Attitudes toward prenatal diagnosis and termination of pregnancy in Saudi Arabia

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

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ABSTRACT

Introduction: Advances in molecular biology will soon make it possible to offer parents prenatal testing for a large number of different genetic disorders. The tests that have been offered to date are available because of technology, not because of the burden or prevalence of the condition. Parents' attitudes to different genetic disorders need to be evaluated, because little is known about how people's attitudes to testing for one disorder relate to their views on testing for other disorders.

Aims: To assess the attitudes of Saudi parents with and without an affected child, towards prenatal diagnosis and termination of pregnancy for a range of different genetic disorders, and the factors that affect their attitudes.

Methods: The study was conducted using structured questionnaires and semi-structured interviews. 400 Saudi parents with and without affected children completed a structured questionnaire and forty of these were then interviewed. The questionnaires were designed to assess parents' attitudes towards prenatal diagnosis and termination of the pregnancy, for thirty different conditions. The interviews were designed to explore the factors that affect parents' attitudes.

Findings: Parents had different attitudes to different conditions. Overall, there was an unexpectedly high level of acceptance of prenatal diagnosis and termination of pregnancy for a range of different conditions in this Muslim sample. It was also found that parents with an affected child held more favourable attitudes towards termination of the pregnancy than parents without an affected child. Fathers without an affected child held the least favourable attitudes towards termination of pregnancy.

Discussion: The evidence suggests that parents perceive genetic conditions differently according to their individual experience. Islam is not the main factor that influences Muslim parents toward prenatal diagnosis and termination of the pregnancy. New technologies provide parents with more reproductive choices but also present them with more dilemmas. Further investigation about factors associated with testing and termination choices is recommended.

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ABBREVIATIONS

S.R	Saudi Rials (seven Saudi Rials = one UK pound)
PND	Prenatal diagnosis
TOP	Termination of pregnancy
PS	Premarital screening
CVS	Chorionic Villus Sampling
amnio	Amniocenteses

CHAPTER 1: INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

Advances in molecular biology will soon make it possible to offer parents prenatal testing for a large number of different genetic disorders. Over the past twenty years or so researchers have tried to gain a better understanding of the psychological correlates and consequences of available tests, and the issue are complex (Green et al., 2002). However, little is known about a situation in which parents are offered tests for more than one condition. The central problem of the present research is: How can we assess parents' attitudes towards prenatal diagnosis and termination of the pregnancy for a range of different genetic conditions in Saudi Arabia?

From the author's experience as the first trained genetic counsellor in Saudi Arabia, he has realized that parents who have an affected child have different attitudes from parents who do not towards prenatal diagnosis and termination of pregnancy. These differences may be caused by many factors surrounding the parents with an affected child, but the parents' own perspective has been little studied. The perspectives of different groups of parents need to be examined in studies of attitudes to testing and termination.

Most of the previous studies in Saudi Arabia have been focused on parents' attitudes towards prenatal diagnosis and termination of the pregnancy for haemoglobinopathy and the influence of parents' faith. Saudi parents' attitudes toward prenatal diagnosis and termination of the pregnancy for a range of different genetic conditions and factors that affect parents' attitudes have long been neglected. One reason for the existence of such a research gap is probably the complexity of parents' attitudes towards different genetic disorders, which is hard to describe and capture, since it involves sensitive issues in Saudi culture. To investigate this issue, the present study assesses the attitudes of Saudi parents towards prenatal diagnosis and termination of the pregnancy for a range of different genetic conditions and the factors that influence parents' attitudes. In addition, the researcher wanted to address issues related to the personal views and experience of parents with and without an affected child.

Although termination is not allowed by Islamic law in most genetic conditions, that should not be used as an excuse to ignore the difficulties faced by parents with an affected child. As Anionwu and Atkin (2001) said, "An emphasis on coping should not be used as an excuse to ignore the difficulties faced by young people and parents". This subject has not been researched in Saudi Arabia. Therefore, it is expected that the results of this research can help counsellors, physicians, and health services providers to understand how the characteristics of genetic conditions might influence parents' attitudes. Likewise, it is hoped that the present study will help the religious authorities understand parents' views toward prenatal diagnosis and termination of pregnancy for a range of different genetic conditions, and to find ways to take parents' views into account. In general, the reason for carrying out this study is in the hope that some useful conclusions can be drawn from it. Hopefully, the most direct benefit may be a marked improvement in our understanding of the crucial need to assess parents' attitudes toward prenatal diagnosis and termination of pregnancy. As Rothman (1997) said, "I have never, ever, in my life come across anything as complicated as prenatal testing. Morally, psychologically, politically, socially – on every level, I have never come up against anything as difficult".

1.2 THE PURPOSE OF THE STUDY

Although there has been growing interest in Western populations and their attitudes towards prenatal testing, little is known about Arab populations (El-Badramany et al., 1997). In addition, attitudes toward prenatal diagnosis for a range of different genetic conditions are perhaps the most neglected in Saudi Arabia. This is surprising, as a major factor in the decision to terminate a pregnancy for abnormality is known to be the perceived "severity" of the condition diagnosed, as reported from different studies (Homes-Siedle, Ryynanen, and Lindenbaum, 1987; Verp, Bombard, Simpson, and Elias, 1988; Drugan et al., 1990; Abramsky et al., 2001). However, people perceive the severity of the genetic disorders differently as found in many studies. (Ekwo and Gosselinkl, 1987; Wertz, et al., 1991, Evers-Kiebooms, et al., 1993; Michie, et al., 1995; Hietala, et al., 1995; Zahad and Nabuls, 2002; Hewison et al, 2004). Therefore, the present study seeks to benefit from recent developments in the field of prenatal diagnosis, and to assess the views of Saudi parents with and without an affected child toward prenatal diagnosis and termination of pregnancy for a range of different genetic conditions. This work is necessary in order to understand parents' views, to examine the way different factors influence parents' attitudes, and to give genetic counsellors insights into differences in attitudes. The present research has the following aims:

1. To provide an understanding of parents' view about the acceptability of testing and termination of pregnancy for a range of different conditions.
2. To compare the views of fathers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions.
3. To compare the views of mothers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions.
4. To compare the views of fathers and mothers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions
5. To find the factors that affect parents' attitudes towards prenatal diagnosis and termination of the pregnancy.

1.3 AN OVERVIEW OF THE METHODOLOGY

An attempt is made to assess Saudi parents' attitudes toward prenatal diagnosis and termination of the pregnancy for a range of different genetic conditions, to examine how the characteristics of the genetic condition might influence parents' attitudes and to perform these tasks using valid and reliable methodologies. Likewise, this study attempts to compare parents with and without an affected child. In pursuing these aims, a combination of research methods from the quantitative and qualitative approaches has been adopted. The quantitative approach was applied via a questionnaire, and qualitative information was obtained by semi-structured interview. By collecting data in different ways, it was hoped to be able to build up a fuller understanding of the parents' attitudes towards testing and termination of the areas to be investigated.

1.4 LAYOUT OF THE THESIS

This thesis is organized into nine chapters. The current chapter is an introductory chapter; it presents the background, the problem of the study, the purpose, research questions and overview of the methodology pursued. At the end of this chapter, the organization of the thesis is highlighted. Chapter two will be an overview of the prenatal diagnosis, some important factors that affect parent's attitudes and previous studies from various countries towards prenatal diagnosis and termination of the pregnancy. Chapter three presents background information on Saudi Arabia and studies conducted there. Chapter four is an overview of religious views towards reproductive issues.

The methodology of the study is presented in Chapter five. The chapter contains an outline of the participants, the procedure and the study design and the data analysis techniques. Chapter six reports the results of the quantitative analysis, while Chapter seven reports the results of the qualitative study. Chapters eight and nine report the major findings of the study, and discuss their limitations, implications, and the recommendations made.

CHAPTER 2: OVERVIEW OF GENETIC TESTING

2.1 INTRODUCTION

The different kinds of diseases affecting humans are wide ranging, from those which are purely acquired (environmental) to those which are purely genetic (Figure 1). Purely acquired disorders are those resulting from infections caused by a wide variety of microorganisms, and those due to nutritional deficiencies. For centuries these disorders have been a major cause of morbidity and mortality. However, over the past few decades, significant advances in immunization, the discovery of antibiotics, improvement in general hygiene and nutritional habits and overall improvement of health status have led to a significant shift, where the overall prevalence of acquired diseases has decreased considerably in most populations of the world. This has led to the surfacing of genetic disorders as a major cause of morbidity and mortality (Weatherall, 1991; Harper, 1993; Emery and Rimoin, 1999). These diseases include the purely genetic diseases, which may be either single-gene disorders or chromosomal disorders, and multifactorial disorder, which results from an interaction between both genetic and environmental factors.

This chapter is divided into four main sections. The first section describes the different kinds of genetic diseases. The second gives a general overview of prenatal diagnosis. The third presents attitudes toward prenatal diagnosis and termination of the pregnancy, and also presents various studies from different countries which are considered directly relevant to the present study. The fourth presents attitudes toward prenatal diagnosis and termination of the pregnancy in the Middle Eastern countries. Issues arising from the literature on disability are considered in the discussion chapter (chapter 9)

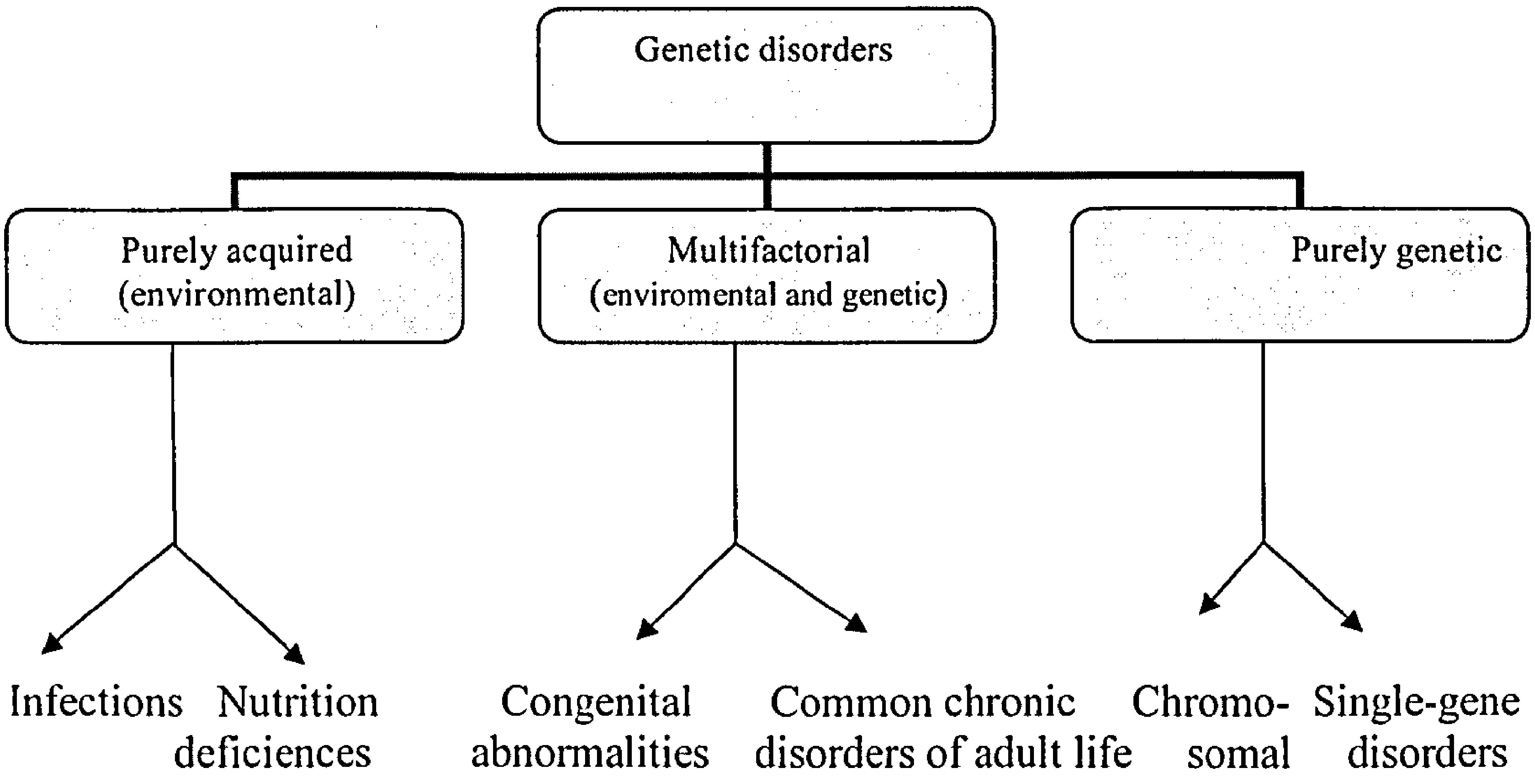

Figure 1: Different kinds of diseases affecting humans

(adapted from Emery and Rimoin, 1999)

2.2 GENETIC DISEASES

Genetic diseases are a large group of disorders resulting from major or minor alterations (mutations) in the genetic component of cells. These diseases can be grouped into:

- Chromosomal disorders
- Single-gene disorders
- Multifactorial disorders

2.2.1 Chromosomal disorders

Down's syndrome was first recognized to be caused by an additional chromosome 21 in 1959. Advances in techniques of chromosomal analysis, including banding techniques, led to the identification of a large of number of other chromosomal disorders, which involve either an increase or decrease in the total number of chromosomes, or abnormalities in the structure of a chromosome (i.e. addition, deletions, translocation, inversions, ring chromosomes) (Emery and Rimon. 1999; Weatrerall.1991; Connor and Ferguson-Smith.

1991; Gelehrter, Collins, and Ginsburg. 1998; Epstein. 1995; Baird, et al., 1988). Hence chromosomal disorders may be numerical or structural. Advanced techniques have also confirmed that loss or gain of a very tiny fraction of chromosome may have a devastating effect (Emannel. 1993). In fact, several rare conditions with serious consequences such as severe learning difficulty result from such minute deletion, which cannot be detected even by the most powerful microscope. They are referred to as submicroscopic deletion syndromes.

2.2.2 Single-gene disorders

The recognition by Garrod of alkaptonuria as a genetic defect led to the discovery of a very large number of such conditions, which result from a mutation in or around a single gene (Emery and Rimoin. 1999; Gelehrter, Collins, and Ginsburg. 1998; Baird et al., 1988; McKusick. 1994; Scriver et al., 1995). Over 6000 such disorders have been identified and many more are expected to be unveiled since it is recognized that the total human genetic component carries between 50 000 and 100 000 structural genes. These disorders may be autosomal or sex-linked (i.e. Y- or X-Linked), which may be either dominant or recessive (McKusick. 1994).

2.2.3 Multifactorial disorders

Most of the common congenital malformations (e.g. cleft lip, cleft palate) and most of the common diseases of adult life (e.g. diabetes mellitus, obesity, coronary heart disease, and schizophrenia) have a significant genetic component in the atiology, in addition to environmental factors which are required for their development (Emery and Rimoin. 1999; Weaterall.1991; Connor and Ferguson-Smith. 1991; Gelehrter, Collins, and Ginsburg. 1998; King, Rotter, and Motulsky. 1992; Mueller and Young. 1995). Such disorders are referred to as multifactorial as they result from the interplay of multiple environmental factors and genes.

Genetic diseases are chronic in nature often with no cure and they often require lifelong care and management strategies (Harper, 1998). The impact of a given disease may vary with the characteristics of the genetic condition itself and also varies with individuals' and families' experiences. In general, these conditions are a leading cause of spontaneous abortion, neonatal death, increased morbidity in children and adults and an increase in childhood mortality. In addition, genetic diseases are a significant health care and psychosocial burden for the patients, family, the health care system and the community as a whole (Weil, 2000). In the literature and in policy making however, two very different positions may be distinguished: A) population control of a global health problem (Weatherall, 2004). B) giving to parents the opportunity of making an informed choice about having a child with a disability, which is the policy of the UK National Screening Committee (www.nsc.nhs.uk/pdfs/secoundreport.pdf). However, the situation is more complicated in Saudi Arabia, because termination of pregnancy is not allowed in many genetic conditions under Islamic law. The approach being adopted is one of population control, but implemented by a policy of premarital screening rather than prenatal diagnosis and termination of pregnancy. Premarital screening for haemoglobinopathies became compulsory in early 2004, and screen positive couples are not permitted to marry (Saudi T.V first channel, 2004). The present study was conducted before compulsory premarital testing, at a time when the burden of genetic disease on health services was beginning to be appreciated, but before any culturally acceptable solution had been identified.

2.3 HISTORICAL OVERVIEW OF PRENATAL DIAGNOSIS

Prenatal diagnosis employs a variety of techniques to determine the health and condition of an unborn foetus. Clark has identified three established reasons for justifying prenatal screening: sparing resources through the termination of affected pregnancies, the avoidance of suffering in affected children through termination and the promotion of information and reproductive choice (Clarke, 1997). The development of diagnostic technology for detection of fetal abnormality began in the 1960s and 1970s, with use of amniocentesis to assess rhesus disease in foetus (Harper, 1998). Rhesus disease causes complications in late pregnancy, which can be prevented by early delivery; the technology was used in these circumstances to assess whether there were likely to be any problems and, if so, to prevent them without any ill effects for mother or child. However, as testing procedures have developed, they have come to be used in a rather different preventative capacity, i.e.

preventing the burden of an affected child rather than preventing the occurrence of disease by treating the child. This has led critics of prenatal testing to suggest that this represents a rather curious anomaly (Harper, 1998).

