefelter's syndrome
17 = Grossly over weight
21 = Huntington's disease
23 =Duchenne muscular dystrophy
29 = Absent/ dysfunctional limb
30 = Not preferred gender

A rank order Spearman's rho correlations was used to analyse the relationship between men's and women's scores by condition for prenatal testing (rho=0.745, p<0.001) The correlation is significant at the 0 .01 level (2-tailed) See figure VII for a graphical representation of the correlation. Similarly, a rank order Spearman's rho correlations was used to analyse the relationship between men's and women's scores by condition for termination of pregnancy (rho=0.745, p<0.001). The correlation is significant at the 0.01 level (2-tailed) see figure VIII for a graphical representation of the correlation. These results shows for both interest in prenatal testing and termination of pregnancy there was a high level of agreement between men and women regarding which were more or less severe conditions.

Figure VII: A scatter plot showing the percentages of men and women's scores for interest in prenatal testing across conditions.

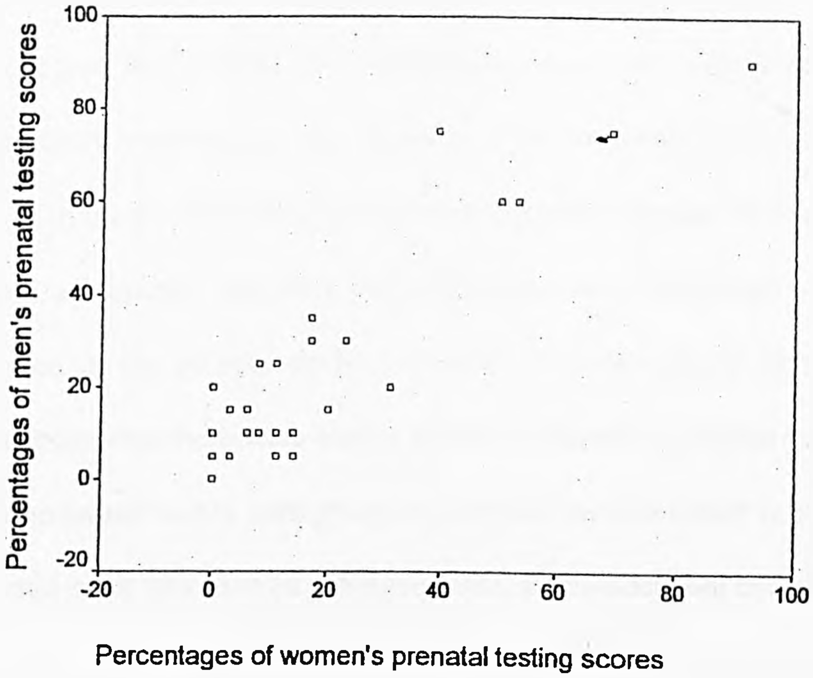
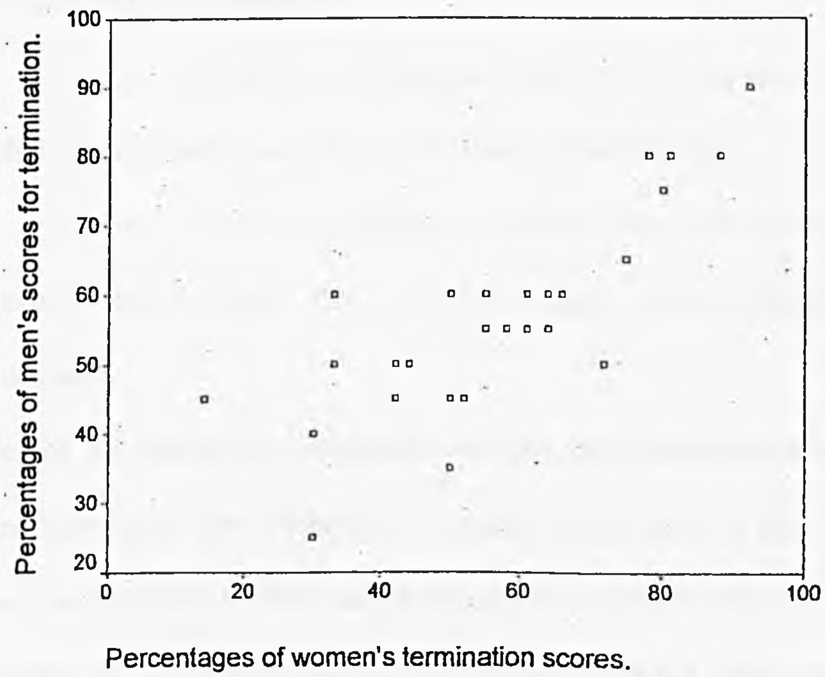


Figure VIII: A scatter plot showing the percentages of men and women's scores for interest in termination across conditions.



Inspection of the percentages and rank orders of men and women's frequencies for interest in prenatal testing across all conditions show larger discrepancies between men and women's percentages and ranking for the conditions dwarfism, cystic fibrosis and diabetes. Inspection of the percentages and rank orders of men and women's frequencies for interest in termination across all conditions show the largest discrepancy between men and women's scores for the condition dwarfism.

In the present study, interest in prenatal testing and interest in termination were treated as separate variables and differences and similarities were not explored or analysed in the present study. However, it is recognised from observation of the frequencies that there were higher levels of interest in prenatal testing than there were for termination within both groups of men and women which is consistent with what is reported in the literature (e.g. Singer, 1993; Evers-Kieboom et al 1993).

4.4 Qualitative information

The ATP questionnaires returned by the 36 women and 20 men only contained a few brief responses to the qualitative sections of the questionnaire. Seventeen (47%) of the women and 6 (30%) of the men gave some qualitative information in response to the following two questions:

Question 1: Is there anything you would like to say about how your religious beliefs have influenced your decisions about prenatal testing.

Question 2: Is there anything you would like to say about factors that have influenced the decisions that you have made about prenatal testing in this questionnaire.

Therefore, the qualitative information was not analysed systematically because of the limited amount of data. However, an attempt was made to pull out some common themes that appeared to relate to the quantitative findings. There were three themes, 1) the quality of life of the child, 2) the amount of care a child would require and 3) cosmetic reasons, which influenced some respondents decisions whether to terminate an affected foetus and/or to have prenatal testing.

4.4.1 Quality of life and the amount of care a child would require

The comments below were individual responses by women to question 2.

"*Depending on the severity of the condition a child might be born with would make me consider termination, for the sake of the quality of life that the child would have and also the strain it would have on myself and my partner*".

"*The only reason I would consider termination would be if I thought the child would have no quality of life or what life they had would only cause them suffering. If I thought my other children would suffer because of the constant care needed and also who would care for them should anything happen to me*".

"*Whilst answering the questions I tried to focus on the quality of life the child may have rather than how difficult it would be to care for the child*".

The above comments reveal how individual opinions and attitudes, even within a particular gender, concerning prenatal testing and termination of pregnancy can be opposing. In the first comment, the women expressed the view that she considered the severity of condition, and the burden the child would have on her and her partner, would determine if she would terminate a pregnancy or not. The comment seemed to imply, the more severe the condition and the more care required, the more likely she was to choose termination. The second comment conveyed similar views to the first women. The third comment also stated that considering the quality of life of the child was an important factor that influenced in her decision-making. However, as regards the burden the child would put on the family, the women implied that she could make a conscious effort not to consider this factor whilst making her decisions, as if she was trying to perceive what life would be like entirely from the child's perspective.

One man commented;

" I think medical testing is excellent. Life is hard enough without medical disabilities. This can cause a strain on the relationships and family. I also think it is only fair on the child if any disabilities is found that it should not suffer a restricted life"

His decision-making process was also influenced by the quality of life the child would have and the strain /burden the child would place on the family.

4.4.2 Cosmetic reasons for and against prenatal testing and termination of pregnancy

One woman commented:

1.Whether the condition is cosmetic (e.g. height)-testing should not be available".

The women expressed the view that testing should not be available for detecting cosmetic differences.

The following comment's made by two men seem to present opposing opinions concerning what importance to place on the appearance of a child and how prenatal testing should be used.

"I think testing is important if it can determine a life threatening/changing illness. I do not agree with screening for cosmetic reasons, as it is too easy for people to terminate if the baby does not fit in with there requirements".

"I believe in prenatal testing as a matter of procedure. I feel this should happen without choice. My parents don't have the capacity to look after many of the children features in your questionnaire. I think looks (as normal a possible) and the ability to communicate are important confidence factors in every day life".