In 1984, prenatal diagnosis was largely limited to amniocentesis to screen foetuses for genetic disease including chromosomal defects such as Down's syndrome (Pilnick, 2002). This testing was generally performed nearly halfway through pregnancy. Women over age 35 were almost the only patients seeking or offered such testing. However, techniques now for prenatal diagnosis include the invasive procedures, amniocentesis, chorionic villus sampling, cordocentesis, fetoscopy, foetal skin biopsy and foetal liver biopsy, as well as non-invasive procedures such as ultrasound, other types of imaging, and examination of foetal cells in the maternal circulation. These procedures have become an integral part of prenatal care and present couples with often-difficult choices in pregnancy (Kenyon et al., 1998). Although most pregnant women worry about the possibility that there might be something wrong with their baby, few have any specific grounds for this. Statham, Green and Snowdon (1992) found the possibility of something being wrong with the baby to be one of the highest scoring worries in a sample of over 1800 women in early pregnancy, with only 11% being not at all worried.

The past three decades have witnessed rapid utilization of prenatal testing. Many tests can be done during pregnancy to determine whether the foetus is normal or has a genetic defect. New molecular biology has determined the genetic structure of individuals and helps to predict their future health. Reliable and low cost gene tests facilitate detection of genetic diseases in the foetus and prediction of the future onset of a variety of diseases prior to any clinical manifestation, as well as determination of the carrier status, in the case of recessively inherited conditions, representing a potential risk for the disease in future generations. In addition, molecular biology has covered a wide range of the multi-factorial disorders such as diabetes, asthma, coronary heart disease, rheumatoid arthritis and many common cancers (Gill& Richard, 1998). These molecular technology developments will enhance genetic testing in public health care in the effort to understand all human diseases (Hayflick & Eiff, 1998). The advance in molecular biology will make it possible to offer parents prenatal testing for a large number of different genetic disorders, characterized by recessive, dominant or sex-linked patterns of inheritance, and associated with a wide range of mental, physical and sensory disabilities. Prenatal testing including ultrasound, maternal serum screening, amniocentesis and chorionic villus sampling has played an important part in antenatal care (Kolker & Burke, 1991; Thorpe et al., 1993; Abramsky&Chapple, 1994;; Rotheenburg & Thomson, 1994; Kurdi, 2001; Vergani, et al., 2002; Svalenius, Dykes, Jorgensen, 2003). Nevertheless, the rapid advances in human genetics will create much anxiety in the general population (Caulfield, 1999). Also advances in DNA technology mean that a wider range of prenatal test will soon become available. However, the tests that have been offered to date are available because of technology, not because of burden of condition or prevalence. Tests for chromosomal disorders such as Down's syndrome have been available for many years. However, molecular tests available more recently need to be investigated according to population attitudes toward genetic testing, rather than preference for the technologies.

Parents' attitudes to different genetic disorders need to be evaluated, because little is known about how people's attitudes to testing for one disorder relate to their views on testing for other disorders. Studies have explored attitudes to genetic testing and how the different genetic disorders might influence people's attitudes toward genetic testing and abortion (Michie et al, 1995; Hietala et al, 1995). Studies in Europe suggest that, on average, around one-third to one-half of people would hypothetically consider termination of an affected fetus, but that this figure varies widely with the perceived severity of the abnormality; for example, it is lower in cystic fibrosis than muscular dystrophy (Denayer et al., 1992; Evers-Kiebooms et al., 1993). In addition, the motive of individuals for accepting or rejecting the test has not been researched (Michie and Marteau, 1999). Acceptance of such a test may vary from one country to another, depending on the religious beliefs, health system and tradition and cultural background of the population. The population in Saudi Arabia investigated in this study has distinctive religious beliefs, health system, tradition and cultural background, but little is known about the influence these may have on attitudes to prenatal testing.

2.4 ATTITUDES TO GENETIC TESTING AND GENETIC SCREENING

The Nuffield Council on Bioethics made the following distinction between genetic testing and genetic screening: The phrases 'genetic testing' and genetic screening are sometimes used interchangeably. There is, however, a significant difference, though not a completely hard and fast one, between testing an individual for a condition or defect that other evidence suggests may be present, and screening all members of a population for a defect or condition where there is no prior evidence of its presence in the individual (Nuffield Council of Bioethics, 1993). It should be noted here that the word "screening" can also be applied to the process of obtaining preliminary information regarding membership of a high risk group. The latter group may then be offered diagnostic tests to provide a definite answer about the presence of an abnormality. Within all of these categories, tests can be applied pre-natally, neo-natally, in childhood or adulthood, depending upon the nature of the disease which is being tested for. Numerous studies in Western countries have shown a predominantly positive attitude, among the public, toward prenatal diagnosis and genetic testing in general (Rowley et al., 1984; Williamson et al., 1989; Decruyenaere et al. 1992; Mennie et al., 1993; Green et al., 1994; Hietala et al., 1995; Henneman et al., 2001). Furthermore, a systematic review of psychosocial aspects of genetic screening of pregnant women and newborns, as conducted by Green et al (2004) found that twenty studies elicited women' views on the value of prenatal screening, eleven for chromosomal disorders [1,2,3,4,5,6,7,8,9,10,11,12] and nine for carrier testing.[13,14,15,16,17,18,19,20,21] table (1). About 80% of women preferred to have the screening option to just the diagnostic test alternative [7,11] and would consider paying for these services. [3,11] Further, about 60-75% of women stated they valued prenatal testing, [1,2,5,15,16,17,18,8,9,10,12,20] felt it empowered and enabled women to make informed choices, [4,9] and perceived it as a maternal responsibility to ensure the health of the baby.[4,9]. A smaller percentage of women (about 10%) stated that prenatal testing medicalises pregnancy,[2] generates worry, [2,14,21] creates false sense of control[2] and may lead to increased stigma within society[2]. These findings suggest that most women positively evaluate prenatal testing programmes but some have concerns about their usefulness and impact on the pregnancy experiences and society. It should also be noted that there is an important distinction between women's personal choice for themselves, and their views on whether or not tests should be legally available (Wertz et al., 1991). In addition, the decision to take up genetic testing may be related to a number of factors, major and minor, as explained below.

Study and country	N=	**Study aim**
1-Heikkila et al., 1997 East Finland	100	To study the attitudes of women in population-wide pregnancy screening for Down syndrome
2-Moyer et al., 1999 San Francisco, USA	75	To elucidate factors that influence women's decisions about genetic screening and testing and learn about their experiences
3-Salonen et al., 1996 Helsinki, Finland	625	To investigate how best to inform mothers about Down syndrome testing and the meaning of results and how to minimise anxiety cause by positive screening results
4-Carroll et al., 2000 Ontario, Canada	60	To explore ideas, opinions, feelings, and experiences of women regarding prenatal genetic screening (MSS)
5-Statham & Green, 1993 UK	20	To describe the experiences of a small group of women who had positive results after serum screening for Down's syndrome
6-Roelofsen et al., 1993 Groningen, Netherlands	280	To describe how women experience MSFAP screening, how the screening affected them, how they interpret the results and what consequences they consider the results to have
7-Weinans et al., 2000 Groningen, Holland	144	To gain insight into users opinions about maternal serum screening for Down syndrome in the Netherlands
8-Kornman et al., 1997 Groningen, Holland	254	To investigate women's opinions of first versus second trimester screening.

9-Press & Browner 1997California, USA	110	To examine the routine application of prenatal screening tests its implication
10-Markens et al., 1999 California, USA	Women who refused MSAF (25), had MSAF n not stated	To compare women's explanations for refusing MSAFP screening with other women's reasons for accepting it
11-Phillips et al., 1998 Tennessee, USA	172	To describe responses of recent mothers to the question: what test (MSS or prenatal diagnosis) she would choose for her self if she were advanced maternal age and had the information sent with the questionnaire about chromosomal abnormalities and accuracy, risks and costs of MSS and prenatal diagnosis
12-Jorgensen, 1995 Copenhagan & County of Sondrjylland Denmark	3667	To describe the opinion of pregnant women about AFP screening with view to determining whether every pregnant women should be offered a diagnostic test and ultrasound scan.
13-Santalahti et al., 1996 Jyvaskyla and Kuopio, Finland	91	To examine the impact of screening positive for Down syndrome and NTD on women's experience of pregnancy
14-Livingstone et al., 1993 Edinburgh, UK	312	To design an information leaflet which would permit the target population to make an informed decision about volunteering for couple screening for CF
15-Witt et al., 1996 Northrn California, USA	6442	To examine issues of the ability to counsel large numbers of patients for CF, the problems posed by inherent test insensitivity and the uncertainty of adverse psychological effects,

		particularly for couples in which only one partner is identified as a carrier
16-Miedzybrodzkaet al., 1995 Aberdeen, UK	2731	To perform a rigorous comparative evaluation of stepwise and couple approaches to antenatal carrier screening
17-Cuckle et al., 1996 Leeds and Hull, UK	6071	To assess practicality of implementing antenatal screening for CF in one area
18-Mennie et al., 1993 Edinburgh, UK	358	To assess the attitudes, understanding and responses of carriers and their partners detected through CF carrier screening in pregnancy
19-Harris et al., 1996 Manchester, UK	75	To assess the acceptability of integrating CF carrier testing into antenatal care by general practitioners at the first booking appointment
20-Fang et al., 1997 Los Angeles, USA	511	To examine the relations among psychosocial factors associated with pregnant women's attitudes toward genetic carrier testing for CF
21-Mennie et al., 1994 Edinburgh, UK	135	To investigate whether decisions of couples to accept prenatal CF carrier screening might be influenced by the advent of gene therapy.

Table 1: Attitudes toward prenatal screening and carrier testing

(adapted from Green et al., 2004)

2.4.1 How test is offered

Uptake of screening varies according to how the test is offered. When offered as a part of a routine visit, as opposed to requiring a separate visit, uptake is higher (Bekker et al., 1993; Tambor et al., 1994). There are many ways of offering a test, such as mailed invitation letter, face to face interview, phone call etc; the outcomes might not be the same. Watson, Mayall, Chapple, Dalziel, Harrington, Williams and Williamson (1991) compared the rate of uptake of cystic fibrosis carrier tests offered by mailed invitation letter, general practice, and family planning clinics. The results showed low uptake rates (10%) when cystic fibrosis carrier testing was offered by a mailed invitation letter, compared to high uptake rates when it was offered at general practice (66%) or family planning clinics (87%).

2.4.2 The person offering the test

In attitude studies, matching the interviewers with clients using the same language, gender, and ethnicity has been shown to be of help in facilitating access and communication in the interview setting (Panter, 1991; Atkin, et al., 1998). In addition, in some societies women feel more comfortable in being interviewed on their own, because in the presence of their husbands they tend to comply with social norms (Saleem et al., 1998). It therefore seems likely that the characteristics of a genetic counsellor or other person offering the test, will influence the decisions made.

2.4.3 Suitable time to offer the genetic test

It is important to select a suitable time and location for the offer of a genetic test. A study in Edinburgh, UK, found there was strong support for carrier screening in family planning clinics and GP health centres, but not in schools (Mennie, et al., 1993). Another study in London, UK (Modell, 1990) indicated that screening in high school may be a good strategy, but it requires a well-informed population and a developed infrastructure, and there is a long interval between testing and the use of the information.

In a Nashville study Clayton., et al. (1996) reported that 156 (74%) of respondents thought that the best time to have the test is prior to pregnancy, whereas 26 (12) indicated that the test was best done when choosing a partner; only 2 (1%) thought that it was best to have CF carrier screening during pregnancy. In addition, other studies have shown that when the test and treatment are available the uptake of testing increases. Craufurd., et al (1989), and Quaid and Morris (1993) found that uptake for Huntington's disease was only 10%, probably because no treatment was available; for breast cancer, for which there is some possibility of prevention and treatment, it is about 50% (Lerman et al., 1996); and it is around 80% for familial adenomatous polyposis, for which there is effective treatment

(Evans et al., 1997). Moreover, most parents believe that prenatal diagnosis is an important reproductive option for families at risk (Watson et al., 1992; Conway et al., 1994).

2.4.4 Culture

The term "culture" refers to socially transmitted values, beliefs, behaviours, customs, social and political institutions (Roandall-David, 1989). The term culture may also be applied to groups of individuals defined by various other criteria, such as the culture of deafness (Israel et al., 1992), and elements of culture and cultural identity associated with characteristics such as sex, and physical or mental disability (Saxton,1998; Finucane, 1998a). Therefore, culture is an important factor that affects attitudes to prenatal diagnosis for the same genetic condition. Thus, while uptake rates in the USA and UK are similar for Huntington's disease (Craufurd., et al. 1989; Quaid and Morris. 1993) rates for deafness are lower in the UK. Middleton, Hewison, and Mueller (1998) studied the attitudes of deaf adults toward genetic testing in UK, and found that culturally deaf participants were more likely than non culturally deaf participants to think that genetic testing would do more harm than good, and only 16% would have a test in pregnancy for deafness. This response was significantly different from attitudes towards genetic testing for deafness in a USA study, where Brungger, et al. (2000) found that the vast majority (96%) of respondents had an overall positive attitude toward genetic testing for deafness. Similarly, deaf culture involves individuals from many ethnocultural groups who are also diverse with respect to education, socioeconomic status, language, and communication modes (Israel et al., 1992; Ahmad, Atkin, and Jones, 2002).

In some societies, an isolated cleft lip and palate may be a defect that is considered serious and may ultimately warrant more decisive intervention such as abortion. A study was conducted in northern Israel in an area considered to be a low risk community for birth defects (Blumenfeld, Blumenfeld, and Bronshtein, 1999). Over a 10 year period (1983-1993), 30,000 trans-vaginal sonography screenings were performed at 14-16 weeks gestation. Most were low risk women without previous medical history or exposure to any known teratogens. Sonography detected 24 cases of cleft lip, and 23 women opted to terminate the pregnancy. A similar study was performed in San Diego, an area considered to have high risk women for birth defects (Jones, 1999). Over a 7 year period, 28 foetuses were identified as having cleft lip at a mean gestational age of 24 weeks. Eight of the 28 foetuses had isolated cleft lip identified before 22 weeks. Six women continued the pregnancies, and two did not. Another study was conducted in Buenos Aires, Argentina (Wyszynski, Perandones, and Bennun, 2003). Over a fourteen months period (June 2000 to August 2001), among 165 parents of children with nonsyndromic oral clefts who were treated at Association Piel, no parent declined to participate in the study. Sixty-three percent of the respondents were mothers, 28.5% of the respondents were fathers, and 9% were other family members (2 siblings, 5 aunts, and 6 grandmothers). Most parents (60%) believed their child's cleft was not a serous condition. None of the respondents would terminate a pregnancy because the ultrasound revealed an oral cleft.

While parents may have come to appreciate cleft lip as surgically correctable, it is important to also realize that not all women worldwide share such views, even within the same culture. In the UK, Allison (2003) has reported that one lady, born with a congenital jaw defect not corrected until her late teens, says that a cleft palate is not a serous handicap and the law should not allow abortion for such a trivial reason. The woman is taking legal action against the doctor who terminated a pregnant woman after 24 weeks of gestation, because her foetus had a cleft lip.

These studies illustrate that not all decisions that can be made on the basis of test results are seen to be acceptable, and which ones are will depend on social variables at that time. Thus, for example, Asian culture includes many countries and ethnic groups that have different histories, language, customs, beliefs, and other elements of culture.

2.4.5 Education

The educational background of the interviewee is thought to play a role in acceptability of prenatal diagnosis. In a Nashville study Clayton, et al. (1996) found that 72% of those who were interested in CF carrier screening had at least a college degree. In a USA study Ekwo, Kim, and Gosselink (1987) found that women's education level related positively to perception of burden. A study carried out in Israel, among 231 Israeli Arab women, by Jaber, et al. (2000) found that women who were willing to accept termination of pregnancy were more educated than those who opposed it. In a UK study Harris and Wertz (1989) reported that educated women of the higher social classes are more likely to request and receive prenatal diagnosis. Two studies in Finland show that highly educated women are more favourable towards abortion for different genetic conditions than other women, especially if the mother's alternative would be to give up her professional career (Rimpela et al., 1993; Aro et al., 1997). In contrast many studies found there is no influence of education level on women's attitudes toward prenatal diagnosis (Kurdi, 2001; Alkuraya et al., 2001; Sher et al., 2003).

2.4.6 Knowledge

Knowledge is central to attitude formation, but studies of knowledge about prenatal testing have to date examined only limited aspects of the subject (Green et al., 2004). Differences in knowledge scores are observed by level of education, socio-economic status and ethnicity. In a Nashville study Clayton, et al. (1996) found that one third of the participants may have misunderstood their risk of being a carrier, saying either that they had no risk or that their risk was medium or high.

Experience with other population based carrier-screening programmes in the past suggests that allowing people to participate without knowing what is at stake is ill advised. Watson, et al. (1992) found differences in knowledge between individuals with a negative test and individuals with a positive test (carrier for CF). 57% (133) of those testing negative realised there was still a small chance they could be carriers; 21% indicated that they thought there was no risk and the remainder were unsure. 70% (86) of those testing positive were aware that there was no risk of a carrier developing CF, 58% (71) understood the recessive nature of the disease, but only 24% (30) could quote the carrier frequency of CF. Decruyenaere et al. (1992) indicate that about half of the group had some knowledge of CF, with, however, serious gaps. Four out of 10 respondents in this sample of adults had never heard of CF. Only 38% of the sample could describe at least one feature of CF; 12% knew that CF is caused by a gene abnormality, and even relatives of CF-patients, who had an increased risk of being carriers of the CF-gene, had a rather poor understanding of the disease, especially about its genetic transmission. Brunger, et al. (2000) found parents who were interested in genetic testing for their deaf child but not for themselves; 53% (17/32) specifically stated that there was no purpose in having such testing, and 8 of the 17 made the statement "I am not deaf". Of these not interested in testing for themselves or their children, half (10/20) of these individuals did not feel that their child's deafness was genetic.

As further illustration of this poor understanding of genetics, some parents believed that their child had inherited deafness from them, but felt that they, as well as their child, had a zero chance of having other children with deafness. Other parents stated that they had a 25%-50% chance of having another deaf child, but that they did not believe that their child's deafness was inherited from either parent. Nevertheless, this study population had a strong interest in genetic testing for deafness, which shows that knowledge of genetic testing is not related in a simple way to parental attitudes to having a genetic test. Zahed, et al. (1997) found most of the families were not completely aware of their genetic risk, although 59% of the couples were definitely in favour of prenatal diagnosis, 18% were opposed to such testing, and 23% were uncertain at the time of interview.

2.4.7 The influence of professionals on informed choice

Informed choices require an accurate assessment of the information about the relevant decision alternatives and their consequences and an evaluation of their likelihood and desirability in accord with the individual's beliefs (Oliver. 1996). However, an informed choice cannot be made if health professionals' present tests in a very positive or negative light, as this may influence the decisions of those offered a test (Anionwu and Atkin. 2001).

Julian-Raynier et al., (1994) in France studied the reasons why eligible women did not utilize amniocentesis and whether or not the existence of social welfare coverage determined women's access to prenatal diagnosis. The crude odds ration of amniocentesis uptake was 4.15 times when the physician suggested the test than if he did not. Tay-Sachs screening is recommended to the entire Jewish population in Israel and is state subsidized (Zlotogra and Leventhal, 2000) but only 70.4% of the Ashkenazi couples and 56% of the non-Ashkenazi couples performed this test. The main reason given by the women for not performing the test (76%) was that they were not referred for testing. Sher et al. (2003) in Israel studied factors affecting performance of prenatal genetic testing by Israeli Jewish women and found that 33.3% of women stated that the reason for not performing amniocentesis was that they were not referred for testing.

Uptake of screening tests varies between health professionals. Women who have been offered tests by health professionals with more positive attitudes are more likely to undergo the test than those offered by health professionals who have less positive attitudes (Simpson et al., 1998; Mavrou et al., 1998). In addition, health professionals who lack knowledge themselves will be unable to inform patients (Smith, Shaw, and Marteau. 1994). Hence, patients will not be able to have accurate information about the test which would influence their informed choice to take up tests which have been offered to them.

2.4.8 Age and life stage of sample

The nature of the individual sample (adults, parents, pregnant women, general population etc) plays an important role in attitudes to prenatal testing and termination of the pregnancy. A study in the Netherlands (Henneman et al. 2001) compared attitudes between adults with cystic fibrosis and parents of children with cystic fibrosis towards termination of pregnancy. The result showed that more parents than adult patients said they would consider abortion; 45% and 14% respectively.

In another study in the USA, Levenkron, Loader and Rowely. (1997) explored the attitudes of pregnant women towards cystic fibrosis carrier testing and the result showed that 57% accepted the offer of such a test, while when the same offer of carrier testing for cystic fibrosis was made to non-pregnant couples in the Nashville population Clayton, et al. (1996) found that over 90% accepted the offer. A study in Finland (Aro et al., 1997) analysed effects of age, education and gender on acceptance of genetic testing for 1169 of

The Finnish population. The result showed that younger people, age 15-24, were more favourable towards testing and more willing to undergo a suggested test, but they were also more worried than others about the harm of test results. Men aged 45-69 with only basic education were more in favour of mandatory genetic testing than other respondents. Hence, the nature of the individual sample needs to be taken into account when considering screening programmes and informing the public for acceptance of genetic testing.

2.5 ATTITUDES TO TERMINATION

Attitude towards abortion generally is predictive of attitude towards using prenatal testing for foetal abnormality (Evers-Kiebooms, Denayer, Decruyenaere, and Van den Berghe, 1993; Norup, 1997). Clarke (1997d) mentioned that one of the potential benefits of prenatal diagnosis is termination of an affected pregnancy. Therefore, acceptance of abortion means acceptance of prenatal diagnosis, but not vice versa.

It was found in many studies (Breslau, 1987; Faden et al., 1987; Green et al., 1993a) that around 30% of women say that they would not consider termination on grounds of foetal abnormality. However, attitude to termination of the pregnancy does not necessarily predict actual uptake of termination. Nevertheless, patients' attitudes toward termination of the pregnancy are also critical and should be considered (Weil 2000). If a patient has personal, cultural, ethical, or religious attitudes opposing the use of pregnancy termination, counselling may help determine if there are limited circumstances under which pregnancy termination would be acceptable. These may include untreatable disorders or those that result in death either pre-or postnatal. For example, some patients would terminate for trisomy 21, whereas others would not. For some patients learning difficulty represents the most serious type of abnormality, for others, physical abnormalities are the most serious, and for some, specific experiences or beliefs determinate particular disorders for which the pregnancy would be terminated (Ekew and Gosselink, 1987; Wertz, et al., 1991, Evers-Kiebooms, et al., 1993; Michie, et al., 1995; Hietala, et al., 1995; Zahad and Tamim, 2002; Hewison et al, 2004). In addition, the trimester of pregnancy has a relation to personal willingness toward termination of the pregnancy (Parsons et al., 1993). In a study by

Wertz (1991) she found the majority believed that abortion should be legal in all 23 conditions during the first trimester and in 20 of the 23 conditions during the second trimester.

A family who already has a child with a disability, for example, may feel that any risk, however small, of a subsequent affected pregnancy is one that they cannot afford. On the other hand, a couple who have had great difficulty in conceiving may feel that any possible risk of miscarriage associated with testing is too great for them to take. Therefore, individual experience plays an important role in influencing patient attitudes toward prenatal diagnosis and termination of the pregnancy (Anionwu and Atkin. 2001).

2.5.1 Termination for different conditions

Many different factors have been studied. However, little attention has been paid to how the condition itself influences attitudes to termination and testing. The studies in this section compare attitudes to testing for different conditions in a number of different cultural settings.

2.5.1.1 United States of America

In a USA study (Wertz et al, 1991) 395 parents of children enrolled as patients in New England were asked to participate, all the parents in this study had an affected child with CF of whom 271 (68%, 228 families) responded. Questionnaires were either given out at regular clinic visits over a 4-month period to be returned by mail, or mailed directly to families. The questionnaire asked about attitudes towards abortion in 23 situations including 12 maternal or family situations and 11 conditions affecting the child. Where asked if abortion should be legal for others, the majority of respondents believed that as noted above abortion should be legal in the first trimester for all 23 situations and in 20 of the 23 situations during the second trimester. In terms of personal decisions, 58% would abort for severe learning difficulty, 40% would abort for genetic disorders leading to death before the age of five years, 41% for a child bed-ridden for life, 35% for moderate learning difficulty, 20% for CF and 17% for a severe incurable disorder starting at the age of 40. Few would abort for a disorder starting at the age of 60, for genetic susceptibility to alcoholism or for sex selection. Men were more likely than women to say either that they would abort or that abortion should be prohibited by law. In addition, men made less differentiation between trimesters. Those with higher education were more willing to abort than those with less education. All the parents in this study had an affected child with CF. However, if the same questionnaire were to be answered by another group of people having a different genetic abnormality, than the attitudes might be different.

In another study in the USA, a survey of 649 women who came for genetic counselling at the Obstetrics and Gynecology Department at the University of Iowa or were referred through physicians' offices (Ekwo, Kim, and Gosselink, 1987) investigated parental perceptions of the burden of genetic disease. During a two year period, 252 women (31%) were recruited (188 women over 35 years of age, 14 women with previous child with Down's Syndrome, 31 women with a family history of genetic disease, and 19 women over 35 years of age and with a family history of genetic disease). Of these, 202 women accepted and 50 women rejected amniocentesis. The women were given a copy of the questionnaire in a private room in the clinic area after they had been counselled about their genetic risk and amniocentesis and were requested to follow along as the research assistant read the questions aloud. The results showed that 53.3 % of women considered prolonged debilitating illness as the most serious, the second serious condition was early death of the infant (39%), the third condition was learning difficulty (27.6%), and facial abnormality was perceived at the least serious (4.3%). It was also found that women who accepted amniocentesis were more likely to perceive congenital malformation as burdensome.

This study only included pregnant women who were carriers of genes that code for genetic disease. The pregnant women in these circumstances would be under stress and their attitudes to the burden of genetic disease would influence their choice. Both of these studies used clinic samples, i.e. high risk samples.

2.5.1.2 United Kingdom

There is an extensive literature in the UK on psychosocial aspects of prenatal and neonatal genetic testing. This has recently been reviewed by Green and colleagues (2004). Little work has however been done in the UK on attitudes to testing for different conditions. In a 1995 study (Michie et al., 1995), attitudes towards testing for genetic conditions were collected from 937 members of the general public from 100 electoral constituencies around the UK and from 163 health professionals. Participants' attitudes towards prenatal diagnosis and abortion were obtained for "non-serious" disorders (minor physical problems and non-disease characteristics) and "serious" disorders (condition that causes the child to die soon after birth, cystic fibrosis, cancer in the early 30s, etc). In addition, participants selected words from a list, which included both positive and negative words (e.g. enthusiastic, horrified), to describe their views about genetic testing.

The results revealed that general public was more likely to use negative words to describe their views about genetic testing than health professionals. Prenatal diagnosis and abortion were endorsed by both general public and health professionals for serious conditions involving physical or mental handicap from a young age. Prenatal diagnosis and abortion were less acceptable for the non- serious conditions. It should be noted that in this study, the distinction between serious and non serious disorders was made by the researchers, whereas in Ekwo et al (1987) the distinction reflected parents' views as seen in the data.

2.5.1.3 Finland

Hietala, Hakonen, Aro, Niemela, Peltone, and Pertti (1995) reported findings relating to attitudes toward genetic testing among the general population and relatives of patients with a severe genetic disease. The sample comprised 1169 of the general population (259 Southern Finland, 295 Western Finland, 227 Middle Finland, 215 Eastern Finland, 173 North Finland). The sample ranged in age from 15-60+ years. 368 were of low education, 672 intermediate and 127 highly educated. The questionnaire consisted of 50 self-rating Likert type statements to evaluate attitudes towards gene tests in general and also respondents' preparedness to undergo gene tests for predictive testing, carrier detection, prenatal diagnosis, and selective abortion for different genetic disorders, as follows:

Cardiovascular disease, hereditary cancer, Schizophrenia, Learning difficulty, lethal metabolic disease, Homosexuality, and Sex selection. The subjects of the study were (1) 1169 general population, 639 females and 530 males; (2) aspartylglucosaminuria (AGU) relatives, 50 females and 32 males; (3) matched sample (drawn from the general population), 50 females and 32 males. The results showed that nearly 90% of all groups agreed with the statement that information on genetic testing should be available to anybody who wants it. 10% of the matched sample and 4% of the relatives were not at all in favour of genetic testing. The relatives of AGU patients were significantly more in favour of testing of those considering marriage than the matched sample (65% vs. 31%). However, the relatives of AGU patients were less supportive of genetic testing of newborns than the sample of general population (19% vs. 46%), and significantly less supportive than the general population towards gene test testing in general because it can lead to an increase in selective abortions (22% vs. 42%). About 70% of respondents would take a test to identify their predisposition to a cardiovascular disease, about 60% for a predisposition to hereditary cancer, and about 50% for a predisposition to schizophrenia. The relatives of the AGU patients were more willing than the general population to take prenatal diagnosis for learning difficulty (89% VS. 68%) and for lethal metabolic disease (85% VS 65%). However, the researchers did not report statistical comparisons between these two groups in any other conditions.

In both groups, prenatal diagnosis was opted for more frequently than selective abortion. A few significant differences were noticed in the respondents of the matched population. They were more willing to choose abortion for lethal metabolic disease than for cardiovascular disorder (P <.01) or cancer (P <.05). Reasons for not opting for testing were cost, discrimination in employment or in insurance policies, and increase in selective abortions. The study covered a wide range of all ages and educational levels. However, the views of people with different levels of educations or of different ages were not mentioned in this study.

Aro et al., (1997) reported the affect of sex, age, and education for the above population separately. In terms of sex; men agreed slightly more often than women with the following statements: individuals should be offered a genetic test when considering; marriage, planning to have children, and during pregnancy (43% vs. 31% P< 0.001; 74% vs. 69% P= 0.048; 71% vs. 68% P = 0.037 respectively). However, 19% men and 15% women (P=0.019) stated that genetic testing should not be performed at all. In the youngest group (15-24y) 33.8% were favourable towards genetic testing during family planning and pregnancy, but less so (12.8%) when considering marriage. 27% of women (25-44y) opposed mandatory testing but only 16% of men of the same age did so (P = 0.021); men older than 45 years old were significantly more likely than other respondents (50% vs. 31% P<0.001) to agree with obligatory testing. In terms of education, mandatory testing, genetic testing in family planning and pregnancy were opposed by those with a university education more than others.

For the intentions to take genetic tests, in terms of sex, men were more favourable than women towards testing for cardiovascular disease, and towards asking for termination if the test reveals a predisposition to hereditary cancer (65% vs. 59 P=0.006; 40 vs. 33% P=0.01 respectively). Women were more favourable than men towards prenatal testing for severe learning disability (72% vs. 62% P=0.001). In terms of age, among different age groups the respondents in the 25-44 years age-group were the most willing to take a carrier and prenatal test for learning difficulty. Men aged 45-69 with basic education were more willing than other respondents to take a prenatal test for cardiovascular disease, cancer, and schizophrenia (50% vs. 28% P< 0.001; 55% vs. 35% P< 0.001; 60% vs. 43% P < 0.001 respectively). Women aged 45-69 with university education tended to be more willing than other respondents to take a prenatal test for learning difficulty, but the difference was not significant (88% vs. 67% P=0.104). However, women aged 45-69 with university education were significantly more favourable than others towards termination of pregnancy for learning difficulty (88% vs. 56% P = 0.009). In addition, 110 of the respondents with experience of hereditary disease or carriership were slightly more willing than others to attend a carrier test for learning difficulty (81% vs. 69% P = 0.029), and were also more worried about being a carrier of five to ten disease genes (67% vs. 51% P = 0.004).

Aro and colleagues have reported a very important study about the affects of age, education, and sex on attitudes toward genetic test and abortion in different genetic condition. However, where "older" men and women are asked about their attitudes towards prenatal test and abortion, it is unlikely that their answer will be about themselves but might be for others, which should be distinguished in the questionnaire, to have a clear view whether respondents were talking about themselves or others. In addition older and basic education groups were different from others which could reflect difficulty in reading or comprehending the material in the questionnaire. Moreover, no statistical comparisons were reported between the respondents with experience of hereditary disease and others in attitudes towards genetic testing and termination for different disorders.

2.5.1.3 Lebanon

Zahed, Nabulsi, and Tamim (2002) assessed the attitudes of health professionals in Lebanon towards prenatal diagnosis and termination of pregnancy, for genetic, non-genetic and non-medical conditions.158 questionnaires were sent to geneticists, family doctors, pediatricians and obstetricians/gynecologists; 75 replies were received. There were 49 males and 16 females. Almost half of the respondents were 40 years old or above. The number of respondents was almost equally distributed between the two main religious communities in Lebanon: Christians (47%) and Muslims (53%).