These comments show how within the same gender there can be completely opposing points of view. One man considers ‘looking as normal as possible’ to be an important factor when considering prenatal testing and termination of pregnancy and the other man did not agree with prenatal testing for cosmetic reasons.

Conclusions cannot be drawn from the qualitative information because of the limited data. However, the comments do highlight how important it is not to make assumptions as to why people would be interested in prenatal testing and termination of pregnancy and that there are individual differences both within and between the genders.

4.5. Summary of results

- A sample of 20 men and 36 women participated in the study.
- Both groups of men and women were comparable on demographic variables such as, age, cohabiting/marital status and education. All women had recently had a baby.
- Within the sample were 19 couples/pairs of men and women.
- No significant difference was found between men and women pairs (n=19) for overall level of interest in wanting prenatal testing across all conditions.
- No significant difference was found between men and women pairs (n=19) for overall level of interest in wanting termination across all conditions.
- No significant difference was found between men and women pairs (n=19) for interest in wanting prenatal testing for high-burden or for low-burden conditions.
- No significant difference was found between men and women pairs (n=19) for interest in wanting termination for high-burden or for low-burden of care conditions.
- There was a significant difference in proportions of those interested in prenatal testing across conditions within both the women's and men's groups.
- Similarly, there was a significant difference in proportions of those interested in termination across conditions within both men's and the women's group
- No significant differences between paired-women (n=19) and unpaired-women's interest in wanting prenatal testing/termination across all conditions. The paired women's sample was therefore considered representative of the whole sample of women.

4.5.1 Summary of exploratory results

- For high-burden conditions there was a trend that men's mean scores were slightly higher than women's mean scores for both prenatal testing and termination.
- For low-burden conditions there was a general trend that men's mean scores were higher than women's mean scores for both prenatal testing and termination.
- 10 different comparisons (5 for prenatal testing and 5 for termination) of men and women's paired data for interest in wanting prenatal testing/termination were inspected for both high-burden conditions and low-burden conditions (n=5).
- Inspection of high-burden conditions for prenatal testing showed a trend that there was no difference between the proportions of men and women.
- The cross tabulations revealed that there was more disagreement within couples (n=5) for prenatal testing for moderate learning disability.
- Disagreement was found within 3 couples for interest in prenatal testing for both Trisomy 18 and fragile X, 2 couples disagreed concerning prenatal testing for both severe learning disability and quadriplegia.
- There was no significant difference in proportions of men and women for termination all high burden conditions
- Within 5 couples there was disagreement concerning whether or not to terminate for, severe learning disability, trisomy 18 and quadriplegia.
- Inspection low-burden conditions for prenatal testing revealed a trend that in 4 cases, men were more interested in prenatal testing than were women.

- In one of the 4 cases the difference was found to be significant for the condition dwarfism in the observed direction that men were more interested than women.
- Crosstabulations revealed that for dwarfism, coronary at 50 yrs old and grossly over weight the same number of couples (n=6) disagreed whether or not to choose prenatal testing, similarly within 4 couples there was disagreement for the condition Turners' syndrome and within 3 couples for cleft lip +palate.
- Inspection of the termination cases revealed that in 4 cases men were more interested in wanting termination than were women.
- In one case men and women's scores were equivalent for the condition of being grossly over weight.
- There were no cases found of women being more interested in wanting prenatal testing or termination than men for low-burden conditions.
- Crosstabulations revealed that the same number of couples (n=4) disagreed whether or not to terminate for the conditions being grossly over weight and dwarfism. Also disagreement within two couples was found for termination of Turner's syndrome and one couple disagreed concerning termination for cleft lip +palate.
- Exploration of the entire sample (20 men and 36 women), across all conditions, revealed that there were larger discrepancies, of men and women's percentages and rank order for the conditions dwarfism, cystic fibrosis and diabetes.
- Inspection of the percentages and rank orders of the entire sample of men and women's scores for interest in termination across all conditions show the largest discrepancy for the condition dwarfism.
- Correlations of the entire sample of men and women's interest in wanting prenatal testing and termination were found to be significant across conditions.

CHAPTER 5: DISCUSSION

The discussion will be divided into three sections: a discussion of the main research findings, limitations of research and suggestions for future research, and finally clinical implications of the present study.

5.1 Research findings

The main aim of the study was to investigate gender differences in attitudes to prenatal testing for a number of conditions that can be detected by a hypothetical non-invasive prenatal test. A sample of twenty men and thirty-six women participated in the study and completed Attitudes to Prenatal Testing (ATP) questionnaires. All women had recently had a baby (babies mean age 46.6 days). The groups of men and women were matched on demographic variables such as, age, cohabiting/marital status and education. Half the sample of women (50%) and just over half the sample of men (58%) had a child or children living at home at the time of the study. Religious affiliation varied between the genders and across Christian denominations, 17% of women and 42% men reported they had no religious affiliation, only two women reported that their religious beliefs had influenced their decisions about prenatal testing. All women had had routine antenatal tests such as, routine blood tests and ultrasound scans. Six women had had the nuchal translucency test. Twenty of the women had had a previous pregnancy during which they had routine tests and ultrasound scans but no other tests.

Statistical analysis, carried out on the entire sample (20 men and 36 women), showed no significant difference between the two groups for interest in prenatal testing or termination across all conditions (n=30). Within the sample of 20 men and 36 women were nineteen couples. Statistical analyses were carried out on the sample of couples (n=19) to test hypothesis 1 and 2. Exploratory analysis was also carried out to observe patterns and trends in the data.

5.1.2 High-burden of care and prenatal testing

Hypothesis 1, predicted the greater the level of the burden of care required for a particular abnormality the more likely women would choose prenatal testing than men. The high-burden conditions were as follows: severe learning disability, quadriplegia, trisomy 18, (Edward's syndrome), moderate learning disability and fragile X. Statistical analysis, carried out on the data for interest in prenatal testing for high-burden conditions from the Attitudes to Prenatal Testing (ATP) questionnaire, showed no significant difference between the paired men and women thus, hypothesis 1 was not supported.

The exploratory analysis of the paired data (n=19 couples) revealed a trend that there was no observable difference between the proportions of men and women for interest in prenatal testing for the high-burden conditions. However, there were certain conditions for which there was disagreement within couples concerning whether or not to choose prenatal testing or/and termination. For the condition moderate learning disability more couples disagreed (n=5) whether or not they would choose prenatal testing than was found for the other 4 high-burden conditions. There was also disagreement within three couples for the conditions Trisomy 18 and fragile X and two couples disagreed whether or not they wanted prenatal testing for severe learning disability and quadriplegia.

5.1.3 High–burden of care and termination

Hypothesis 2, predicted the greater the level of burden of care required for a particular abnormality the more likely that women would choose termination than would men. Statistical analysis, carried out on the data for the interest in termination for high-burden conditions showed no significant difference between the paired men and women. Inspection of the mean scores of men and women for both, interest in prenatal testing, and termination of pregnancy, revealed a trend that scores for the men and women were almost equivalent.

These findings may suggest that couples are equally keen to have prenatal tests. Similar findings were found in a study by Sjogren (1992) who interviewed twenty men between six to seven weeks after their partners had received normal Prenatal Diagnostic (PND) test results. Sjogren (1992) found that the majority of the men considered that they themselves and their partners were equally motivated for PND.

The exploratory analysis of the paired data (n=19 couples) revealed that for interest in termination for the high-burden conditions there was a trend showing no difference between the proportions of men and women. However, there were certain conditions for which there was disagreement within couples concerning whether or not to choose termination. For example, there were the same number of couples (n=5) who disagreed whether or not to terminate for the conditions severe learning disability, trisomy 18 and quadriplegia, two coiuples disagreed for fragile X and one couple disagreed concerning termination of moderate learning disability.

5.1.4. Low-burden of care

Although there was no specific hypothesis relating to low-burden of care conditions statistical analyses were conducted. Low-burden of care conditions were as follows: dwarfism, cleft lip + palate, Turner's syndrome, coronary heart disease at 50yrs old and being grossly over weight. No significant differences were found between the men and women pairs for either, interest in wanting prenatal testing, or interest in wanting termination for low-burden conditions. However, observation of the mean scores for low-burden conditions for both prenatal testing and termination showed a trend in the direction that men's scores were higher than those of women. These findings appeared to be in the opposite direction to what one would have predicted.