The questionnaire consisted of three sections as follows: Section A contained nine specific conditions that may currently be diagnosed in utero, five others that are not currently diagnosable but are only hypothetical; the conditions included were of varying severity and age of onset, or "were merely behavioural". Section B, included cases of hypothetical requests for prenatal diagnosis that may present a dilemma to the health professional, such as anxiety, paternity, foetal sexing, and prenatal diagnosis during late gestation. Section C included five cases of hypothetical request for social abortion, for example, pregnancy of a single young mother or a rape victim. the results were: section A: a high proportion would undergo termination of pregnancy affected with conditions associated with major congenital malformations such as anencephaly (96%), Down's syndrome (80%) and severe learning difficulty (86.7%), but a lower number of them would abort foetuses with minor malformations like cleft lip/palate (16%) or obesity (1.3%), or behavioural conditions such as depression (10.7%) or homosexuality (18.7%). Section B: the majority of respondents (76%) agreed to do prenatal diagnosis for an older woman with advanced gestation and poor socio-economic status, and the lowest acceptance (18.7%) of prenatal diagnosis was observed in the case scenarios involving medically un-indicated foetal sexing. Section C: the highest percentage of positive responses (90.5%) was obtained for pregnancy resulting from rape, while the lowest percentage (20%) was for a pregnant woman requesting termination of pregnancy without her husband's knowledge. Muslims were more favourable than Christians towards termination of pregnancy in the clinical cases, which was rather unexpected.

This study again shows that perceived severity of the disorder affect people's attitudes toward abortion. However, the outcome from the study cannot be generalized to population attitudes, because professionals' attitudes are known to be different from population attitudes (Michie et al, 1995). In addition, the low response rate in this study could lead to bias, but the researcher does acknowledge that in her discussion.

2.6 ATTITUDES TO PRENATAL DIAGNOSIS AND TERMINATION OF THE PREGNANCY IN THE MIDDLE EAST COUNTRIES.

The characteristics of Arabs vary so widely from one community to another that the validity of any generalization to Arabs as a whole, like generalizing a unitary national character, is doubtful. Cultural differences between Arab societies are usually important and influence public attitudes. During the last two decades, genetic counselling programmes have been established in most Arab countries, due to an awareness of the genetic load exerted upon infant morbidity and mortality. In the Arab world, genetic services are a part of health services provided by ministries of public health, as in Saudi Arabia and United Arab Emirates, or part of activities by universities and academic institutions, as in Lebanon (Teebi and Farag, 1997).

2.6.1 Attitudes to prenatal diagnosis and termination of the pregnancy in the Middle East countries: Different studies

Previous studies in Western countries might not be applicable in the Arab societies. While there is wide experience about the Western population and its attitudes towards prenatal testing, little is known about the Arab population (El-Badramany et al., 1997). This knowledge is particularly important, since genetic disorders are relatively frequent in the Arab world. Thus, this section presents findings of studies of attitudes to or acceptance of, prenatal diagnosis and abortion in Arab populations.

2.6.1.1 Lebanon

In a Lebanese study. Zahed and Bou-Dames (1999) reviewed 90 couples at risk of different genetic disorders (chromosomal 59/90, autosomal recessive 23/90, autosomal dominant 5/90, and X-linked 3/90) to assess their acceptance of prenatal diagnosis and the variables that might influence their choice. All the interviews were conducted by an experienced geneticist and were structured as follows: the first two sections obtained information about religious, economic and socio-economic backgrounds, participants' family and reproductive history, awareness of their genetic risk and understanding of prenatal diagnosis. A detailed explanation about prenatal diagnosis was offered to all couples. Of the ninety couples interviewed, 34 were first cousins, 4 were distant relatives. In twenty-five couples, there was a positive family history; seventy-two couples expressed their wish to have additional children. 49% of the couples interviewed were of low education (primary school or below), 29% were of moderate education, and 22% have received higher education. Regarding the religion of the participants, 72 were Muslims and 18 were Christians.

The findings showed that 54% of the couples said they would request prenatal diagnosis in their next pregnancy, 26% of the couples said they were completely opposed to any prenatal diagnosis, while 19% of the couples were hesitant and unable to decide at the time of the interview; 87.5% of those refusing, said that they would not opt for prenatal diagnosis on religious grounds, while other reasons stated were risk of foetal loss, cost of the procedure and health concerns. The findings suggested that religion plays a role in the Muslim couples' attitudes towards abortion. Nonetheless, the couples had various genetic disorders, and their views about prenatal diagnosis would be influenced by their previous experience. In addition, men and women were interviewed in this study, and women might have felt more comfortable in being interviewed on their own, because in the presence of their husbands, they tended to comply with social norms (Saleem et al, 1998).

2.6.1.2 Tunisia

In a Tunisian study. Chaabouni et al. (2001) reported a result of 3110 fetal karyotypes carried out in a Tunisian population, by cultured amniocytes analysis. The foetal karyotypes were analysed from cultured amniotic cells for pregnancies at risk from September 1996 to September 2000. The patients were referred by obstetricians from private health institutions (29%) and public hospitals (71%). Amniotic fluid was obtained between the 14th and 35th weeks of gestation. Before the sample was collected, information was given to patients at genetic department clinics about significance of foetal karyotype abnormalities and about prenatal diagnosis outcomes including amniocentesis risk and pregnancy termination indication. If any abnormality was found, pregnancy interruption was discussed, and in case of acceptance, the termination was performed by the obstetrician in charge. Patients were divided into two groups, bad prognosis and good prognosis. The bad prognosis included autosmal aneuplodies 45,X; 47,XXY and poly X with total chromosomes number more than 47. The finding showed 130 cases of abnormal foetal karyotype giving an incidence of 4.18%. The total number of bad prognosis was 95, a rate of 3.05%. For all the bad prognosis cases, pregnancy termination was discussed with parents and was accepted by 90 couples.

The finding showed a high rate of acceptance of prenatal diagnosis and termination of pregnancy among Muslims parents. However, religious law does not allow termination after three months of gestation and it has been stated that the amniotic fluid was obtained between 14 to 35 weeks of gestation, while the diagnostic work in the laboratory would take from 11 to 12 days. Termination was discussed with parents with bad prognosis only, even though for parents with a good prognosis, their child would still have the risk of bad behaviour as a result of the abnormal karyotype.

2.6.1.3 Israel

Three studies were conducted in Israel assessing Muslims' attitudes toward prenatal diagnosis and termination of the pregnancy.

1) A study was conducted in Israel (Saleem et al, 1998) to characterize the effect of counselling on parental attitudes towards prenatal diagnosis and pregnancy termination as well as the factors affecting parental coping with burden. The researcher used a pre-structured questionnaire and interviewed 32 Arab-Muslim families with an affected child from the Jerusalem area whose affected children were listed in the Pediatric-Metabolic clinic of Hadassah Hospital; all parents were interviewed once, in their own language (Arabic) by the same person (R.S) Seven mothers, 3 fathers and 10 couples were interviewed in the clinic. Seven mothers and 5 couples were interviewed at home. At the time of interview, 16 families of the 32 (7 couples, 7 mothers, 2 fathers), had already had formal genetic counselling. The fathers were the only providers, and on average were of low income. Parents' age range was 23-50 years. The parents in 20 families were first-degree cousins. The total number of children in each of the families ranged from 1 to 7, healthy and affected. Free conversation was held after the closed question sections, and was structured to obtain further information according to the goals of the study.

The results show that all parents were ready to comply with all diagnostic tests and procedures needed for prenatal diagnosis. Eleven families were against pregnancy termination. Parents in one family objected to pregnancy termination as a rule, without specifying the reason for it, but would agree to terminate the pregnancy in case of severe "learning difficulty". Also, 9 families mentioned that the burden was found to increase as the number of affected children increased; and parents were mostly concerned about what people might say about them and their parenthood. Almost all families were concerned about social burden, which was the most prominent and disturbing factor to almost all families, regardless of the disease. In addition, the mothers felt uncomfortable in the presence of their husbands during the interviews.

Saleem's study is important in that it indicates that social norms and the burden of the affected child in the family were considered to be among the important factors influencing families' attitudes toward prenatal diagnosis and termination of the pregnancy. Also, genetic counselling and population education may be helpful in family planning. However, over a quarter of the families had undiagnosed genetic diseases which could have affected their attitudes toward prenatal diagnosis and termination of pregnancy. No statistical comparisons were reported.

2) A study on prenatal testing for genetic disorders among Arabs was conducted in Israel by Zlotogora and Reshef (1998) specifically exploring Arab women's attitudes to terminate pregnancy in case of an abnormality if detected early (CVS) or late (amnio) in prenatal tests at the Human Genetics Department in Hadassah. From 1992 to 1996, 816 prenatal tests were performed on Arab women (143 chorionic villi sampling and 673 amniocenteses). The foetus was found to be affected in 26 of the early prenatal tests and early abortion was chosen in 25 out of the 26 couples. In 31 cases of the late prenatal test, the foetus was found to be affected and late abortion was chosen in 21 couples. These figures show that the proportion of couples choosing termination was lower following the later testing, but that even at this stage, the majority (21/31) were still in favour of termination.

3) A study on prenatal diagnosis for detecting congenital malformations was conducted in Israel (Jaber et al., 2000). 231 Arab women of childbearing age 16-46 years from Taibe, Tira and Kalansuwa were interviewed on the third day after delivery in the Department of Obstetrics at Sapir Medical Center, Kfar Saba from September to December 1998. The

interviews were conducted by an experienced psychologist and consisted of three sections. Section 1 was about demographic characteristics, Section 2 reproductive history and Section 3, women's knowledge about prenatal testing. The results showed that 29.4% were consanguineous, 113 women (49%) thought that prenatal diagnosis was an inaccurate test for the detection of the foetal anomaly, and a further 55 women (23.8%) had poor knowledge about prenatal diagnosis. Fifty-one women (22%) did not believe that prenatal diagnosis gave the correct diagnosis, while four (1.7%) thought that prenatal diagnosis carried the risk of injury to the foetus or injury to the mother. Eight women (3.4%) had no opinion at all. High propositions of respondents were favourably inclined towards prenatal diagnosis (94.8%). Eighty-three of the respondents (36%) would agree to the termination of the pregnancy in case of a "severely" affected foetus. Comparisons were made between the obstetric histories (number of pregnancies, number of terminations, number of spontaneous abortion, and number of family members) of those who accepted and did not accept the termination, and no significant difference was found between the two groups. Respondents who were willing to accept termination of pregnancy were more educated, and of higher socioeconomic status than those who opposed it ($P < 0.001$). Of those who rejected termination of the pregnancy 67.9%, gave reasons associated with their religious beliefs, 6.1% said "it is my luck," 8.4% said "The doctors are not always right," 4.6% said "My husband does not agree," and 13% gave no reason.

Jaber's study is an important study, since he reported Muslim women's attitudes towards prenatal diagnosis and termination of the pregnancy, and the influence of the women's personal characteristics, and obtained a high response rate. However, the researcher did not ask the women if they had an affected child in the family, which might influence their attitude as found in the Finland study (Aro et al., 1997). In addition, the word "severity" did not reflect the characteristics of the disorders, therefore women in this study might perceive the characteristics of the disorder differently, as found in other studies (Wertz et al., 1991; Hietala et al., 1995).

2.7 SUMMARY OF CHAPTER

Previous research shows that attitudes were highly favourable towards prenatal diagnosis and very variable towards termination of the pregnancy. A number of factors appear to impact on the decisions of the participants toward prenatal diagnosis and termination of the pregnancy. However, studies which have examined attitudes toward prenatal diagnosis and termination of the pregnancy for a range of different genetic disorders are few, of diverse methodology and populations, and some are 10 years or old more. Parents in Saudi Arabia have a different culture from other countries which might influence their attitude toward prenatal diagnosis and termination of the pregnancy and this will be discussed in the next chapter.

CHAPTER 3: BACK GROUND ON SAUDI ARABIA

3.1 INTRODUCTION

The Saudi Arabian State was first established in the central region of the Arabian Peninsula in the early 18th century, and there is a rich history that traces its roots back to the earliest civilizations (Lipsky, 1959). Saudi Arabia is known for its influence on the international economy and for the significant position it occupies in the Arabic and Islamic world. It represents about four fifths of the Arab peninsula with an area of around 2.24 million square kilometres and estimated populations of 21.2 million, about 70% of whom are Saudi nationals (Peters, 2000). The region's ancient nomadic peoples developed a deep love for the land as well as a strong sense of independence. With the advent of Islam in the 7th century, tribes and clans were unified under one religion. Over a period of the last three decades (El-Islam, 1984) the Kingdom has transformed itself from a largely agricultural country, short on the amenities of modern life, to a vibrant community of people enjoying first rate social, medical and educational services and actively involved in global economics and commerce.

Today, the Kingdom of Saudi Arabia is a modern, technologically advanced nation with a strong sense of heritage and tradition. Saudi Arabia is poised for a promising future both at home and abroad, pressing vigorously forward in the service of Islam and securing the welfare of its people. This chapter discusses some aspects which have an impact on parents' attitudes toward prenatal diagnosis and termination of the pregnancy. The discussion will include the following sections: Saudi culture, health care, and different studies in Saudi Arabia that assessed prenatal testing and termination of the pregnancy.

3.2 SAUDI CULTURE

The religion of Islam is the main, though not the only, factor that shapes the Saudi culture. Culture can be shaped by many factors, including but not limited to religion, race, economic status, level of education, and environmental factors (Weil, 2000). The family has always been the most important social institution in Saudi Arabia. For Saudis generally, the family is the primary basis of identity and status for the individual and the immediate focus of individual loyalty, just as it was among those who recognized a tribal affiliation (Panter-Brick, 1992). Families form alignments with other families sharing common interests and life-styles, and individuals tend to socialize within the circle of these family alliances. Usually, a family business is open to participation by sons, uncles, and male cousins, and functions as the social welfare safety net for all members of the extended family.

Marriage must be arranged by the family, because there is no everyday contact between the sexes in Saudi's family culture, for example in the form of friendships, clubs or premarital sexual contact, so the arranging of marriage is begun by the families of the couple. Before living with each other, the couple should be married by a clergyman in an Islamic ceremony. The rule of thumb for choosing a marriage partner has been simple: keep it in the family, a cousin if possible, or at least a tribal kin who could help conserve resources and contribute to support the woman if she were divorced or widowed, according to Islamic law. In fact, Islam discourages marriage within the same tribe, but people in Saudi Arabia still have this tradition. Men are permitted in Islam to marry as many as four wives provided they are treated equally. In addition the father in the family appears as an authoritarian figure, at the top of a class structure based on age and sex (Teebi and Marafie, 1988).

Saudi Arabia's population presents a picture of cultural contrasts. Muslims try to live their lives according to God's laws as revealed through the Quran and the life of Prophet Muhammad. On the other hand, the interpretation of what it means to live according to God's laws has assumed different meanings to different groups of people; some seek to adjust traditional values to the circumstances of the present; others seek to adjust the circumstances of the present to traditional values.

The way that Saudi families live alongside other families, sharing common interests and life-styles, may increase the likelihood of stigma, because nothing can be hidden from other families. Saudi parents are very careful, if anything happens to their children, such as genetic abnormalities, not to tell anyone, to save the family's face (Panter- Brick, 1991). Therefore, a disabled child would create major changes in the family's social life, such as isolating the family from others and keeping the family constantly busy, and unable to think about their social life (Anionwu and Atkin. 2001). Those who suffer from the stigma of disease are socially isolated (Savulescu and kerin, 2000); hence stigmatization may be less visible or more widespread, depending on where the parents of disabled children live (Michie and Marteau. 1996). If they live in a capital city, then there is less stigmatization than if they live in a small town, where families are close to each other. In addition, parents might face another difficulty if they are willing to undergo genetic testing, because of the social norms.

Social norms play a role in influencing parents' attitudes towards genetic screening, as found in Zlotogora and Reshef's study (1998). They reported that the decision whether to terminate a pregnancy after the 19th week among Arab Muslim parents was heavily influenced by the social norms that forbid late abortion. Saleem, et al. (1998) found that in an Israeli Arab-Muslim population, parents were mostly concerned about what people might say about them and what their image in society would be, with regard to their parenthood.

3.3 HEALTH CARE IN SAUDI ARABIA

The inherited disorders pose a major problem for the Kingdom. Due to consanguineous marriages and the tribal nature of the country, cousin marriages are customary and contribute to the emergence of inordinately large numbers of these diseases, as do the high fertility of Arab families, and the reduced mortality due to better health care generally (Panter-Brick, 1991). Although no exact figures are established, the existing number of patients suggests the incidence of such conditions to be 40-80 times higher than that observed in the West (Ozand, personal communication).

Consanguineous marriages might be responsible for the presence of certain very rare inborn defects. Preliminary molecular genetic studies indicate such rare diseases to be due to a founder effect; i.e. a mutation that occurred in a distant ancestor, preserved and transmitted to further generations by consanguinity. Some of these disorders are manageable to an extent that permits a normal life style for the child. However, others cause significant morbidity. Therefore, prevention of these diseases is an important public health priority.

During the latter half of the twentieth century, Saudi Arabia has put into place one of the most sophisticated health care systems in the world (Sebai, 1985). The Kingdom now has a modern two-tier system that relies first on primary health care centres that provide preventive, prenatal, emergency and basic health care, and secondly on a network of hospitals that offers the most advanced treatments and surgical procedures. Between 1970 and 1980, the number of primary health care centres rose from 591 to 3,254 (Maloner, 1982). The number of hospitals grew from 74 with 9,039 beds to 279 with more than 42,000 beds, and 3,254 clinics, and more than 90,000 physicians and nurses are employed by the health service in Saudi Arabia with the great majority of them (more than 80%) being expatriates (Ministry of Health, Kingdom of Saudi Arabia, 1998). Saudis suffering from serious illnesses were once obliged to travel abroad in search of treatment, whereas now, hospitals in the Kingdom routinely perform organ transplants and other complex operations once associated with only a handful of western hospitals (Gallagher, 1984). Although Saudi Arabia's ratio of one hospital bed per 411 people is among the lowest in the world, the Kingdom is continuing to build new health care facilities.