Therefore, the results of the low-burden conditions were inspected using exploratory analysis. The results revealed that for the majority of low-burden conditions the trend was in the direction that men were more interested in prenatal testing and termination than women. In the case of dwarfism the results showed a significant difference in the direction that men were more interested in prenatal testing than were women. Disagreement was found within 6 couples concerning whether or not to choose prenatal testing for the conditions dwarfism, coronary at 50years old and being grossly over weight. Also disagreement was found within 4 couples concerning prenatal testing for the condition Turner's syndrome and within 3 couples for cleft lip + palate.

As regards termination of pregnancy for dwarfism, no women were interested in termination for the condition, compared to 21 % of men. In the case of interest in testing for prenatal testing for Turner's syndrome men and women scores were equivalent. Similarly, interest in termination for the condition being grossly over weight was the same for men and women. Disagreement within 4 couples concerning termination was found for conditions being grossly over weight and dwarfism and 2 couples disagreed whether or not to terminate for cleft lip and palate.

In summary, there were slightly more couples who disagreed concerning prenatal testing for low-burden conditions than for high-burden conditions and slightly more couples who disagreed concerning termination of high burden conditions than for low-burden conditions. Some understanding about these disagreements (e.g. what conditions couples are more likely to disagree about) within couples is particularly useful for health professionals when considering what psychological and practical help may be required to facilitate couples through very difficult decision making processes of whether or not to terminate a pregnancy. Furthermore, it is important for health professionals to be mindful of the significant psychological stress placed upon a couple's relationship when there is a difference of opinion concerning such life changing issues.

The results from this study found there were more couples who disagreed whether to terminate for the conditions, severe learning disability, Trisomy 18, quadriplegia, dwarfism and being grossly over weight than for any of the other high or low-burden conditions. These conditions are so varied, from those that require a lot of looking after, with a disability of a physical nature such as, quadriplegia, or with an intellectual disability such as, severe learning disability. Others, such as dwarfism and being over weight, do not require a lot of looking after, have no intellectual deficits, and are conditions which are visibly noticeable.

Why couples disagree concerning termination for these particular conditions is a question beyond this study to answer and would need further qualitative research to investigate such a complex question. However, the results of the study show that conditions for which couples disagree about concerning termination are very varied and health professionals need to be able to offer the appropriate counselling to help couples to talk about and hopefully to help them resolve there differences. Health professionals need to be able to direct the couple to those professionals who can offer them expert advice and/or information on the particular condition of their unborn child.

5.1.5 Differences across conditions within groups of men and women.

Within the male group there were highly significant differences in proportions of those interested in prenatal testing and termination across all conditions. Thus, there were differences, within the group of men, in their attitudes to prenatal testing and termination for different conditions indicating that men did not treat conditions as homogenous. Similarly, within the female group there were highly significant differences in proportions of those interested in prenatal testing and termination across conditions. Thus, women did not treat the conditions as homogenous.

In order to find out if the paired-women's (n=19) results were representative of the whole sample of women, statistical analyses was conducted. For interest in prenatal testing, and interest in termination of pregnancy, across all conditions, there were no significant differences found between the paired-women (n=19) and unpaired-women's (n=17) scores. Thus, one can assume that the nineteen paired-women's results as discussed above are representative of the women in the whole sample and are more likely to generalise to the wider population.

Further, exploratory analyses on the entire sample (20 men and 36 women) were conducted to inspect if the severity of judgement of condition was similar for within the groups of men and women and to look for agreement between the groups for high-ranking conditions. A significant correlation was found between men and women across conditions for interest in prenatal testing. From observation of the rank order of conditions for interest in prenatal testing one could see that there was less agreement between the groups for the conditions dwarfism, cystic fibrosis and diabetes. The trend was in the direction that men ranked dwarfism and cystic fibrosis higher in severity than did women. However, women ranked the condition diabetes higher in severity than men.

conditions for interest in termination show high levels of agreement of the severity of conditions within the groups of men and women, except for the condition dwarfism. For the condition dwarfism there was a large discrepancy between the groups in the direction that men's ranking was higher in severity than women's ranking of dwarfism. Therefore, there appears to be high level of agreement of severity of conditions between men and women except in the case of dwarfism.

On the whole there appears to be a general trend in the results that suggests men express as much interest in both prenatal testing and termination of pregnancy across conditions as women do. Furthermore, there is a trend that men are slightly more interested in prenatal testing and termination for low-burden of care conditions. One can only speculate as to why this is the case. For example, it is widely reported that men generally take a supportive role towards their partners during pregnancy, childbirth and caring for children (Sommer-Smith, 1999). The supportive role of a man may influence his decision when considering the burden a child with disability would have on his partner and therefore more likely to want to terminate an affected foetus. Two men in the study expressed their concern of the burden a disabled child would have on the family.

Furthermore, fathers 'hands on' experience of caring for children, gained through their increased involvement in child-care within the home as reported in the literature (Heaman, 1995; Cabrera, 2000), may have had an affect on their attitudes to prenatal testing and termination making them comparable to the attitudes of women. Another speculative explanation may be that the couples in the study had similar views to each other on important life issues such as prenatal testing and termination and therefore expressed similar attitudes.

Concerning the low-burden of care conditions, one could speculate that men, more than women, are influenced by what a child would look like when making decisions about prenatal testing and termination. For example, dwarfism, is a condition that is visibly recognisable and for which more men were interested in prenatal testing than women. Furthermore, low burden conditions such as, cleft-lip and palate and being grossly over weight are physically visible conditions and although there were no significant differences between the genders, there was a trend that showed that men were more interested in prenatal testing for these conditions than were women. However, there were some conflicting comments made by men in the study concerning using prenatal testing and termination for cosmetic reasons. One man said he thought termination for cosmetic reasons was acceptable as another man said that it was unacceptable.

Whilst considering these findings one must keep in mind that attitudes towards prenatal testing and in particular termination are complex. For example, a person might hold a favourable, or unfavourable attitude towards people with severe learning disability, and they might also hold a favourable or unfavourable attitude towards terminating a pregnancy for severe learning disability (Greenwald, 1989; Rothenberge & Thompson, 1994).

However, one can only speculate why there is a trend, that men are at least equally and in some cases more interested in termination of pregnancy and prenatal testing than women. In addition, one must be cautious when interpreting the results and mindful that the more robust parametric statistical analyses were not significant when analysing the gender differences in attitudes to prenatal testing and termination and that the speculative explanations arose from the exploratory data which revealed a trend that there were some differences between the genders. Although the present study aimed for 50 couples, as reported above, only 19 couples participated thus, the sample size is small and with a larger sample size the results may have reached significance.

5.2 Limitations of the research and implications for further research

The recruitment aim of the study was to recruit 100 couples on the expectation that there would be a 50% response rate for the postal questionnaires (Robson, 1993). However, due to the limited time available for recruitment and the unpredictability of how many women one could recruit at clinics (e.g. spending a morning at a clinic and only recruiting one women yet, in another clinic the next day 10 were recruited) the target number was not achieved. Sixty-one couples were recruited of which 36 (59%) women and 20 (33%) men participated in the study. Information, such as demographic details, about non-responders was not obtained for the present study for either the women or men and so it is acknowledged that there may be a self-selection bias for both groups that is discussed later with particular reference to men. Demographic information was collected from all women at recruitment but was kept by the large-scale SEDPT project in order to adhere to confidentiality protocol only demographic information on women who participated in the present study was obtained.

Possible contributory factors to the low recruitment number may have been because the initial contact about the study was not with the researcher but a midwife and therefore the researcher had less control over the accuracy and consistency of the information given to the women about the study. In addition, some women were not introduced to the study because midwives were either too busy or simply forgot. However, it must be noted that initial face-to-face contact with a researcher in this study would not be ethically acceptable/approved.

There are a number of limitations in the method used for recruiting men that may have contributed to the small sample size and a self-selection bias sample. Certainly the lack of direct contact with men may have been a contributory factor that influenced the lower response rate of fathers compared to mothers. For example, only those men whose partners had agreed to participate in the study were recruited. The recruitment was also reliant on the women to give the partner's the information sheets and some verbal information about the study to her partner. It was only later that a researcher phoned to talk to the men directly.

It may have been only the women who themselves were really keen to participate in the study that introduced their partners to the research. Or/and members of couple's may have disagreed about taking part, for example there were 36 women participants compared to 20 men out of which only one of the men had a partner who did not participate. Of the 36 women, 17 men did not participate in the study creating a possible self-selection bias. Self-selection bias refers to issues of sampling representativeness and generalisability (Braver and Bay, 1992).

Bias is introduced if the target population who do not participate (either because they cannot be located or because they refuse differ in a systematic way from those who do (Karney et al., 1995). Generally, evaluating self-selection bias is very difficult to do because the researcher typically does not have the information about the non-participants and therefore cannot compare them with participants. Evaluating self-selection bias was not possible in this study as no information was gathered about those men who did not participate. Following-up phone calls to non-responders did take place in an attempt to obtain demographic information but the non-responders were rarely available. Phares (1996) provides practical suggestions for recruiting fathers in to family research, including, flexible times of data collection and home visits. Home visits would be another way of recruiting fathers which would guarantee face to face contact, however this method of recruiting fathers was beyond resources available and the time constraints of this present study but should be considered for future research.

The reliance on the women for informing their partners about the study and the lack of face–to-face contact with men was a weakness of the recruitment methodology. In addition, although men were contacted by phone a few days after their partners had been recruited there were a large number of men who were unavailable. Therefore, there were a number of men who were sent questionnaires who had no contact with a researcher and the only information they had was an information sheet and verbal information from their partner.

Furthermore, because the majority of mothers were phoned, two weeks, and then six weeks, after the birth of their baby, by a researcher from the large-scale research SEACP project, there was delay in contacting fathers of approximately one to two weeks after the baby was six weeks old. This time delay may have been a contributory factor to the unavailability of men to speak to by phone as they may have returned to work after their paternity leave had expired. Interestingly, the availability of men to speak to by phone increased when I took over the two week postnatal phone calls to the mothers and found that it was often the men who answered the phone. This may have been because some fathers had paternity leave and were perhaps also more paternally minded and thus, more available to engage in thinking about parental issues such as prenatal testing. This seems to be reflected in the 60% response rate of those 17 men contacted in this way.

5.2.1 Summary of research limitations and implications for future research

The main aim of this research was to obtain a snapshot look at gender differences in attitudes to prenatal testing rather than in-depth analysis of particular complexities such as, the relationship between attitudes to prenatal testing and termination of pregnancy. However, it is acknowledged that some parents want prenatal test information to help them plan a life with a disabled child rather than to help them decide whether or not to terminate the pregnancy. (Rothenberg & Thompson, 1994; Schwartz-Cowan, 1994). Furthermore, one must be cautious about interpreting the use of prenatal testing as being in direct relationship to having negative attitudes to the particular disability tested for. This relationship is complex and would need further qualitative research to explore why participants were interested in prenatal testing for particular conditions and not for others. Thus, further qualitative research is needed to explore in more depth, 'how' and 'why' men and women, individually and as couples, make their choices about prenatal testing and termination of pregnancy.

The findings from this study suggest that men and women generally hold similar attitudes towards prenatal testing and termination and in some cases the trend is that men are slightly more interested than women. Although these results are not generalisable due to the small sample size and the bias sample of men, the results do indicate that the role of men concerning attitudes to prenatal testing and termination are as equally developed as women's attitudes. Furthermore, despite the methodological limitations of this study a modest number of men did participate in the study, suggesting that men do want their opinions/attitudes to be taken into account in an area that may have once been considered a woman's domain. Including men in research on such issues that affect the couple and or family as a whole is important. The results seem to suggest that men do have a role to play in the decision-making process concerning prenatal testing and termination. Assumptions cannot be made that men who did not respond or those who were not recruited would not want to participate and other ways of recruiting men need to be addresses in future research. Furthermore, alternative methods of recruiting men may result in a greater percentage of participating fathers and a more representative sample obtained. Importantly, alternative methods of obtaining demographic information for both men and women non-responders need to be considered in order to have the information necessary to ascertain if there is self-selection bias and to determine how representative the participants are of the target population (Costigan, 2001).

5.3 Clinical implications of this study.

The findings of this research has challenged the assumption that men are less likely to choose prenatal testing and termination of pregnancy for high-burden conditions because they are less likely to have the responsibility for the day-to-day care of a disabled child. However, the results of this study imply that this was not the case and that men's interest in prenatal testing and termination across conditions was comparable to that of women. The implications for service providers, is that decisions concerning prenatal testing and termination should be considered the responsibility of both parents. Therefore, men and women's individual beliefs regarding prenatal testing and termination should be recognised, the role of these beliefs in connection with the target condition however has received little attention. Informed choice concerning prenatal testing and termination is important, the present study has revealed that there was a significant relationship between men and women's attitudes to prenatal testing and a significant relationship between men and women's attitudes to termination. Furthermore, the results revealed that men and women discriminate between conditions, that is, they do not treat conditions/disabilities as a homogenous group.

Therefore, it would seem fundamentally important that information is given about the tests and the conditions being tested for and that the tests are not presented as blanket routine tests or/and screening. Prenatal testing for abnormality should not be presented as routine component of standard antenatal care even when it is offered to all women or within a normal antenatal appointment. Parents who obtain a screen positive result, for example, are confronted with difficult decisions to be made that are unlikely to be experienced as routine. Prenatal testing/screening should be presented in a context of decision-making, rather than in the context of enhanced choice. The relevance of knowledge, attitudes, and information about the target condition to these decisions should be made explicit so that the couple can make informed choices.

5.3.1 Informed choice

Informed choice is a very complex area and beyond the scope of this study to cover in depth therefore, informed consent is only briefly discussed. Firstly, It should be recognised that midwives and obstetricians are unlikely to be experts on the range of disabilities/conditions but are individuals with their own subjectivity. Personal views about disability should not be communicated to parents as expert knowledge. Couples who are faced with the decision of whether to terminate a pregnancy may benefit from counselling that allows them to access their own attitudes and beliefs about disabilities within a non-directive, non-judgmental counselling context. Service providers should recognise that there are often individual differences within couples that must be respected. Furthermore, conflicts of view within a couple concerning termination need a space where these can be explored in a non-judgemental, non-directive counselling arena. Such counselling may help couples hear and possibly understand the others point of view and feelings concerning such profound, life changing, decisions on whether to choose terminations or not. Or the counselling may strengthen a couples resolve to either choose or not to choose termination and therefore, be in a less dis-empowered position if presented with directive advice given by health professionals such as obstetricians (Shakespeare, 1998). Counsellors should be aware of their limitations and be able to refer or direct to other sources of support or information about particular disabilities. Disabilities are not a homogenous group, expert advice and information on particular disabilities should be available. There is often the assumption that people know about particular conditions or disability but this is often not the case. For example, research has revealed that generally, women know very little about Down's syndrome (Gekas et al., 1999) but that it is often assumed that they do.

Information can present a bias view about disability, recommendations have been that information about the target condition must be provided and that information in general should be delivered in as non-directive a manner as possible to avoid any value judgement (Advisory Committee on Genetic Testing, 2000; Royal College of Physicians, 1989). The questionnaire (ATP) used in this study was designed to attempt to avoid value judgement about conditions by giving close attention to the order of wording and language used when describing foetal conditions. Attention to language and word order should be considered, when service providers present written information for leaflets on foetal conditions and disabilities, so as to avoid conveying any kind of value judgements that may influence parents decisions concerning termination of a pregnancy.

In summary, women, men and/or couples must have the option of receiving counselling and obtaining accurate, unbiased information avoid of any value judgements. Furthermore, couples that have received a prenatal diagnosis should be able to obtain information concerning the specific foetal condition or disability. Ideally, the couple should be able to have face-to-face contact with a health professional. The health professional should be an expert in the area and trained in the ability to maintain a neutral stance during such interactions. Or if a neutral stance is not possible then this should be acknowledged, any personal biases, prejudice, leanings or persuasions should be made explicit to the parents so they can weigh up the information more accurately before making their decision.

In conclusion, the results of the present study suggest that the paired men and women hold similar attitudes to termination and prenatal testing for a range of foetal conditions. However, one must be cautious of these findings and view them in the light of the research limitations. It is acknowledged that the men in the study may not have been representative of the target population and furthermore due to the small sample size the results must be viewed with caution when considering generalisablility. Recruitment methodology, in particular recruitment of men, and the method of obtaining demographic information on the non-responders, needs to be revised and addressed in future research.