In Saudi Arabia, during the last decade extensive efforts have been directed toward management, control, and prevention of genetic blood disorders. The national programme includes a comprehensive management protocol for patients with genetic blood disorders; this exists at the primary health centres, regional hospital, and referral centre levels. The programme is designed to educate the public about the need for programmes such as premarital counselling, neonatal screening, and genetic counselling (El-Hazmi, 1992b). The sensitization of patients, families, and the general community is achieved by a comprehensive awareness programme: the programme supports public lectures, conferences, pamphlets, posters, mass media discussions, inclusion of the subject in school curricula, and meetings between patients, families, and health-care providers (El-Hazmi, 1992b, and 1995a). After a massive programme in the media about genetic inheritance, the implication of genetic diseases for the family, and the importance of premarital screening in Saudi Arabia, premarital screening has now become compulsory in Saudi Arabia (Saudi T.V first channel, 2004) in order to reduce haemoglobinopathy disease. However, it has been shown that the results of such testing can cause stigma to individuals or family (Anionwu. 1993; Savulescu and Kerin, 2000). Therefore the results of the test should be treated as highly confidential.

3.3.1 King Faisal Specialist Hospital and Research Centre

With adequate numbers of general hospitals already in place, most of the new ones are specialised institutions. One of these new hospitals is the King Faisal Specialist Hospital and Research Centre (KFSH&RC). KFSH&RC, named after His Majesty the late King Faisal, was inaugurated in June 1975 in Riyadh, Saudi Arabia. KFSH&RC is a tertiary care hospital which handles special cases referred to it from all over the Kingdom. The facility has, since its inauguration in 1975, been at the forefront of health care and research.

KFSH&RC handles thousands of patients each year, performing organ transplants neurosurgery and a variety of other surgical procedures. Its extensive research centre conducts studies in pharmacology, oncology, pathology, toxicology and a wide range of other fields. If there is any abnormality found during the course of routine maternal care, parents are referred to gynaecology and given full counselling about the abnormality. The options available, such as amniocentesis are discussed with the parents. Depending on test results, parents would have the option of termination, if the foetus was found to be severely afflicted, based on religious laws.

The IVF Laboratory in the KFSH&RC performs up-to-date assisted reproductive procedures/techniques from conventional IVF to all types of micro manipulative techniques. Currently, the laboratory is carrying out more than 800 cycles annually. In addition, the IVF laboratory in the KFSH&RC can perform preimplantation genetic diagnosis for parents who have had a previous affected child and genes can be mapped such as cystic fibrosis. Today, the Institution is known to have one of the most sophisticated medical and research facilities combined with the latest advances in technology. The Research Centre is housed in a four-story, technologically-orientated building covering an area of 140,000 square feet. The building has been architecturally and organizationally integrated within the Hospital.

The emphasis in Saudi health care in recent years has steadily shifted towards improving the quality of care and broadening the scope of specialized fields of medicine covered by the Saudi network. However, Saudi Arabia has a large area of about 2.25 million kilometres, there are several hundred villages spread around the country, and some of the villages have very basic primary care. When patients have a very serous illness, they would be referred to a tertiary hospital in the capital city free of charge. Nevertheless, parents with a disabled child face a very difficult decision whether to stay in the village or transfer to the capital city for daily or weekly treatment. Not all parents have enough money to transfer to the cities and leave their jobs and family. This kind of difficulty might influence Saudi parents' attitudes towards prenatal diagnosis and termination of the pregnancy.

It is known that a country's health system plays a role in influencing parents' attitudes toward genetic screening (Anionwu and Atkin. 2001). As an example; Zahed, Nabuulsi, and Tamim study (2002), reported that the Lebanese health system is private and under Lebanese law, abortion for medical reasons is permitted before 22 weeks of gestation only if the mother's physical health is at risk. In the British context, Atkin, et al. (1998) reported that the National Health Service (NHS) and other services have neglected the long term care of people with haemoglobinopathy. Is seems likely that the quality of care which parents perceive to be available will influence their attitudes to having a child with a disorder.

3.4 ATTITUDES TO PRENATAL DIAGNOSIS AND TERMINATION OF PREGNANCY IN SAUDI ARABIA

Genetic diseases are frequently manifested in the Saudi population because of three factors: the widespread practice of consanguineous marriages, the high fertility of Arab families, and the reduced mortality due to infections (Panter-Brick, 1991). Saudi Arabia is an affluent country with access to technology, but a very different cultural context and almost no information on public attitudes. The following section presents some examples of studies in Saudi Arabia.

3.4.1 Attitudes to prenatal diagnosis and termination of pregnancy in Saudi Arabia : Different studies

1. A study on the attitude of Saudi families affected by thalassaemia, sickle cell anemia, (SCA), or both towards prenatal screening and abortion and the influence of religious rulings (Fatwa) was conducted in 32 Saudi families (Alkuraya and Kilani, 2001), by King Khalid University Hospital and by two Ministry of Health hospitals in Riyadh . The study took the form of personal interviews conducted by the same individual (one of the authors) who filled in the data in a pre-structured questionnaire. The following patient information sex was collected: (26 mothers, 5 fathers, and one couple); Age (mothers age 24-40 years, fathers' age 40-47years); Education (mothers' 70% primary school, fathers' 67% primary school). Religion (all were Muslim); Consanguinity (23 families were cousins)]. Participants were given full information about prenatal diagnosis and pre-implantation diagnosis. Twenty-six (81%) accepted prenatal diagnosis before and after the Fatwa was explained. Twenty-eight (87%) rejected abortion before the Fatwa, but 13 of these (46%) changed their minds after they were given the Fatwa on abortion.

Alkuraya and Kilani's study is important in that it specifically looks at families' attitudes towards prenatal diagnosis and termination of pregnancy before and after an explanation of the Fatwa, specifically in the Muslim country of Saudi Arabia, where all the population are Muslims. In this study the interviewers were males. However, Saudi women cannot express their feelings in front of males that they do not know (Panter, 1991). In this circumstance a male interviewer cannot go in depth with female clients, and the feedback from the interviews will be very limited (Atkin, et al., 1998). Only 4 out of 32 families were at risk of having a child with thalassaemia. Sickle cell and thalassaemia have different clinical features and the parents' perception of the burden of the conditions is likely to be different (Ekwo, 1987).

2. A study on awareness of inborn errors of metabolism among parents in Saudi Arabia was conducted in patients presenting a cross-section of those admitted for these disorders to Paediatrics at King Faisal Specialist Hospital And Research Centre, Saudi Arabia (Al-Essa, et al, 1997) and included 500 parents (263 fathers and 237 mothers). Both the fathers and mothers accompanying the children were asked to fill in the questionnaire separately by themselves; if the parents were illiterate, the interviewer helped them. Over 50% of the parents had no knowledge of the cause of their children's disease, its symptoms, inheritance and therapeutic modalities. Correct answers were more likely to be given when a family member was affected or in the case of a previously deceased child of an unknown cause.

The researcher did not mention if the parents had received genetic couselling following the birth of a child, or if it was their first visit. However, Mendelian inheritance is commonly misunderstood, and the numeric or probabilistic risks of a disease's recurrence are poorly remembered even in Western countries (Kessler, et al, 1987). In addition, the medical terminology in the questionnaire was difficult to answer by the parents, which might influence parents' attitudes (Finucane, 1998b). Nevertheless, the study shows the need to increase public health education programmes and shows that genetic counselling is particularly important in this population.

3. A study on parental response to consanguinity and genetic disease in Saudi Arabia was conducted in patients representing a cross-section of those admitted for neuro-metabloic disorders to Pediatrics at King Faisal Specialist Hospital and Research Centre, Saudi Arabia (Panter-Brick, 1991). The aim of the study was to assess, among Saudi families with an affected child with neuro-metabolic disorders, understanding of disease and attitudes towards future births and consanguineous marriages and to evaluate coping behaviours that included denial and resignation to the situation, divorce and remarriage. The study consisted of 36 families. Parents were seen on two or three separate occasions, each spouse individually. In fourteen cases, only one spouse could be seen. The author repated that a total of sixty-five interviews were conducted and that one refused to participate in the study. Parents were interviewed through the assistance of Arabic-speaking hospital personnel, most of whom were female who volunteered their help. Two-thirds of the respondents (67%) acknowledged that the disease could have a genetic basis, but only a third (31%) of them were sure. Eight parents quoted a probability for future children being affected as follows: four of them quoted the recurrence risk of 1/4, other families quoted "50:50", "30:70", "four will be ill, six will be healthy", or "after the fourth, the child will be all right". Seven claimed they were not told, two did not know because the doctors had yet to reach a final diagnosis, and one did not care. The author noted that twelve *families* said they would consider terminating a pregnancy if the doctors could tell the foetus was affected and advised this as the best course action. In contrast, sixteen *parents* would refuse a therapeutic abortion on religious grounds.

Panter-Brick's study is an important study for it showed some of the factors that affect Saudi families' attitudes towards the genetically inherited diseases. However, the author gives two different descriptions of the respondents, and the exact number of participants is unclear. For example the author states that she interviewed only 65/72, but gives no details of who was missing, fathers or mothers, and this could have introduced bias. No statistical comparisons were reported between fathers' and mothers' attitudes towards termination of the pregnancy.

Further, although the interpreters from the hospital had the skill to translate from Arabic to English, they did not have the experience to interview the parents in depth. This is likely to have been a particular problem if the interpreters and the researchers were not Saudi; they would have had a different culture and traditions which would have affected the parents' disclosure (Weil, 2000). If a counsellor or researcher is not from the same culture as the patient or researcher, he or she should use a good interpreter with special skills (Cox, 1976). All parents in this study had had an affected child, which might influence their attitudes toward termination of the pregnancy. Therefore, parents without an affected child need to be considered.

4. A study on maternal attitudes towards ultrasound screening for foetal abnormalities in a tertiary care setting was conducted in patients presenting for routine antenatal care at King Faisal Specialist Hospital and Research Centre, Saudi Arabia Kurdi (2001), specifically explored women's attitudes towards ultrasound screening for fetal abnormalities and towards termination of pregnancy. The study sample consisted of 65 women, of whom 2 women did not complete the study questionnaire (one of these two women had previous children with congenital abnormality), and 4 women with a previous history of an affected child were excluded. Thus, 59 women were presented with a questionnaire. After receiving full information about the study, the women were asked to fill in the questionnaire. It was found that fifty-eight patients wanted an ultrasound examination during pregnancy to confirm foetal normality; other reasons for wanting an ultrasound examination included wanting to know the foetal sex (12.5%) and wanting to see the foetus (6.9%). Forty-six patients (78%) would want to be informed during pregnancy if a foetal abnormality was diagnosed, 10 patients (16.9%) would not want to be informed during pregnancy, and 3 patients (5.1%) were undecided. Thirty-two patients (54.2%) would consider termination of pregnancy as an option in cases of "severe" foetal abnormalities, 24 patients (40.7%) would not accept termination of pregnancy for any kind of abnormality, and 3 patients (5.1%) were undecided.

Kurdi's study is important in that it specifically looks at women's attitudes towards routine antenatal tests. However, the study does not mention the time when the patients filled in the questionnaire: before or after the ultrasound. Furthermore, some of these women had no previous experience, this was their first pregnancy. These women would not have had an ultrasound scan before, so their opinions may not be as accurate. In addition, these results should be interpreted with caution because of possible differences in the nationalities of the patients, as these were not specified. It was not clear how the author collected and used information on the previous reproductive history of respondents and it was possible this might have introduced bias. In addition, there may be a problem with the paper's use of the word "severe", which does not convey information about the characteristics of the genetic disorder. Parents have been shown to have different views toward termination of the pregnancy according to the characteristics of the genetic disorders in question (Wertz et al., 1991).

Very limited information is available on attitudes to testing and termination for different conditions in the Saudi Arabia context. In the light of an ongoing study conducted in Leeds, U.K., by Professor Hewison, which compares the attitudes of indigenous white UK women and women of Pakistani origin, it was realized that this study could be adapted to the Saudi Arabian context, and that this would provide much needed attitude information in Saudi Arabia. In the Leeds study the attitudes of 420 postnatal Pakistani and indigenous white women towards prenatal testing and termination of pregnancy, for a range of conditions, are being compared using quantitative data collected by postal survey and one-to-one visits at the woman's home; the effect of educational level on attitudes is also being examined. The reasons underpinning these attitudes are being compared using detailed qualitative data from 60 one-to-one in-depth interviews. In addition, the attitudes towards prenatal testing of women who have recently used the Regional Genetic Services are providing supplementary data for comparison.

3.5 SUMMARY OF CHAPTER

Saudis have a great deal of common cultural aspects with Arabs and Muslims worldwide. However, the Saudi culture, like every other culture, is still unique in many ways. Studies that have been conducted in Saudi Arabia have considered the main factor that influences parents' attitudes toward prenatal diagnosis and termination of the pregnancy to be religious belief. A more detailed account of the views of the religious authorities about reproductive technologies is given in the next chapter.

CHAPTER 4: RELIGIOUS AUTHORITIES' ATTITUDES TOWARDS REPRODUCTIVE TECHNOLOGIES

4.1 INTRODUCTION

The theory of heredity was first known in Islamic thinking some 1400 years ago. At the dawn of Islam, the Prophet Mohammed directed his followers to be careful in selecting spouses because individual characteristics are inheritable. Islam is the third of the monotheistic Abraham religions, following Judaism and Christianity. It recognizes both as divine religions and shares their moral code. It has its own comprehensive legal system, called the Sharia. This is based on the Quran, which to Muslims is the divine word, on the teachings of the Prophet Mohammad (Sunna), and, for issues not specified by these teachings, on a process of synthesis and deductive reasoning (Ijtihad) that seeks the most appropriate answer in keeping with the directives of the Quran and Sunna. Ijtihad is done by scholars, and conclusions may vary with time, place, and circumstances (Hathout, 1997).

All the Saudi population are Muslims, and Islamic law encourages each individual to look after people with a disability. The Prophet Mohammad said, on the Day of Judgment, parents without a disabled child, will wish that they had had a disabled child during their life time, as a result of the kind of treatment given by God to those parents with a disabled child, because these parents suffer in their life but God will reward their efforts. Also, Prophet Mohammad said, all people in heaven will enjoy perfect health, even those people who were disabled in this life. However, Islam also permits people to avoid having a disabled child, and makes a number of reproductive options open to them. This chapter discusses some factors which are likely to have an impact on parents' attitudes toward prenatal diagnosis and termination of pregnancy. The discussion will include the following sections: religious views towards premarital screening, prenatal diagnosis, and termination of the pregnancy, marriage in Islam, and the Islamic view of genetic preventive options.

4.2 RELIGIOUS VIEWS TOWARDS PREMARITAL SCREENING, PND, AND TOP.

The researcher consulted one of the religious scholars who works as Prof. Associate and head of the department in Imam Mohammed bin Saud University in Riyadh, which is considered the biggest religious law University in Saudi Arabia (Alshatry. 2003). The researcher explained to the scholar about three preventive options from genetic conditions (premarital screening, prenatal diagnosis, and termination of the pregnancy), described to him parents' concerns as found in the present study, and pointed out to the scholar that there is no clear religious view toward the different preventive options for parents of affected children. During the meeting, the scholar wrote notes about what the researcher said, then after two weeks the scholar gave his opinion about the Islamic views toward these options. He did this in his own handwriting, in Arabic and signed the document (see appendix 2).

The researcher had intended to translate the text himself but he found difficulty in translating difficult meanings from Arabic to English, and the translation needed to be exact. Hence, the researcher asked for help from a colleague, Mr. Mahdi, who graduated from a religious school in Morocco. Mr. Mahdi's native language is English and he translates teachings on Fridays from Arabic to English, for non- Arabic worshippers in Leeds Grand Mosque. As translated by Mr. Mahdi, the opinions of the religious scholar on premarital screening, prenatal diagnosis, and termination of pregnancy were as given in section 4.2.1 to 4.2.3 below.

4.2.1 Premarital screening

"Indeed, knowledge of the Islamic legal ruling in these affairs produces numerous benefits, among which is the attainment of Allah's pleasure, Lord of the Worlds, and the attainment of benefit, for the Islamic Sacred Law is built on bringing about benefits and averting harm, as Allah says in the Qur'an[to the Prophet(*sala Allah alaihi wa salam*)] : "And We have not sent you except as a mercy to the worlds."[al-Anbiyya]. Notice how Allah uses the term *al-alamin*, which includes the people of Islam and other than them. By considering the explanation of the rules one finds that there are many legal texts that make the reason for legislating a law the attainment of benefit for creation and the protection of it from harm. Any issue, big or small, the Sacred Law has included it in its rulings, as Allah says in the Qur'an: "And we have revealed to you the Book, explaining every affair." Therefore, it is incumbent upon jurists to return to the texts of the Qur'an and the Sunna in order to extract rulings, as they are required to regarding new issues.