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APPENDIX 1

Chairman Bill Kilgallon OBE
Chief Executive David Johnson

THE LEEDS TEACHING HOSPITALS

Local Research Ethics Committee

Room 8.7,Clinical Sciences Building
St James's University Hospital
Beckett Street, Leeds LS9 7TF
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Ms E Deeks
Psychologist in Clinical Training
Academic Unit of Psychiatry & Behaviour Science
15 Hyde Terrace
University of Leeds
Leeds
LS2 9LN

Enquiries to: Ann Prothero
(Ethics Secretary)

Direct Line: 0113 (20) 65652

Our Ref: 02/093

15 April 2002

Dear Ms Deeks

Project No 02/093: Gender differences in attitudes to prenatal testing (sub study of Project No 01/258)

Thank you for your letter of 22 March enclosing details of your research project. I am happy to take Chairman's action and approve your study on the basis that it is a sub study to Project No 01/258 which has already been approved by the Committee and involves approaching partners of the mothers taking part in the main study with their consent.

We would be very interested in receiving a copy of your findings at some future date.

Yours sincerely

Ann Prothero

fo

Dr P R F Dear
Chairman
Leeds Health Authority / St James's and Seacroft University Hospitals
Clinical Research (Ethics) Committee

APPENDIX 2

The Leeds Teaching Hospitals NHS
NHS Trust

Division of Children's Services and Obstetrics

St James's University Hospital
Beckett Street
Leeds
West Yorkshire
LS9 7TF

Tel: 0113 243 3144

www.leedsteachinghospitals.com

Elaine Deeks
Psychologist in Clinical Training
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15 Hyde terrace
LEEDS LS2 9LT

Ref: AG/RH
Tel: 0113 20 /65401
Fax: 0113 20/66461
Email: ann.geddes@leedsth.nhs.uk
Date: 5th April 2002

Dear Elaine

Re: Postgraduate research project that is a sub-study of a main study, project number: 01/258 Social and Ethnic differences in attitudes to consent and prenatal testing (Professor Jenny Hewison, Janet Hirst and Shenaz Ahmed)

Thank you for your letter of the 8th March 2002 regarding the above project, from which you recruit mothers for your own sub-study. I have spoken to both the lead clinicians and have obtained their permission that you can go ahead in any clinics on the Leeds General Infirmary or St James's Hospital sites, provided that you have received ethical permission.

I have copied your letter and a copy of this response to Margaret Chippendale and Julie Stockton, who are the clinic sisters on both sides of the city and you should contact them if you require any further assistance.

I hope your study goes well.

Yours sincerely

Ann Geddes
Divisional Head of Midwifery

APPENDIX 3

DEMOGRAPHIC QUESTIONNAIRE (men's version)

Attitudes to Prenatal Testing

Participant's name: ……………………………………………………………………………………

Participant's address: ………………………………………………………………………………

………

………………………Post code……………………………Telephone number…………………………

Participant's name: ……………………………………………………………………………………

Participant's address: ………………………………………………………………………………

………

…………………………………………………………………… Post code: …………………………………

Telephone number:……………………………………………………………………………………

Could you please tell me a little about yourself and your partners pregnancy

1. When is your baby due? ………………………………………………………………………

2. How many weeks pregnant is your partner? ……………………………………………………

3. Has your partner had any antenatal tests or screening such as ultrasound scans or blood tests in <u>this pregnancy</u>?

   ☐ YES
   ☐ NO - *Go to question 5*

4. If Yes, do you know what they were?

   ……………………………………………………………………………………………………

   ……………………………………………………………………………………………………

5. Is this your first time of being with a partner through pregnancy?

   ☐ YES - *Go to question 7*
   ☐ NO

6. Has the partner had any antenatal tests or screening such as ultrasound scans or blood tests in a <u>previous pregnancy</u>?

   ☐ YES
   ☐ NO

If Yes, do you know what they were?

....

....

7. How old are you? ....

8. And how old were you when you left fulltime education?

....

9. What is your highest educational qualification? **Tick <u>one</u> box**

☐ No formal qualifications	
	☐ NVQ level 1, Foundation GNVQ
☐ 1+ O levels/CSE's/GCSE's/ SCE Ordinary (any grade)	☐ NVQ level 2, Intermediate GNVQ
☐ 5+ O levels, 5+ CSE's (grade 1), 5+ SCE Ordinary	
☐ 5+ GCSE's (grade A-C), 5+SCE Ordinary (band A-C)	
☐ 1+ A levels/ SCE Higher /AS level	
☐ 2+ A levels/SCE Higher	☐ NVQ level 3, Advanced GNVQ
	☐ NVQ level 4-5, HNC, HND
☐ First Degree (e.g. BA, BSc)	
☐ Higher Degree (e.g. MA, PhD, PGCE)	
☐ Other qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexel)	

10. Do you have any professional qualifications? Please write here:

....

11. Do you mind telling me who you live with? __Tick all that apply__

Your children ☐
Your wife or partner ☐
Your parents ☐
Your husband's parents ☐
Female friends or relatives ☐
Male friends or relatives ☐
By yourself ☐
Other people ☐
Please list the other people: ……………………………………………………

12. Which of these describes your ethnic origin?

Indigenous white UK ☐
Pakistani ☐
Other ☐ (Discontinue)

13. …and where were you born? …………………………………………… [ ] Code
[Code: 1 Attock district (Chhachh area): 2 Mirpur district in Azad Kashmir: 3 Nowsera Sub-districts and Peshawar: 4 Rawalpindi, Jhelum, Gujrat and Faisalabad districts mainly known as Punjabis: 5 England: 6 Northern Ireland: 7 Scotland: 8 Wales: 9 Other]

14. What religion were you raised in?

None …………………………………………… ☐
Christian Catholic ………………………………… ☐
Christian: Church of England/Church of Scotland/Methodist/protestant and all other Christian denominations…☐
Buddhists …………………………………………… ☐
Jewish ……………………………………………☐
Islam …………………………………………… ☐
Sikh ……………………………………………☐
Hindu ……………………………………………☐
Other …………………………………………… ☐

15. …And what is your religion now?

None …………………………………………… ☐
Christian Catholic ………………………………… ☐
Christian: Church of England/Church of Scotland/Methodist/protestant and all other Christian denominations…☐
Buddhists ……………………………………………☐
Jewish ……………………………………………
Islam …………………………………………… ☐
Sikh ……………………………………………☐
Hindu ……………………………………………☐
Other …………………………………………… ☐

APPENDIX 4

WOMEN'S RECRUITMENT FORM

Gender Differences in Attitudes to Prenatal Testing

Participant's name:..

Participant's address: ....

....

.... Post code: ....

Telephone number:..

Could you please tell me a little about yourself and your pregnancy?

1. When is your baby due? ....

2. How many weeks pregnant are you? ....

3. Have you had any antenatal tests or screening such as ultrasound scans or blood tests in this pregnancy?

   ☐ YES
   ☐ NO - *Go to question 5*

4. If Yes, do you know what they were?

   ....

   ....

5. Is this your first pregnancy?

   ☐ YES - *Go to question 8*
   ☐ NO

6. Have you had any antenatal tests or screening such as ultrasound scans or blood tests in a previous pregnancy?

   ☐ YES
   ☐ NO - *Go to question 8*

If Yes, do you know what they were?

....

....

7. How old are you? ....

8. And how old were you when you left fulltime education?

....

9. What is your highest educational qualification? **Tick one box**

☐ No formal qualifications	
	☐ NVQ level 1, Foundation GNVQ
☐ 1+ O levels/CSE's/GCSE's/ SCE Ordinary (any grade)	☐ NVQ level 2, Intermediate GNVQ
☐ 5+ O levels, 5+ CSE's (grade 1), 5+ SCE Ordinary	
☐ 5+ GCSE's (grade A-C), 5+SCE Ordinary (band A-C)	
☐ 1+ A levels/ SCE Higher /AS level	
☐ 2+ A levels/SCE Higher	☐ NVQ level 3, Advanced GNVQ
	☐ NVQ level 4-5, HNC, HND
☐ First Degree (e.g. BA, BSc)	
☐ Higher Degree (e.g. MA, PhD, PGCE)	
☐ Other qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexel)	

10. Do you have any professional qualifications? Please write here:

....