One of the first-mentioned means is the running of medical tests for a couple that wants to marry. By testing both of them before the consummation of the marriage by means of completing a blood test it is possible to confirm that both of them are free of any contagious diseases and be certain that neither of them are carrying any specific diseases that can be passed on to their children. This is according to what researchers in hereditary transmission have arrived at by discovering the nature of diseases.

The Islamic Sacred Law, as it appears to me, makes the running of these tests a recommended and preferable act, and to indicate that is the number of Islamic legal evidences, which include the following: 1) The legal evidences that indicate that marriage is legally established in order for the couple to obtain many benefits, such as tranquillity and stability between them, in addition to love and mercy. As Allah, Exalted is He, says in the Qur'an: "And from His signs is that he created from your selves mates, so that you may dwell in tranquillity with them and He made between you love and mercy. Indeed, in this are signs for a people who reflect."(ar-Rum) With the obtaining of recurring diseases some of the wisdoms and purposes of marriage are denied. However, by running tests before marriage we increase for ourselves the extent to which the benefits of marriage can be obtained by the couple. 2) The legal evidences that indicate the encouragement to desire suitability in marriage, for a man or a woman, as the Prophet, peace be upon him, said: "If someone comes to you, and you are pleased with his religion and character, then marry him [to your daughter], or else there will be tribulation in the earth and vast corruption." The people of the Sunan and Ibn Majah narrate that the Prophet, peace be upon him, said: "Choose for your offspring and marry those who are suitable." In other narrations: "Choose for your offspring for indeed women will give birth to those who resemble their brothers and sisters." For the sake of choosing suitable partners there is the running of necessary medical tests before marriage. Therefore, there are successive sayings of Muslim jurists in considering suitable partners, for part of the right of the child over his father is: The censuring of the mother, a beautiful name, and the teaching of manners. It is also mentioned that Uthman bin Abu al-'As said to his son: "Oh my marrying son, rapacious, let man look at where he places his seed and an evil stem, for when he is noble they choose, even if after some time." We can find in some chains of narration that choosing the wife is not simply a desire to give birth to a child that free from hereditary illnesses. 3) The encouragement of the Sacred Law to marry a fertile partner who will bear children, as the Prophet, peace be upon him said: "Marry those who are devoted and fertile." In order to know that the wife is fertile it is necessary to run tests before marriage. As the Sacred Law encourages the wife to be fertile, it desires for children to be born with healthy bodies and running tests before marriage can attain this. 4) Indeed there are benefits in these tests for creation, and the Sacred Law came to bring benefit and avert harm. These tests are means to fulfilling the purposes of the Sacred Law, and among the established maxims of the jurists is that means must be according to the purposes of the Sacred Law. The evidence that indicates the legality of the treatment can be found in the saying of the Prophet, peace be upon him: "Treat the servants of Allah, and do not be cured with that which is unlawful, for indeed there is a cure for every sickness." which also indicates the legality of treatment in order to prevent diseases and eliminate them. This wisdom is found in running tests before marriage, so they are lawful. 6) The jurists have established a maxim: "Prevention comes before cure." What is meant by prevention is to stop harm before it takes place, and by cure we mean the elimination of harm after it has taken place. The running of medical tests before marriage stops expected harms before they occur and before marriage we can ensure neither partner carries these diseases and so we can eliminate them or lessen their harmful effects. 7) The maxim of Sacred Law: Harm ceases and we say: "No harm and no distress." These numerous sayings are indicated by the legal evidences and by means of these tests we are able to prevent harm before it occurs. 8) The Sacred Law has forbidden any thing that affects the psyche of human beings and makes them feel irritated and disturbed and does not allow their souls to settle. For this reason the Sacred Law has prohibited the derision of others and speaking about their faults. It commands us to good conduct and the use of kind words, for kinds words are a charity, and to smile in the face of your brother is charity, and is indicated by the Prophet, peace be upon him. There is no doubt that what affects the psyches of individuals afflicts their children with illnesses, and this is a further affliction. What can prevent this is the running of medical tests before marriage, and this is lawful. There is an abundance of legal texts that prohibit extravagance and waste, as Allah says: "Do not waste, for indeed those who waste are the brothers of Shaitan, and Shaitan was ungrateful to his Lord." And He also said: "Eat and drink, but not to excess. Indeed, Allah does not love those who are excessive." And he said: "And [in] this world, when they spent they were not excessive and they did not slacken, and He was a guardian over them." There is no doubt that the treatment of hereditary illnesses requires a lot of expenditure which people provide to treat themselves or their children, or governments can do so. If we are able to avoid these massive expenses by running these necessary medical tests before marriage it would be a rightful thing".

4.2.1.1 The precepts of the Sacred Law

"Before running these tests we must make sure we observe the precepts of the Sacred Law, and the restrictions and conditions which we are commanded to comply with by this Immaculate Law, and from these conditions are the following:

1) Confinement to what achieves the purpose and to not run any tests that do not confer any benefit toward achieving the purpose of the test. This is related to being certain that the couple is free are from any contagious or hereditary diseases.

2) Concealment of information; to inform the patient himself only, of the complete results of the test. As for the other partner, he or she is informed of the suitability of the two partners or the lack thereof. The Sacred Law commands the concealment of secrets.

3) To observe proficiency in performing the tests in the best way possible and the Sacred Law commands proficiency of any work that is designated for the benefit of man.

4) Not to utilize of these tests in studies and researches etc. or run of other tests for a blood sample without the permission of the patient. To do so is wrong because the blood is the property of the patient and nobody has the right to act freely with it.

5) That there is not, in the context of running these tests, anything that would contradict the honour of a human being, decreed by Sacred Law, as Allah says on the Qur'an: "We have honoured the sons of Adam; provided them with transport on land and sea; given them for sustenance things good and pure; and conferred on them special favours, above a great part of Our Creation."[1] If it is decreed that the axiom of running these tests before marriage is that it is recommended then running these tests may be necessary in certain conditions, and may be obligatory in the following instances:

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[1] Al-Isra 17:70

Firstly: If the guardian enjoins the running of these tests, for Sacred Law commands obedience to guardians, as Allah says: "Oh you who believe! Obey Allah, and obey the Messenger and those charged with authority among you."[2]

Secondly: If the children are certainly afflicted with an illness, or this is presumed to be the case, Sacred Law forbids man to harm other, as Allah says: "And those who harm believing men and women undeservedly bear (on themselves) a calumny and a glaring sin."[3] One of the means of preventing this harm from afflicting children is to medically test those who desire to get married before they do so. When the affliction of children, attributed to a sickness, is high in any country it is imperative to take measures that lead to the prevention of this sickness. One of the means of doing this is to run the necessary tests before marriage".

4.2.2 Prenatal diagnosis

"As for the ruling regarding running these necessary tests on the embryo, whilst in the womb of the mother, in order to make certain of its safety and treatment in an early enough time, there is no doubt that it is from amongst those things that draw the slaves closer to their Lord, for it is treatment that is decreed by Sacred Law and it is part of co-operating in commanding to that which is good, as Allah says: " Help ye one another in righteousness and piety, but help ye not one another in sin and rancour."[4] It is imperative to observe the precepts of Sacred Law in this matter, and this includes the prevention of harm to the embryo and its mother, hiding the results of the test, not treating affairs that are forbidden by Sacred Law and likewise to follow what is right according to the jurists and what they have to say regarding the general rules of medical treatment.

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[2] An-Nisaa 4:59
[3] Al-Ahzab 33:58
[4] Al-Ma'ida 5:2

As for taking a cell from the cells of the embryo whilst in the mother's womb to confirm its soundness or to know the extent of its affliction by the sickness, the principle of its permissibility, and many legal opinions have been issued from juristic councils permitting the taking of samples from the body of the patient in order to examine it, and taking a sample from the embryo in the womb of the mother is likewise permitted by determined maxims: prevention of the greatest of two harms from committing that which is terrible, and bringing about the greatest of two benefits, by leaving that which is useless. As for the case in which certain harm to the embryo is the result of taking a sample, then Sacred Law prohibits harming others and the embryo in the womb of the mother has a sanctity that the doctor has no right to abuse or transgress against. If anyone transgresses against it, it is obligatory upon the transgressor to pay 10% of the indemnity of a grown person. As for taking a sample, which contains one of the cells, in order to examine it and the placing of an appropriate method of dealing with the embryo, this includes the slightest possibility of harm coming to the embryo and likewise the possibility of the embryo falling from the womb. The decision is the responsibility of the doctors and if they do not think that there is a strong risk and it is not a medical consideration, then there is no objection to running these tests and taking these samples. However, if the doctors consider that there is a high or average risk, at that point it becomes impermissible to run these tests because the doctors are specialists and Sacred Law rules in favour of the majority and hence the jurists have decreed that the majority rule is the consensus".

4.2.3 Termination of the pregnancy

"As for the issue of abortion of the embryo, if it is made clear to us that the one afflicted has a sickness or a disease that will affect him or her in their life, and will prevent them in participating in building their society and because of their state the parents suffer, more burdens are placed upon the parents and they have to pay huge sums of money for treatment, at that point it is necessary that this decision is not considered unless we find the following conditions:

1) That the decision is issued by people of jurisdiction (i.e. doctors).

2) If in this decision there is a legally valid number including no less than two doctors, who reach their decisions independently.

3) That this decision is established on scientific foundations, and not to base it merely on theories or on what is not officially acknowledged.

4) That the decision is certain regarding the occurrence of the sickness, and it is not dependent on mere conjecture.

5) Observance of the other precepts that are demanded medically and officially. If the decision is issued in that regard, it is not permissible to have an abortion if the parents refuse or one of them does. Therefore it is necessary to take permission from one of them, and if permission is obtained then the abortion must take place in a time that is agreed upon. Most jurists have prohibited abortion after forty days, and this is the opinion of the Shafi'i and Hanbali schools of jurisprudence, in accordance with the saying of the Prophet, may the peace and blessings of Allah be upon him: 'When forty two nights have passed by Allah sends an angel which shapes it and creates its hearing, its sight, its skin, its flesh and its bones, and then it says, "O Lord, is it a male or female?" Then your Lord decrees what He wishes and the angel writes it.' In another narration: 'The angel is commissioned with responsibility of the womb, when Allah wants to create something, by the permission of Allah, for forty days and a bit.' All of this is narrated by Muslim. Some scholars of the Hanafi school of jurisprudence permit up to 120 days, according to the hadith, 'Verily the creation of one of you is gathered in the womb of the mother for forty days, then likewise it clings (to the womb for a similar period), then it is an embryo (for a similar period), then Allah sends the angel which breathes into it its spirit.' The Maliki school of jurisprudence completely forbids abortion from the moment the sperm settles in the womb, and this is because the

texts generally indicate that it is impermissible to violate the embryo and this is one of the strictest of opinions regarding this issue, because the previously mentioned texts indicate a time in which the spirit is breathed into the embryo and they do not indicate that it impermissible to violate the embryo before that time. Likewise, it is impermissible for the man to act freely without legal justification, and in the same way is not permissible for the woman to act freely with her embryo without legal justification. It is also impermissible to end the life of a patient when we are certain of his affliction with a sickness. Therefore, the embryo and the issue is an area of difference and for every research and jurist there is evidence. If the doctors decide that the embryo will die immediately after it has been born, then this issue requires further research."

4.2.4 Marriage in Islam

The scholar's opinions about the Islamic view of reproductive technologies are given above. In addition, the position of marriage within Islam needs to be described.

Marriage is described by the prophet as half of the faith; celibacy is not acceptable to Islam. Certain categories of women are unlawful for a man to marry (the reverse will apply to a woman), such as mother, daughter, sister, aunt, niece, mother-in law, daughter-in law, step-daughter, and "mother in lactation" and her daughters. (The latter means that man who had previously been breast fed by a woman cannot marry her or her daughter). Marriage among cousins is not prohibited by Islamic law but it is recommended by scholars to marry from afar to avoid near relatives. Consanguinity is prevalent in certain Muslim communities, a feature of local culture but not of religion, which indicates that some marriage traditions, although not recommended by Islamic law, are still prevalent in the Muslim community. Marriage is the only legitimate venue for sex and reproduction. Extramarital sex (adultery with a female or male) is forbidden as a grave sin; upon certain legal specifications, it can also become a legal offence deserving court punishment (Hathout, 1997). In addition, the Prophet (may peace be upon him) encouraged men to chose a wife for her piety rather than other characteristics such as beauty, prosperity, and status: "Abu Hurira (Allah be pleased with him) reported Allah's Messenger (may peace be upon him) as saying: A women may be married for four reasons: for her property, her status, her beauty and her religion so try to get one who is religious, may your hand be besmeared with dust" (Khan 1997). It is generally the worldly consideration which predominates the mind of man in making the choice of a woman with whom to enter a marriage contract. The prophet (may peace be upon him) exhorts his followers to make religious piety the first consideration in the choice of a bride, but this is totally different from the Saudi culture where the mother 'shops' for a prospective bride for her son and the piety of the woman is not the first concern for the mother.

4.3 THE ISLAMIC VIEW OF GENETIC PREVENTIVE OPTIONS.

Section 4.2 above gives a contemporary account of the Islamic view on reproductive technologies. In addition, the literature contains a range of views about the various options that can be given to parents, and their acceptability under Islamic law (Shaltout, 1959; Hathout, 1972; Islamic code of medical ethics, 1981; Human Life: its inception and end as viewed by Islam, 1985 Albar, 1987; Human reproduction in Islam, 1989). The options considered in the literature may be listed as follows:

1. Avoidance of pregnancy by contraception or sterilisation;
2. Diagnosis during early pregnancy;
3. Donation of a sperm, ovum or pre-embryo;
4. Preimplantation genetic diagnosis;
5. Adoption.

The Islamic perspective on these options is discussed below.

4.3.1 Contraception and sterilisation

Muslims accept the use of temporary means of contraception, if the couples wish to use them, and if there is no harm from such a method. However, sterilisation is not accepted unless the health of the expectant mother would be endangered by pregnancy. However, if the couple already has two or three congenitally affected children, and few unaffected ones, then they may choose sterilisation, which would find support from some Islamic jurists (El-Hashemite, 1995)

4.3.2 Prenatal Diagnosis and genetic termination of pregnancy.

Muslim jurisprudents agree that if genetic testing proves definitely that a foetus is affected by a serious disease, which will leave him disabled after birth, then abortion is permissible and lawful. However, pregnancy termination should be carried out before the time of "breathing the soul"(i.e. Muslims believe that the soul is sent by an angel from God to the foetus in the uterus, and the foetus' life starts from that day) that is, before 120 days of gestation (El-Hashemite, 1995). Termination is only acceptable if a medical committee of specialised competent physicians decide that the foetus is grossly malformed and that his life will be a calamity to his family and to the foetus. The malformation should be untreatable, unmanageable and very serious. On the basis of that agreement, abortions of fetuses with serious congenital diseases are carried out in the hospitals of Saudi Arabia. However, there are still many dilemmas common to people of all religions. Is it permissible to abort a Downs syndrome foetus who could still live a quiet peaceful life? Is it permissible to perform an abortion when the disease will not appear until the age of forty or more, or where treatment is available, for instance, thalassaemia?

The differing views of religious scholars leave Muslim parents with no clear view about the time within which termination of pregnancy is permissible. Their Fatwa (judgments) vary considerably from the first zygote to the 19th week of gestation; parents have to select one of these Muslim jurists' Fatwa. In addition, Muslim jurists have agreed that termination is to be confined to 'severe conditions', without specifying which conditions may or may be terminated. The physicians have to decide which condition is severe in their view, regardless of how the parents perceive the condition. While parents may choose to follow one of the Fatwa (about gestation or condition), in relation to termination, the hospital policy might follow another Fatwa. This conflict might affect parents' attitudes to termination of the pregnancy.

Among Muslims, religious commitment plays an important role in accepting genetic screening (Panter-Brick, 1991) Empirically speaking, Saleem, et al. (1998) found among a sample of Arab-Muslim families living in Israel that religious commitment was the main reason that influenced parents' decisions against termination of the pregnancy. In studies by Zahed's et al., 1999; Alsulaimn, 2000; and Alkuraya and Kilami, 2001 which explored the attitudes of Muslim's parents to termination of the pregnancy, religious beliefs were again found to be the primary reason for refusing termination of the pregnancy.

4.3.3 Donation of a sperm, ovum or a pre-embryo

Via the new technology of procreation and through semen banks and in vitro fertilisation projects, a sterile couple (or one spouse) can, in the west, get a donated sperm, a donated ovum, a donated pre-embryo (blastula or morulla) or a donated uterus (surrogate mother) (Equinox, 1993). However, Islamic teachings limit procreation to within wedlock, and hence to husband and wife only. There should be no third party in the process of procreation, that is, no donated sperm, ovum, pre-embryo or womb. Therefore, a Muslim couple carrying a lethal gene or a serious disease gene cannot use any of these technologies. They are all rejected by all Islamic jurists who insist that procreation should be limited to spouses alone, without the intervention of third parties (Albar, 1987).

4.3.4 Preimplantation diagnosis

In-vitro fertilisation is permissible in Islam if the sperms and oocytes are from the husband and wife. Muslim jurists have agreed that preimplantation diagnosis of genetic disorders is permissible in Islam because in-vitro fertilisation does not conflict with God's desire and might (El-Hashemite, 1995). Furthermore, this technique is not considered a modification of God's creation because it is a kind of treatment. Preimplantation diagnosis may be preferable to prenatal diagnosis for parents, because it is done when embryos are only at the eight-cell stage and "breathing the soul" has not occurred at this stage.

4.3.5 Adoption

The Holy Quran abrogated adoption, and adoption is not recognised as parenthood. The lineage of the child should be to his natural parents, from a legitimate pregnancy, as Islam allows procreation only within wedlock. The Glorious Quran says: "He (Allah) didn't make your adopted ones your sons. That is only a saying from your mouths, which has no reality.

Call them by (the names of) their true fathers. That is just in the sight of Allah, but if you know not their fathers, call them your brothers in faith". (Sura 33:4,5).However, bringing up orphans is a great act of charity encouraged by Islamic teachings, but even then, the lineage of the child should remain to his true father. Therefore, couples at high genetic risk cannot adopt a child, though they can care for one or many orphan children or children of unknown parents.

4.4 SUMMARY OF CHAPTER

God sends his messengers to the entire world for a reason, that is, to protect people from any harms that might affect them. Therefore, Islam as a religion wants to protect Muslims from anything that might affect people's lives. Religious authorities have described the important options to parents who are at high risk of having an affected child. However, religious authorities rely on physicians' opinions as to which genetic conditions should be terminated.

Having considered the context of this study, the next chapter will explain how the study's research questions were addressed. It will present and discuss the methodology of this study as well as explain the procedure for its implementation.

CHAPTER 5: THE METHODOLOGY OF THE STUDY

5.1 INTRODUCTION

This chapter aims to provide a methodological framework for the present research. The study's primary aim is to assess parents' attitudes toward prenatal diagnosis and termination of the pregnancy in a range of different conditions. Hence, the research questions examined in this study are designed to fulfil the following objectives: 1. To provide an understanding of parents' view about the acceptability of testing and termination of pregnancy for a range of different conditions. 2. To compare the views of fathers with and without an affected child toward prenatal diagnosis and termination of pregnancy for a range of different conditions. 3. To compare the views of mothers with and without an affected child toward prenatal diagnosis and termination of pregnancy for a range of different conditions. 4. To compare the views of fathers and mothers with and without an affected child toward prenatal diagnosis and termination of pregnancy for a range of different conditions. 5. To find the factors that affect parents' attitudes toward prenatal diagnosis and termination of the pregnancy.

This study proceeded according to the following stages: First, the research problems were identified and defined. This provided the basis for the formulation of precise research questions and they in turn determined the selection of a method of research, either quantitative (questionnaire) or qualitative (interview) (Snape & Spencer; 2003:5). These methods were then applied and their resulting data were analysed and evaluated (Figure 2).

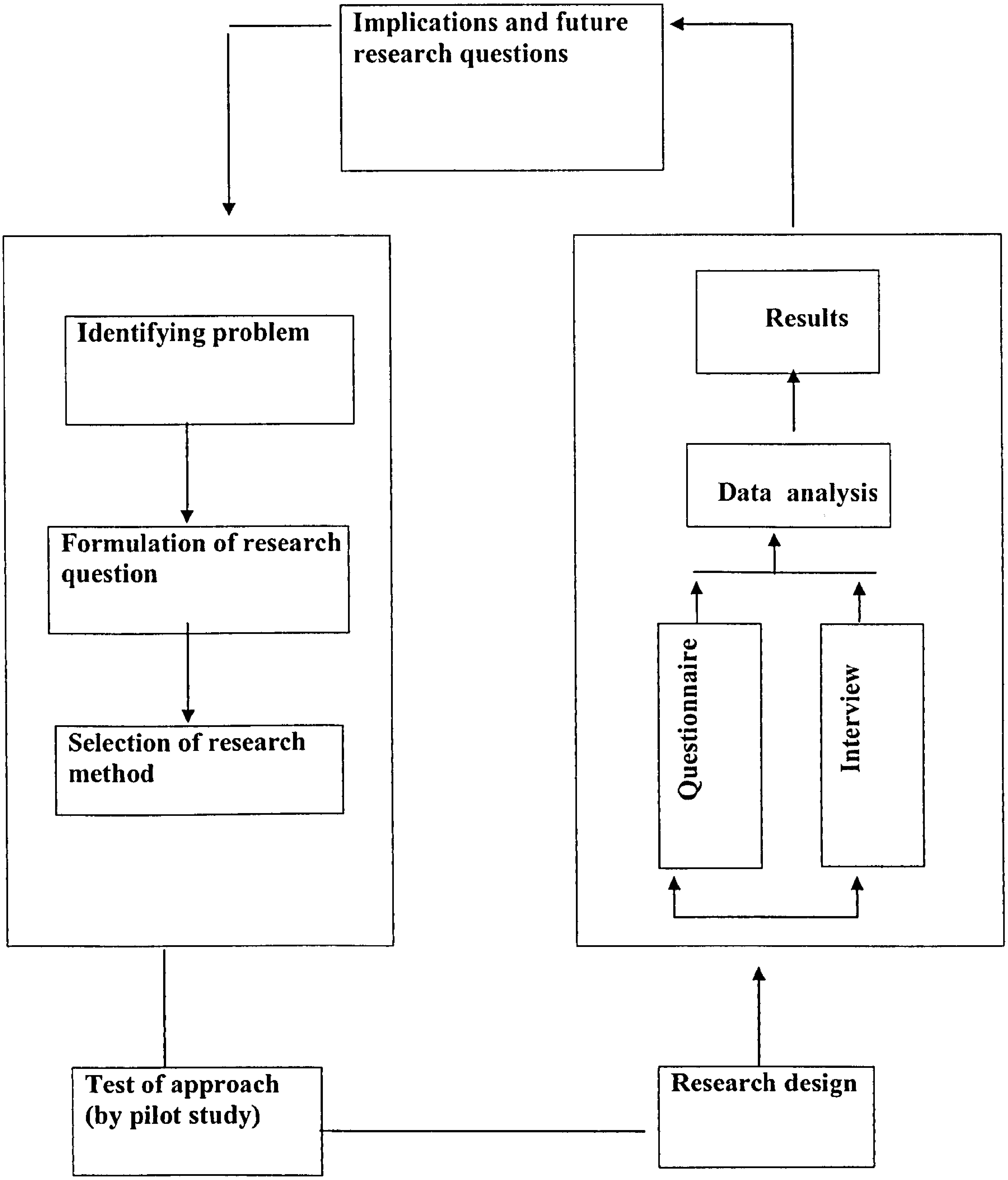


Figure 2: Research design

5.2 METHODOLOGICAL STRATEGIES

Before going on to describe in detail the instruments used in this study, the overall methodological strategy used for both phases of the research will be described. The methodological strategies to be used had to be compatible with the above-stated purposes of the study. This section aims to set the scene for a description of the research design of the current investigation by setting out the fundamental aspects of any research strategy (Lewis, 2003:47). It will be selective and will attempt to highlight important issues in current research. The areas under discussion in this section are: the type of data needed, and methods used in previous research, research design, and the participants.

5.2.1 Type of Data Needed

Collecting data is about using appropriate methods of investigation, in a systematic, professional fashion (Robson, 1993:304). The major objectives of data collection in this study to find out Saudi parents attitudes toward prenatal diagnosis and termination of the pregnancy and the reasons for the attitudes held. In collecting data, it is important to use procedures which elicit high quality data, since the quality of any research study depends largely on the quality of the data collected and quality is directly related to the data collection procedures.

There are two main types of data: qualitative and quantitative (Bland, 1995:46). It is widely recognized that the purpose of the study is a crucial determinate of the approach used and hence, the type of data that should be collected. Robson (1993:303) maintains that qualitative and quantitative data are different and must be dealt with in rather different ways. Qualitative research aims to broaden the scope of the understanding of phenomena by employing more naturalistic and less structured data collection procedures. It aims to explore and describe constructs by collecting rich and in-depth data, taking full account of individual circumstances. Qualitative research, therefore, tends to be closely associated with relatively open and less structured strategies for data collection, such as the use of participant in-depth interviews, in order to generate a detailed account of human experience and behaviour (Legard, Keeganand and Ward, 2003: 139). The focus on meanings and the attempt to understand the culture of those being studies enables researchers to explore the reasons people have for the views they hold. This, qualitative methods were ideally suited to address the last of the study aims.

Quantitative research, on the other hand, seeks to identify relationships between different constructs through the use of controlled and objective instruments, with little emphasis on the individual's state of mind. This type of research is closely associated with survey or experimental data collection procedures (Ritchi, 2003; 39). The quantitative approach is ideally suited to the collection of data from relatively large numbers of people, which was necessary in order to address the first four study aims.

By collecting a combination of both types of data, using a variety of sources, it is possible to build on the strengths of each type, while minimizing the weaknesses of any single technique. In other words, through complementary use of methods, it was hoped that validity of information would be obtained (Ritchi, 2003; 39).

In selecting appropriate approaches and methods, it is useful to consider what other researchers have done in order to see what methods have proved useful and to identify weaknesses and omissions (Lewis, 2003: 56). Thus, in the following section, the main methods used by previous researchers studying attitudes toward prenatal diagnosis and termination of the pregnancy will be considered.

5.2.2 Previous Research Methods

Researchers have sought a variety of ways to measure attitudes towards prenatal diagnosis and termination of the pregnancy. However most studies have only used a single method, i.e. qualitative or quantitative, but not both. Adopting a quantitative approach, a number of researchers have used a self-report questionnaire. These include Evers-Kiebooms (1993); Wertz et al (1991); Hietala et al (1995); Zahed and Nabulsi (2002). Others have adopted a qualitative approach, and have used face to face interviews, for example, Ekwo (1987).

Recently, there have been a few studies that combine quantitative with qualitative approaches in studying attitudes toward prenatal diagnosis and termination of the pregnancy by using questionnaires and participant interviews, for example, the Leeds study (Hewison et al., 2004). The present study used similar methods to those used in Leeds, to assess Saudi parents' attitudes toward prenatal diagnosis and termination of the pregnancy, and to discover the reasons behind these attitudes. Therefore, in the present study, both qualitative and quantitative techniques were adopted.

5.2.3 Research Design

The research design of this study involved both quantitative and qualitative approaches. For the quantitative component, the first task was to assess parents' attitudes. Attitudes are hypothetical constructs and thus cannot be directly observed but only inferred from other responses (Ajzen, 1988). The most commonly measured expressions of attitudes are verbally expressed cognitive responses, beliefs and affective responses or emotions. These have been shown to relate reliably to overall evaluations of an attitude object. It was acknowledged that the relationship between attitudes and behaviour is complex, and the former are not necessarily a good guide to the latter. However in the present context basic information on attitudes to testing and termination was not available in the literature, and collecting such information would be an important contribution to knowledge in its own right

To achieve the first purpose of this study, that is, assessing Saudi parents' attitudes toward prenatal diagnosis and termination of the pregnancy, the structured questionnaire was selected as the most appropriate instrument because of its capacity to generate quantifiable data from a large group of parents. It was acknowledged, however, that questionnaires are techniques used by researchers to convert into data the information directly given by a person. These approaches make it possible to measure what a person knows (knowledge or information), what a person likes and dislikes (values and preferences), and what a person thinks (attitudes and beliefs), but they are less well suited to exploring the reasons behind the views and opinions expressed (Ritchi, 2003: 40). In the present study, it was important to understand the reasons people had for the views they held, so it was essential to supplement the quantitative data with material collected using a qualitative approach.

5.2.3.1 The First Phase: Quantitative Technique

The aim of the first phase of the research was to investigate the following research topics:

1. Parents' attitudes towards prenatal diagnosis in a range of different conditions;
2. Parents' attitudes towards termination of the pregnancy in a range of different conditions.

In addition, information on parents' demographic characteristics was required, to assist in the interpretation of the attitude data collected.

Controlling and regulating study variables and features are basic aspects of research design. Experimental Research hypotheses propose that independent variables are formulated and tested and cause an alteration in the outcome being measured (Davis, 1998:54). In observational studies such as the present one, patterns of association between independent and dependent variables are investigated, but it is acknowledged that the nature of the study design does not permit robust conclusions to be drawn about cause and effect. Alternative explanations, e.g. derived from demographic factors, had to be considered and examined when possible. Two independent variables were considered in this study, gender of parents (mothers or fathers), and presence of an affected child (yes or no) as shown in Figure 3, and group differences were examined.

Attitude data were collected by a questionnaire (see section below) the responses were analysed with a statistical package, SPSS (see chapter 6, section 6.2).

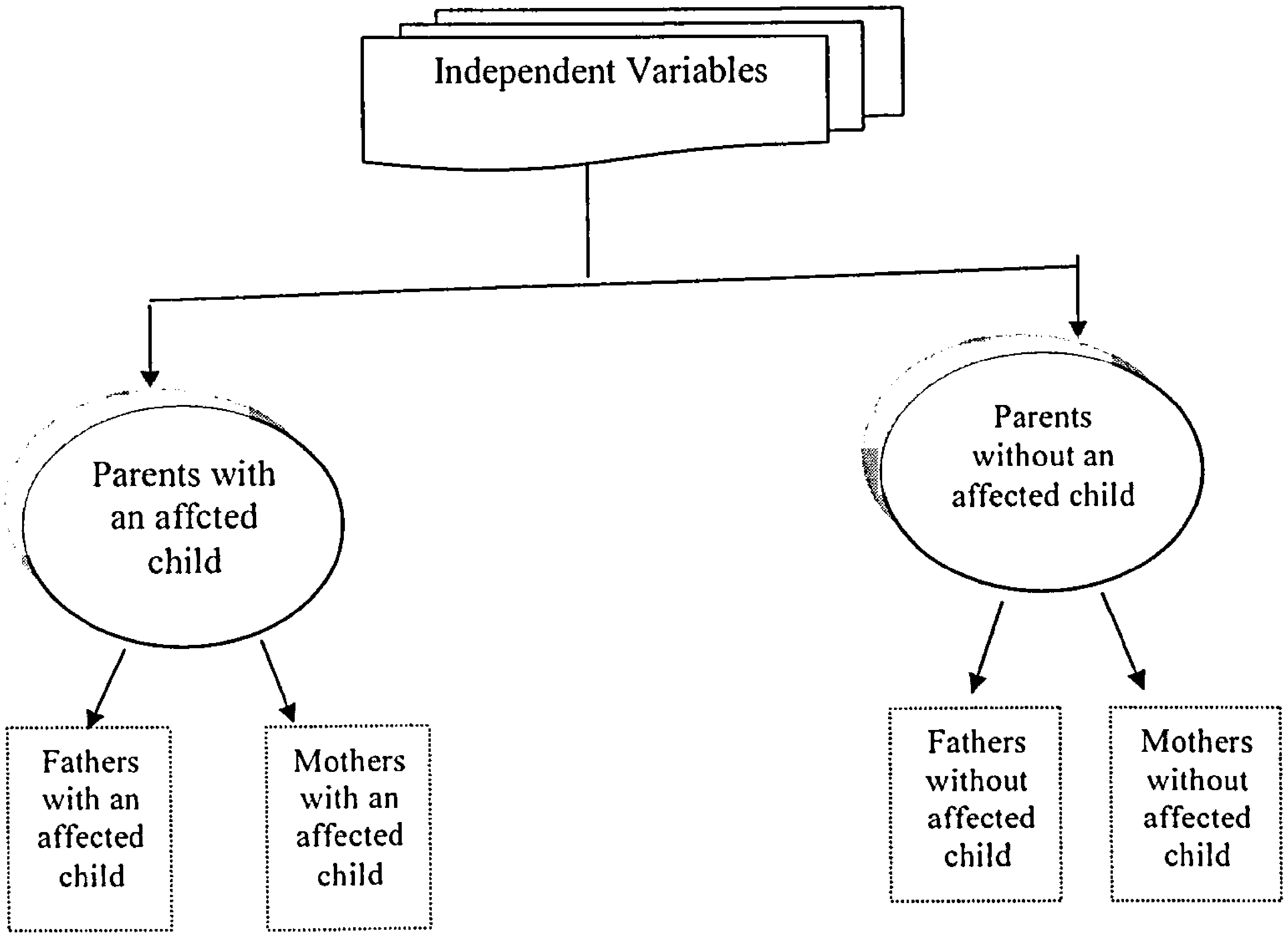


Figure 3: Independent variables

5.2.3.2 The Second Phase: Qualitative Technique

The second phase of the research aimed to go in-depth with parents, to clarify the outcome from the quantitative questionnaire and to seek more information than was collected in most other previous studies. Details of the interview content and data collection methods are given in section 5.4.1 below.