11. Do you mind telling me who you live with? <u>**Tick all that apply**</u>

Your children ☐
Your wife or partner ☐
Your parents ☐
Your husband's parents ☐
Female friends or relatives ☐
Male friends or relatives ☐
By yourself ☐
Other people ☐
Please list the other people: ……………………………………………………………

12. Which of these describes your ethnic origin?

Indigenous white UK ☐
Pakistani ☐
Other ☐ (Discontinue)

13. …and where were you born? ……………………………………………… [ ] Code
[Code: 1 Attock district (Chhachh area): 2 Mirpur district in Azad Kashmir: 3 Nowsera Sub-districts and Peshawar: 4 Rawalpindi, Jhelum, Gujrat and Faisalabad districts mainly known as Punjabis: 5 England: 6 Northern Ireland: 7 Scotland: 8 Wales: 9 Other]

14. What religion were you raised in?

None …………………………………………… ☐
Christian Catholic ……………………………… ☐
Christian: Church of England/Church
of Scotland/Methodist/protestant
and all other Christian denominations…☐
Buddhists ………………………………………… ☐
Jewish ……………………………………………… ☐
Islam ……………………………………………… ☐
Sikh ………………………………………………… ☐
Hindu ……………………………………………… ☐
Other ……………………………………………… ☐

15. …And what is your religion now?

None …………………………………………… ☐
Christian Catholic ……………………………… ☐
Christian: Church of England/Church
of Scotland/Methodist/protestant
and all other Christian denominations…☐
Buddhists ………………………………………… ☐
Jewish ………………………………………………
Islam ……………………………………………… ☐
Sikh ………………………………………………… ☐
Hindu ……………………………………………… ☐
Other ……………………………………………… ☐

Confirm details:

1) Would you like us to post the questionnaire out to you and telephone you to see how you are getting along... OR ... would you like a visit to help you complete the questionnaire?

☐ Post questionnaire and telephone

☐ Visit to help complete the questionnaire

Check name, address and telephone details on page 1
Checked and correct ☐

We will telephone you (or call) to see if you have had your baby around

(date)..

Debriefing and chat about the questionnaire and the interview:

- We hope you will feel able to complete the questionnaire when your baby is between 6-8 weeks old.
- Some women will be asked to take part in an interview
- If you complete the questionnaire you do not have to take part in the interview.
- Decide after you have completed the questionnaire.

UNIVERSITY OF LEEDS

APPENDIX 5

Partner's Attitudes to Prenatal Testing questionnaire

In booklet format

Partners' Attitudes to Prenatal Testing

Code:

Thank you for your time, honesty and interest in completing this questionnaire. Your views are very much valued as they will help those who develop prenatal screening techniques, those who provide the maternity and genetic services and, ultimately, those of us who use the maternity and genetic services.

Please return the questionnaire using the STAMPED, self-addressed envelope provided to:

Elaine Deeks
Gender Differences in Attitudes to
Prenatal Testing Study,
School of Medicine,
15 Hyde Terrace,
University of Leeds,
Leeds, LS2 9LT

Your baby:
On what date was your baby born?……………………………………………

Your children:
How many times have you been a biological father?………………………
And how many children do you have?……………………………………………

Prenatal Testing:
The next section gives a list of various conditions for which testing in pregnancy could become available. Please read and consider each condition and tick the box next to either 'Yes', 'No' or 'Not sure' in answer to the two questions. These are a) would you want your partner to have a prenatal test? And b) would you consider termination if the test showed that the baby has the condition?

Whilst you are making your decision please assume for the purpose of this questionnaire that the result from the prenatal test would tell you <u>whether the baby **definitely** does or does not have the condition</u>. Please also assume that the prenatal test would be carried out early in pregnancy, it carries no risk to your partner or the pregnancy, and it is carried out using routinely collected blood.

The questionnaire will take a little time to complete, so please make yourself comfortable and take your time.

We have asked you a lot of questions, thank you and well done for reaching this part of the questionnaire. We would like to give you the opportunity to tell us about other factors that have influenced your decisions. For example, some men find that their family, friends, place of work or religious beliefs influence their views.

Is there anything you would like to say about how your religious beliefs have influenced your decisions about prenatal testing:

....

....

....

....

....

....

....

....

....

....

Main features of the condition 	**Would you want your partner to have a prenatal test?**	**Would you consider termination if the test showed the baby had this condition?**
5 Child would develop a degenerative mental condition (Alzheimer's) by age 60, require a lot of looking after and possibly have a shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
6 Child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
7 Child would have severe learning disabilities/mental handicap, requires a lot of looking after and die within first few months of life.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
8 Child would have mild learning disabilities/mental handicap, able to work and live independently and have a normal lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Main features of the condition 	Would you want your partner to have a prenatal test?	Would you consider termination if the test showed the baby had this condition?
23 Child would have a progressive muscle-wasting disease (muscular dystrophy), be wheelchair-bound by 11 or 12 years and have a much-shortened lifespan (death probably before 20 years of age).	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
24 Child would have a normal lifespan, behavioural and communication problems, have moderate learning disabilities / mental handicap and require looking after.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
25 Child would be blind from birth and have a normal lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
26 Child would develop bowel cancer in early adulthood, require surgery and medication and have a potentially shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Main features of the condition 	Would you want your partner to have a prenatal test?	Would you consider termination if the test showed the baby had this condition?
13 Child would be at high risk of becoming alcoholic and have a potentially shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
14 Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
15 A male child would have mild learning disabilities/mental handicap or behaviour problems, unusually tall and not very masculine appearing, need some looking after, be unable to father a child and have a normal lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
16 Child might have disfiguring large lumps on head and face, which are noticeable from a distance, have a normal lifespan and might need medical care in childhood .	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

APPENDIX 6

Mothers' Attitudes to

Prenatal Testing

Code:

We look forward to speaking to you on the telephone and receiving the questionnaire back. As we have mentioned before, the answers that you give us will remain strictly confidential.

Your baby:

On what date was your baby born? ....

Pregnancy:

How many times have you been pregnant? ....

And how many children do you have? ....

Prenatal Testing:

The next section gives a list of various conditions for which testing in pregnancy could become available. Please read and consider each condition and tick the box next to either 'Yes', 'No' or 'Not sure' in answer to the two questions. These are a) would you want a prenatal test? And b) would you consider termination if the test showed that the baby has the condition?

Whilst you are making your decision please assume for the purpose of this questionnaire that the result from the prenatal test would tell you <u>whether the baby **definitely** does or does not have the condition</u>. Please also assume that the prenatal test would be carried out early in pregnancy, it carries no risk to you or the pregnancy, and it is carried out using routinely collected blood.

We are interested in your own personal views about prenatal testing so we ask if you could <u>please try not to confer with your partner.</u> Your partner has the opportunity to give their personal views about prenatal testing by completing the almost identical questionnaire enclosed.

Main features of the condition 	Would you want a prenatal test?	Would you consider termination if the test showed the baby had this condition?
5 Child would develop a degenerative mental condition (Alzheimer's) by age 60, require a lot of looking after and possibly have a shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
6 Child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
7 Child would have severe learning disabilities/mental handicap, requires a lot of looking after and die within first few months of life.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
8 Child would have mild learning disabilities/mental handicap, able to work and live independently and have a normal lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Main features of the condition 	Would you want a prenatal test?	Would you consider termination if the test showed the baby had this condition?
13 Child would be at high risk of becoming alcoholic and have a potentially shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
14 Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
15 A male child would have mild learning disabilities/mental handicap or behaviour problems, unusually tall and not very masculine appearing, need some looking after, be unable to father a child and have a normal lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
16 Child **might** have disfiguring large lumps on head and face, which are noticeable from a distance, have a normal lifespan and might need medical care in childhood .	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Main features of the condition 	**Would you want a prenatal test?**	**Would you consider termination if the test showed the baby had this condition?**
20 Child would have a normal lifespan and a high risk of developing mental illness in adulthood (schizophrenia), need some looking after and long-term medication, be unable to work or relate to others.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
21 Child would develop an incurable condition (Huntington's disease) by age 40, which has both severe mental and physical deterioration, require constant looking after and medical help and have a shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
22 Child would have severe behavioural and communication problems (autism), have a normal lifespan and require looking after.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Main features of the condition 	Would you want a prenatal test?	Would you consider termination if the test showed the baby had this condition?
27 Child would have a neurological condition (epilepsy) that causes fits/convulsions from early life, have a normal lifespan and require long-term medication.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
28 Child would have a physical illness (diabetes) requiring daily injections, there might be possible complications such as heart and kidney disease, blindness, would have limitations on diet throughout life and have a potentially shortened lifespan.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
29 Child would have a normal lifespan and be born without a limb, or have a limb that does not function.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐
30 Child is not the sex desired by the parents.	Yes ☐ No ☐ Not sure ☐	Yes ☐ No ☐ Not sure ☐

Is there anything you would like to say about other factors that influenced the decisions that you have made about prenatal testing in this questionnaire:

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APPENDIX 7

Gender differences in Attitudes to Prenatal Testing

Women's Study Information Sheet

You are being invited to take part in a research study. Before you decide to take part or not, we want to tell you more about the study and what your participation would involve. If anything is unclear or you would like further information please ask us.

What is the purpose of the study?

This study will be carried out along side a larger scale main study and thus bares many similarities. The major difference of this study is that it is interested in the separate views held by women and their partners about prenatal testing as opposed to the main study that is interested in women's views alone.

There already exists a number of tests that can be carried out in the early months of pregnancy to check for certain conditions the baby might be at risk for. Advances in technology means that the list of conditions we can test for will increase in number. We currently have very little evidence of what women and men think about the many different conditions that are, or will be testable, and whether or not they would wish to have their pregnancy tested. This research will begin to describe the attitudes women and men have and whether there are any differences in their attitudes.

Why have I been chosen?

We want to seek the views and attitudes of a variety of couples who are having, or recently had, a baby. We are asking couples at this time of their lives because it is a time when testing in pregnancy is, or has been, relevant and as such you have been faced with a real life situation of whether you would want prenatal tests.

Do I have to take part?

It is up to you to decide whether to take part or not. If you do decide to participate you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw or not to take part will not affect your health care in any way.

What will I have to do if I agree to take part?

1. **When your baby is about 6 weeks old:** You and your partner will be contacted to see if you are happy to take part. If you agree, two separate questionnaires and stamped self addressed envelopes will be sent to your home, one to you and the other to your partner and a researcher will contact you within a few days to see how you are getting on. If only one member of the couple wants to take part we will still be interested in that persons views and therefore would appreciate it if they completed and returned their questionnaire to us. If either of you prefer, a researcher will arrange to visit you at home and go through the questionnaire with you.

Are there any possible advantages of taking part?
There are no personal advantages of taking part. Your involvement will help improve the way in which antenatal testing is offered in the future, which should benefit many parents and parents-to-be. Furthermore, partner's views are often underrepresented in research of this kind and so taking part will help to redress the imbalance.

What happens to information about me and answers that I give?
All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any information you give so that you cannot be recognised from it. Your details will be held securely on a database and deleted once the study is complete. The questionnaire will be coded and be anonymous so that responses you give will not be traceable to you personally.

What will happen to the results of the research study?
As this study is part of a larger scale main study the use of the results are twofold. The main study will use the results to help develop procedures for offering prenatal testing in the future. The results of this study will be used for the basis of a thesis to be submitted for a higher degree (Doctor of Clinical Psychology).

Who is funding the research?
The main project has received national funding from the Economic and Social Research Council and is being carried out by researchers and medical staff from the University of Leeds and the Leeds Teaching Hospitals. This project is being carried out by a post-graduate student from the Doctor of Clinical Psychology Course funded by the University of Leeds and St James and Seacroft Teaching Hospitals.

Who can I contact for further information?

Either: Shenaz Ahmed: 0113 233 2441 or Dr Janet Hirst: 0113 233 2702	**At:** Attitudes to Prenatal Testing Study School of Medicine University of Leeds 15 Hyde Terrace Leeds, LS2 9LN

Attitudes to Prenatal Testing

Partner's Study Information Sheet

You are being invited to take part in a research study. Before you decide to take part or not, we want to tell you more about the study and what your participation would involve. If anything is unclear or you would like further information please ask us.

What is the purpose of the study?

This study will be carried out along side a larger scale main study that is researching women's attitudes alone. This study is interested in the attitudes to prenatal testing held by women and their partners.

There already exists a number of tests that can be carried out in the early months of pregnancy to check for certain conditions the baby might be at risk for. Advances in technology means that the list of conditions we can test for will increase in number. We currently have very little evidence of what women and men think about the many different conditions that are, or will be testable, and whether or not they would wish to have their pregnancy tested. This research will begin to describe the attitudes women and men have and the differences in their attitudes.

Why have I been chosen?

We want to seek the views and attitudes of a variety of couples who are having, or recently had, a baby. We are asking couples at this time of their lives because it is a time when testing in pregnancy is, or has been, relevant and as such you have been faced with a real life situation of whether you would want prenatal tests.

Do I have to take part?

It is up to you to decide whether to take part or not. This information sheet is yours to keep and is aimed to help you to decide if you want to participate or not. Furthermore, if you decide to take part you are still able to withdraw at any time and without giving a reason. A decision to withdraw, or not to take part, will not affect your family's health care in any way.

What will I have to do if I agree to take part?

I will telephone you at home to ask if you are willing to take part, if you agree I will ask you a few questions over the phone about your life style, education and religion. **Then when your baby is about 6 weeks old** you will be contacted again to ask if you are still happy to take part. If you agree, a pack will be sent to your home. The pack will contain a letter, a questionnaire and a stamped self-addressed return envelope. You will then complete the questionnaire and return it to me using the envelope provided.

Are there any possible advantages of taking part?

There are no personal advantages of taking part. Your involvement will help improve the way in which antenatal testing is offered in the future, which should benefit many parents and parents-to-be. Furthermore, father's views are often underrepresented in research of this kind and so taking part will help to redress the balance.

What happens to information about me and answers that I give?

All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any information you give so that you cannot be recognised from it. Your details will be held securely on a database and deleted once the study is complete. The questionnaire will be coded and be anonymous so that responses you give will not be traceable to you personally.

What will happen to the results of the research study?

They will be used to help develop procedures for offering prenatal testing in the future and will be used for the basis of a thesis to be submitted for a higher degree (Doctor of Clinical Psychology).

Who is doing the research?

The research will be carried out by a post-graduate trainee who is on the Doctor of Clinical Psychology Course, University of Leeds and is employed by Leeds Teaching Hospitals NHS Trust.

Who can I contact for further information?

Dr Janet Hirst 0113 343 2441 and leave a message for Elaine Deeks (Psychologist in Clinical Training) I will return your call ASAP.	**At:** Attitudes to Prenatal Testing Study School of Medicine University of Leeds 15 Hyde Terrace Leeds, LS2 9LN

You will be given a copy of this information sheet to keep.

Version: DClinPsychol Study Date:

APPENDIX 9

Cover letter posted with ATP questionnaire.

Elaine Deeks
Psychologist in Clinical Training
Academic Unit of Psychiatry &
Behavioural Science
15 Hyde Terrace
LS2 9LT

Dear

Thank you for agreeing to considering taking part in the study. I hope the information sheet about the research helped you to make an informed choice as to whether you wanted to take part or not in the study. I remind you that you are still free to choose not to take part and that such a decision would not affect the health care of you and/or your family in any way. If you decide to take part I have enclosed two questionnaires for you to complete and return using the stamped, self-addressed envelope provided.

If you have any questions or have any difficulties filling out the questionnaire please do not hesitate to contact me. It would be an advantage to the research if you could try not to confer with your partner when completing the Attitudes to Prenatal Testing questionnaire, so that, the answers you provide will represent your own personal attitudes to prenatal testing. Thank you for your time in taking part in the study.

Yours Sincerely

Elaine Deeks
Psychologist in Clinical Training.

UNIVERSITY OF LEEDS

APPENDIX 10

Attitudes to Prenatal Testing

Consent Form

Please delete as applicable

- I have read the Study Information Sheet. **Yes / No**
- I have spoken with the researcher. **Yes / No**
- I have received enough information about this study. **Yes / No**
- I have had the opportunity to ask questions and discuss the research study. **Yes / No**
- I am satisfied with the answers to my questions. **Yes / No**
- I understand that I am free to withdraw from the study at any time without having to give a reason and without my health care being affected. **Yes / No**
- I agree to take part in this research study. **Yes / No**
- I give consent for you to contact my partner. **Yes / No**

Signature ______________________________ ***Date:*** ________

Name (block capitals): ____________________

Researcher Signature ____________________ ***Date:*** ________

Name (block capitals): ____________________

Appendix 11

Table 28: Gender x Prenatal Diagnosis

"Would you want a prenatal test?"

	YES		NOT SURE		NO	
Condition	**Males (n=20)**	**Females (n=36)**	**Males (n=20)**	**Females (n=36)**	**Males (n=20)**	**Females (n=36)**
1. Severe learning dis	16 (80%)	29 (81%)	0	4 (11%)	4 (20%)	3 (8%)
2. Quadriplegia	16 (80%)	28 (78%)	2 (10%)	5 (14%)	2 (10%)	3 (8%)
3. Dwarf	12 (60%)	12 (33%)	3 (15%)	3 (8%)	5 (25%)	21 (59 %)
4. Cleft lip and palate	10 (50%)	15 (42%)	4 (20%)	2 (6%)	6 (30%)	19 (52%)
5. Alzheimer's	9 (45%)	15 (42%)	0	3 (8%)	11 (55%)	18 (50%)
6. Turner's syndrome	9 (45%)	18 (50%)	2 (10%)	3 (8%)	9 (45%)	15 (42%)
7. Trisomy 13	16 (80%)	32 (88%)	0	2 (6%)	4 (20%)	2 (6%)
8. Mild learning dis	10 (50%)	16 (44%)	2 (10%)	1 (3%)	8 (40%)	19 (53%)
9. Anencephaly	18 (90%)	33 (92%)	1 (5%)	2 (6%)	1 (5%)	1 (3%)
10. Thalassaemia	11 (55%)	23 (64%)	3 (15%)	5 (14%)	6 (30%)	8 (22%)
11. Coronary at 50	10 (50%)	12 (33%)	1 (5%)	3 (8%)	9 (45%)	21 (59%)
12. Cystic fibrosis	12 (60%)	21 (33%)	3 (15%)	5 (14%)	5 (25%)	10 (28%)
13. Alcoholism	5 (25%)	11 (30%)	1 (5%)	2 (6%)	14 (70%)	23 (64%)
14. Mod learning dis	11 (55%)	20 (55%)	4 (20%)	7 (19%)	5 (25%)	9 (25%)
15. K'felter's synd	7 (35%)	18 (50%)	3 (15%)	7 (19%)	10 (50%)	11 (30%)
16. Proteus syndrome	9 (45%)	19 (52%)	3 (15%)	4 (11%)	8 (40%)	13 (36%)
17. Grossly o' weight	8 (40%)	11 (30%)	2 (10%)	8 (22%)	10 (50%)	17 (47%)
18. Phyenylketonuria	11 (55%)	21 (58%)	0	2 (6%)	9 (45%)	13 (36%)
19. Deafness	11 (55%)	20 (55%)	0	3 (8%)	9 (45%)	13 (36%)
20. Schizophrenia	12 (60%)	20 (55%)	2 (10%)	6 (16%)	6 (30%)	10 (28%)
21. Huntington's	12 (60%)	23 (64%)	3 (15%)	5 (14%)	5 (25%)	8 (22%)
22. Autism	12 (60%)	22 (64%)	4 (20%)	7 (19%)	4 (20%)	7 (19%)
23. Muscular Dyst	15 (75%)	29 (80%)	2 (10%)	3 (8%)	3 (15%)	4 (11%)
24. Fragile X syn	12 (60%)	22 (61%)	3 (15%)	7 (19%)	5 (15%)	7 (19%)
25. Blindness	11 (55%)	22 (61%)	2 (10%)	2 (6%)	6 (30%)	11 (30%)
26. Bowel Cancer	12 (60%)	18 (50%)	2 (10%)	5 (14%)	6 (30%)	13 (36%)
27. Epilepsy	12 (60%)	24 (66%)	0	1 (3%)	8 (40%)	11 (30%)
28. Diabetes	10 (50%)	26 (72%)	0	1 (3%)	10 (50%)	9 (25%)
29. Absent limb	13 (65%)	27 (75%)	1 (5%)	2 (6%)	6 (30%)	7 (19%)
30. Not prefer gender	9 (45%)	5 (14%)	0	0	11 (55%)	31 (86%)

Abbreviations

1. dis = disability
2. syn= syndrome

Condition

1 =Severe learning disability
8 =Mild learning disability
14 = Moderate learning disability
15 = Klinefelter's syndrome
17 = Grossly over weight
21 = Huntington's disease
23 =Duchenne muscular dystrophy
29 = Absent/ dysfunctional limb
30 = Not preferred gender

APPENDIX 12

Table 29: Gender x Termination of Pregnancy

"Would you consider termination if the test showed the baby had this condition?"

Condition	YES		NOT SURE		NO	
	Males (n=20)	**Females (n=36)**	**Males (n=20)**	**Females (n=36)**	**Males (n=20)**	**Females (n=36)**
1. Severe learning dis	12 (60%)	19 (53%)	6 (30%)	11 (30%)	2 (10%)	6 (17%)
2. Quadriplegia	15 (75%)	14 (39%)	3 (15%)	16 (44%)	2 (10%)	6 (17%)
3. Dwarf	4 (20%)	0	4 (15%)	6 (17%)	12 (60%)	29(83%)
4. Cleft lip and palate	1 (5%)	1 (3%)	5 (25%)	3 (8%)	14 (70%)	31 (88%)
5. Alzheimer's	1 (5%)	1 (3%)	4 (20%)	11 (30%)	15 (75%)	23 (67%)
6. Turner's syndrome	3 (15%)	1 (3%)	7 (36%)	11 (30%)	10 (50%)	23 (67%)
7. Trisomy 13	15 (75%)	25 (69%)	2 (10%)	7 (20%)	3 (15%)	4 (11%)
8. Mild learning dis	0	0	3 (15%)	7 (20%)	17 (85%)	28 (80%)
9. Anencephaly	18 (90%)	33 (92%)	1 (5%)	3 (8%)	1 (5%)	0
10. Thalassaemia	4 (20%)	11(31%)	9 (45%)	6 (17%)	7 (35%)	18 (51%)
11. Coronary at 50	0	0	4 (20%)	5 (14%)	16 (80%)	30 (86%)
12. Cystic fibrosis	6 (30%)	8 (23%)	6 (30%)	12 (34%)	8 (40%)	15 (43%)
13. Alcoholism	0	0	3 (15%)	5 (14%)	17 (85%)	30 (86%)
14. Mod learning dis	2 (10%)	4 (11%)	9 (45%)	13 (37%)	9 (45%)	18 (51%)
15. K'felter's synd	2 (10%)	5 (14%)	8 (40%)	13 (37%)	10 (50%)	17 (49%)
16. Proteus syndrome	1 (5%)	4 (11%)	8 (40%)	8 (23%)	11 (55%)	23 (66%)
17. Grossly o' weight	2 (10%)	2 (6%)	7 (35%)	9 (26%)	11 (55%)	24 (68%)
18. Phyenylketonuria	2 (10%)	0	2 (10%)	7 (20%)	16 (80%)	28 (80%)
19. Deafness	2 (10%)	0	3 (15%)	4 (11%)	15 (75%)	31 (89%)
20. Schizophrenia	7 (35%)	6 (17%)	6 (30%)	16 (46%)	7 (35%)	13 (37%)
21. Huntington's	6 (30%)	6 (17%)	6 (30%)	17 (47%)	8 (40%)	13 (37%)
22. Autism	5 (25%)	4 (11%)	8 (40%)	15 (43%)	7 (35%)	16 (46%)
23. Muscular Dyst	12 (60%)	18 (50%)	6 (30%)	10 (28%)	2 (10%)	8 (22%)
24. Fragile X syn	3 (15%)	7 (20%)	8 (40%)	13 (37%)	9 (45%)	15 (43%)
25. Blindness	3 (15%)	2 (6%)	3 (15%)	4 (12%)	14 (70%)	28 (82%)
26. Bowel Cancer	5 (25%)	3 (8%)	9 (45%)	8 (23%)	6 (30%)	24 (68%)
27. Epilepsy	1 (5%)	4 (11%)	3 (15%)	3 (8%)	16 (80%)	28 (82%)
28. Diabetes	1 (5%)	5 (14%)	5 (25%)	12 (34%)	14 (70%)	18 (51%)
29. Absent limb	2 (10%)	3 (8%)	7 (35%)	10 (28%)	11 (55%)	23 (64%)
30. Not prefer gender	1 (5%)	0	0	0	19 (95%)	36(100%)

Abbreviations

1. dis = disability
2. syn= syndrome

Condition

1 =Severe learning disability
8 =Mild learning disability
14 = Moderate learning disability
15 = Klinefelter's syndrome
17 = Grossly over weight
21 = Huntington's disease 23 =Duchenne muscular dystrophy
29 = Absent/ dysfunctional limb
30 = Not preferred gender