5.2.4 Participants of the Study

The participants that were recruited for this study were from King Faisal Specialist Hospital and Research Centre (KFSHRC), for many reasons. First, KFSHRC is one of the largest hospitals in the Middle East. Saudi parents are referred to KFSHRC from different hospitals from around the Kingdom, free of charge. Therefore, parents with affected children at KFSHRC who come from different regions of Saudi Arabia, represent a sample of the Saudi population. Second, the researcher has spent about ten years at KFSHRC. This experience gave him familiarity with most of the physicians and nurses in the hospital, which facilitated communication, gave easy admission to the clinics and enabled the researcher to ideally obtain empty rooms that could be used to accomplish the interviews with the parents; the research required two such rooms, so that fathers and mothers could be interviewed separately. Third, other hospitals in Saudi Arabia do not have all the facilities of in KFSHRC, and most genetic conditions can only be seen in KFSHRC, because KFSHRC has a genetic department, which is not available in other hospitals in Saudi Arabia. Furthermore, other hospitals do not have enough rooms to allow the researcher and his trained nurse to interview the parents separately. The study aims required parents to be recruited which had, or did not have a child with a genetic disorder. Parents without an affected child were recruited in the family health clinic (for the hospital employees). This situation gave the researcher complete knowledge of the chosen samples and facilitated gaining access for the study.

5.3 RESEARCH METHODS

In order to fulfil the research purposes and answer the research questions properly, appropriate methods of investigation have to be chosen. The procedure for such methods should be presented in a convenient, comprehensible and acceptable form for participants (Robson, 1993:31). This study attempted to assess Saudi parents' attitudes toward prenatal diagnosis and termination of the pregnancy. A research method was therefore required which would provide a valid and reliable medium for collecting applicable, rich and deep data. To achieve these, it was decided to see parents separately, so that they would feel free to talk about themselves without feeling any kind of barrier from their partner or the interviewer's gender. The researcher planned this study according to his experience with Saudi parents. Hence the researcher's gender was matched with participant's (the researcher is a male and interviewed only fathers and the research assistant is a female and interviewed only the mothers; see 5.4.3 (in the methodology section).

5.4 QUESTIONNAIRE

A questionnaire is not some sort of official form, nor is it a set of questions which have been casually jotted down without much thought. We should think of the questionnaire as an important instrument of research, a tool for data collection. The questionnaire has a job to do: its function is measurement (Oppenheim, 1998:100). In this regard, Richterich & Chancerel (1980:59) have defined a questionnaire as a structured instrument for the collection of data which translates research hypotheses into questions.

Many researchers have used a questionnaire because it is a quick way of gathering information from hundreds of people or more. The advantage of using a questionnaire is: efficient use of time in reaching large numbers and in analysing responses if closed questions are used. Also, standardised questions mean that there is no interviewer interpreting/distorting meaning. However, care is needed to make questions clear. Time needs to be set aside for thinking about the purpose of the questionnaire, drafting questions, and piloting. Even if questions are clear, responses can be superficial. In addition to this, whilst questionnaires are good at producing straightforward descriptive information, it is more difficult to get at explanations. However, with self-completing questionnaires there is the potential for anonymity and finally, the potential for high return rates which generate a large quantity of data (Lewis, 2003: 48).

5.4.1 The Design of the Questionnaire

The development of the questionnaire was informed by a number of methodological discussions on the use of surveys in health-related research (McColl, 1993; Kirk-Smith and McKenna, 1998; Ritchi and Lewis, 2003). There are many valid and reliable ways of capturing the responses to questionnaire items. Questionnaire items can be relatively closed or open ended. A closed item is one in which the range of possible responses is determined by the researcher. An open item is one in which the respondents can decide what to say and how to say it. The subject has to comment and give his/her opinion. Questionnaires can consist of closed questions, or open questions, or a mixture of closed and open questions. While responses to closed questions are easier to collect and analyse, one often obtains more useful information from open questions. It is also likely that responses to open questions will more accurately reflect what the respondent wants to say. However, ordinary people might have difficulty expressing their own views in words.

The researcher designed the questionnaire in the light of an ongoing study conducted in Leeds, U.K., by Professor Hewison, which compares the attitudes of indigenous white UK women and women of Pakistani origin toward prenatal diagnosis and termination of the pregnancy for a range of conditions. It was realized that this study could be adapted to the Saudi Arabian context, and that this would provide much needed attitude information in Saudi Arabia. The questionnaires in the Leeds study contains 64 items and consists of two sections: section one (4 items) collects demographic information about the respondent. Section two contains 30 scenarios covering a range of different conditions. For each scenario, there are two question, covering attitudes to prenatal testing and to termination of pregnancy.

The scenarios in section two briefly describe the condition as it affects the child, to avoid listing names of specific disorders (e.g., instead of Turner's syndrome, "child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children"; instead of anencephaly, "child would be born without a brain and die before or soon after birth"; instead of thalassaemia, "child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan". For the 30 conditions, parents were asked to answer one box for each of the two questions in regard to prenatal diagnosis and termination of pregnancy. (See appendix 3).

In the present study, the questionnaire was translated into Arabic (See section 5.5) and the demographic questions were slightly amended. Thus, the questionnaire in this study contained 72 items in total, and consisted of two sections: section one (12 items) collected demographic information about the respondents. Section two contained the original 30 scenarios covering a range of different conditions. For each scenario, there were two questions, covering attitudes to prenatal testing and to termination of the pregnancy (See Appendix 4). In the Leeds study, data was collected using a self completion questionnaire sent by mail. It was decided that this method would not be suitable in the present study, for the following reasons.

1. In the Saudi system, mail does not go to people's homes, but to a mail centre, where the collector has to pay for it. Not everyone would be willing to pay, and it would be time consuming for the parents to collect the survey.

2. Some of the genetic conditions that parents had not encountered before would be difficult to understand, such as late onset.

3. Parents might discuss the questionnaire together and their attitudes would be influenced, or one of the parents might fill in the questions for himself and his partner.

It was therefore decided to administer the questionnaire face to face "interviewer assisted" (See section 5.4.2 below)

In the quantitative section, parents would show their inclination to select or reject a prenatal test and termination of the pregnancy in different genetic conditions, without giving the reasons for their choice. To explore the factors that affect parents' attitudes to select or reject the prenatal test and termination of the pregnancy in these different conditions, a qualitative investigation was required.

5.4.2 Qualitative Interview

The interview is a flexible and adaptable way of finding things out because it can be conducted face-to-face or by telephone. The nature of the interview will determine the type of data obtained. There are three types of interviews to be considered according to McKernan (1996:129): a) Structured interview in which the interviewer has a list of specific questions and he/she does not deviate from the wording of these questions. Questions are often fixed-response; b) Semi-structured interview in which the interviewer has certain questions that he or she asks of all interviewees but also allows the respondent to raise issues and questions as the interview progresses; c) Unstructured interview, where the issues and topics to be discussed are left entirely to the interviewee. Once the interviewee has touched upon an issue or topic, the interviewer can ask him or her to explain and expand. During the initial stages of an inquiry this style (i.e. "c") is generally preferred as it allows respondents to raise issues which may not be tapped by other styles of interviewing.

However, the interview as a data collection instrument has its disadvantages. Interviews can be costly, time consuming and often difficult to administer. Furthermore, they depend on good interviewing skills that might require extensive training. In contrast, the primary advantage with interview data collection is the richness of the description obtained of the respondent. As has already been stated, the first phase of this study used an interviewer assisted, structured questionnaire. For the second, qualitative phase, it was decided that a semi-structured interview should be used.

A semi-structured interview was chosen for three main reasons in preference to a more open-ended approach. First, the researcher had very limited time to meet with each parent, and if parents were left to tell all their stories, they might talk about something different from what the researcher was looking for (See section 5.7). Second, it was not anticipated that the interview data could be analysed using an in-depth approach such as grounded theory, since the researcher's supervisor does not speak Arabic, and translated material would be unsatisfactory. Third, the literature on genetic screening has already identified several factors as playing a crucial role in the formation of attitudes to prenatal diagnosis in Muslim couples; such as severity of the disorder, religious commitment, effect on the family, and shame (Panter, 1991; Zlotogora and Reshef, 1998;; Saleem et al., 1998 Tsianakas and Liamputtong, 2002; Zahed, Nabulsi, and Tamim. 2002). The researcher's experience as a genetic counsellor and also his previous research in the Saudi population (Alsulaiman, 2000) confirm that these factors are highly relevant in the Saudi context. The qualitative component of the present study was therefore designed to investigate the relevance of these factors to parents' attitudes to testing and termination; a semi-structured approach was therefore appropriate

5.4.3 Interviewers

Based on the researcher's previous study (Alsulaiman, 2000), a male researcher experiences difficulty in interviewing mothers, due to established boundaries in Saudi culture. Therefore, a female trained nurse, Ms. Ahoud, was chosen to conduct the interviews (structured and semi-structured) with mothers in order to obtain a better view of their feelings and attitudes. The trained nurse had two-years' experience with Dr. P. Ozand (Chairman, Department of Genetics) in the genetics clinic. She is also a professional interpreter between Dr. Ozand who speaks English and Saudi families who speak Arabic. In addition, she has been involved in many projects with Dr. Ozand. Her academic background is a BS in English from King Saud University, Riyadh.

5.5 RELIABILITY AND VALIDITY OF TRANSLATED MATERIALS

The use of a second language has implications for the reliability and validity of the results obtained. Therefore, it is important to state the steps taken by the researcher to ensure reliability and validity of the questionnaire when translated from English to Arabic for use with non-English speaking participants. This section describes why the questionnaires were translated into Arabic and the process of translating the questionnaires.

5.5.1 Reasons for Translating to Arabic

The questionnaires, which were originally produced in English (and Urdu), were translated in to Arabic because all the participants were from an Arab country and used only the Arabic language.

5.5.2 The Process of Translating Questionnaires into Arabic

The quality of translation can depend on the translator's knowledge of the language and the culture of the people under study, and his/her position in relation to the researcher (Sechrest, Fay and Hafeez Zaidi, 1972; Vulliamy, 1990). For the studies in this thesis, the researcher translated all materials himself from English to Arabic. The researcher is a Saudi male who had been born, brought-up and educated in Saudi Arabia, and so, considers himself to be of the same culture as the people under study in this thesis. Also, the researcher is not only fluent in Arabic but considers himself to have a reliable understanding of the everyday language used by lay people.

The researcher aimed to ensure 'measurement equivalence' between the English and Arabic versions of the questionnaires. This is a form of validity that refers to measuring the same construct using a measure in different languages (Chang, Chau and Holroyd, 1999). A number of authors refer to the important issue of translation and establishing measurement equivalence (Sechrest et al., 1972; Temple, 1997; Twinn, 1997), suggesting that translated measures should include 'content, 'semantic', 'grammatical-syntactical' and 'experiential' equivalence. Published literature on measurement equivalence focuses on the translation of questionnaires usually from English to a target language (Chinese, Polish, Urdu) and for comparison between people of different cultures. However, the Arabic version of the questionnaires developed for use in this thesis, was for use with participants from only one culture – Saudi. Nevertheless, the researcher wanted to ensure that the same concepts were being measured within this group, regardless of the language and the way (self-completed or researcher assisted) in which the questionnaires were administered, and also ultimately to make comparisons with data collected in the UK.

Techniques for enhancing equivalence include back-translation, consultation and collaboration with other people during the process of translation, and pre-testing or piloting (Birbili, 2000). The Arabic version of the questionnaires was not fully back-translated because this is a time consuming process and there were time constraints on the researcher. Instead, while translating the questionnaire, the researcher continuously consulted with four individuals: Dr. A. Badahdah (Social Psychologist), Dr. A. Al-Odaib (Deputy Chairman, Department of Genetics), Dr. Abeer (Ethical Committee member), and a professional interpreter. All are fluent in English. The researcher and the interpreter translated the initial version of the questionnaires. This was submitted to Dr. Al-Odaib, who verified the medical and genetic terminology. The questionnaires were then submitted to the Ethical Committee member, who did some corrections to the Arabic terminology.

Dr. Badahadah and the researcher then reviewed the first version of the questionnaires, which was approved by the ethical committee.

After translating the questionnaires into Arabic, the researcher instructed the nurse on how to start the interview and how to reply to difficult and sensitive questions. Then, the nurse practised the interviews, in the presence of the researcher, on her friends in order to make sure that she could handle difficult and sensitive situations. In addition, the researcher met with the trained nurse at the end of each day's meeting with mothers, to discuss the outcome and make sure that the trained nurse covered all the questionnaire parts and find out if there was any outcome from the mothers' side that needed to be added or deleted.

For the qualitative interview, no translation was necessary, but the researcher had trained the nurse in how to question parents and how to ensure that all necessary topics were covered.

5.5.3 Piloting the Translation

The researcher applied the Arabic version of the questionnaires to untutored Saudis, by interviewing friends and relatives from a range of educational backgrounds, in order to verify that the questionnaires were unambiguous and comprehensible. The questionnaires were found to be clear and understandable, and no amendment appeared necessary. Subsequently, the questionnaires were assessed by the parents in a pilot study to make sure all the questions were clear and understandable, before starting to collect the main data. A few amendments were made as a result of this pilot study.

5.6 PILOT STUDY

In order to identify potential problems or misunderstandings prior to the main study, the researcher conducted a pilot study which helped refine the design of the main study. A pilot study is very important for any researcher because it helps him/her to refine data collection plans with respect to both the content of the data and the procedures to be followed. Furthermore, conducting the pilot study would also give the researcher a degree of experience which would be of great help when undertaking the main study. Likewise, a pilot study provides an opportunity to evaluate the appropriateness and practicality as well as the validity of the study procedure and instruments proposed for the collection of the data. In addition, the statistical procedures can be tested to ensure that they can be applied to the data (Oppenheim, 1998:49). Thus, this pilot study was undertaken in May 2002, as the researcher wanted to check the timing and procedural aspects of data collection on part of planning the study.

5.6.1 Consent Procedures

Permission to conduct the recruitment for both pilot and main studies was obtained by Dr. Al-Odaib from the chairmen of Pediatrics, Family Health and Polyclinics as well as from the Medical Director of Ambulatory Care Services and Outpatient clinic. Head nurses of the clinics were also involved in organizing the rooms, depending on the clinic's schedule, for interviewing the parents separately.

5.6.2 Ethical Approval

Ethical approval for the study was obtained from the KFSHRC Ethics Committee prior to the commencement of the research (Research Proposal Number 2011035).

The study aims required families to be recruited which had, or did not have a child with a genetic disorder. Families for the pilot study were therefore recruited in genetics clinics and family health clinics (for the hospital employees). The researcher and the trained nurse met with 20 parents with and without affected children in different genetic and family health clinics. This number was not included in the main data. Based on the pilot study, the researcher reviewed the quantitative and qualitative questionnaires and decided what kinds of amendments needed to be made.

The purpose of piloting the questionnaire was to allow the researcher and his assistant to gain insight into parents by asking them in a direct way about their background experience, attitudes and beliefs towards prenatal diagnosis and termination of the pregnancy for a range of different conditions. The pilot was designed so as to obtain parallel information from the parents with and without an affected child. It was also intended to find out how long it would take to fill in the questionnaire and whether the language and the layout of the questionnaire were appropriate and clear. Furthermore, it attempted to measure the validity and reliability of each question applied in the main study. As a result of the pilot study, items for which the wording was confusing, were modified and the final form proceeded. The pilot study revealed some advantages and disadvantages which the researcher had to consider before conducting the main study

5.7 FINDINGS FROM THE PILOT STUDY

The pilot study revealed some important issues as to the advantages and limitations of the research methods and instruments. A pilot study may be costly, but it actually saves time in the end. There was satisfaction in seeing the emergence of a reliable research tool from the mass of pilot data. In addition, the pilot study paved the way for the researcher to deal with research instruments of different kinds, and indicated the appropriateness of the procedures. Moreover, it gave the researcher a first impression about the procedures so that he could predict problems which might occur. The implications of the pilot findings for planning the main study are considered further in section (5.7.1)

A) There are some words such as child, which in English could mean male or female but in Arabic would differ in pronunciation ("tefl" for male and "tefla" for female). Another difficulty was with the word "lifespan" which Muslim societies, like that in Saudi Arabia, believe to be according to God's will. Most of the scenarios in different genetic diseases involved various lifespans but when these were mentioned to the interviewees, they elicited the response, “Only God knows when a person will die”.

The researcher and a trained nurse explained to the interviewees that "child" in the questionnaires meant male or female, unless specified; and "lifespan" was addressed by explaining that we are aware, as Muslims, that anyone will die by God's will, but that there are various reasons for one's death, such as old age or from an accident or from some kind of disease. In such scenarios we mentioned that the genetic disease may or may not be the reason for the death.

B) The researcher faced some difficult and sensitive questions, such as whether abortion is permissible in Islam or not; parents might seek a termination if it is permissible and will not terminate if it is not. The researcher and the nurse agreed to say to all the parents before starting the questionnaire that according to the Fatwa (Islamic ruling) if the genetic condition is severe the foetus can be aborted before 12 weeks but that it is not clear what would be considered as a severe condition.

C) The researcher faced some difficulty with parents in the family health clinic without an affected child. Most of the parents in the family health were employees in the hospital, and did not have enough time to meet the researcher and trained nurse. Moreover, most of the parents in family health were from Riyadh and highly educated, which did not meet the study requirements. The researcher had to find a place in the hospital where parents came from different parts of the Kingdom of Saudi Arabia, with different levels of education. After the researcher's investigation with the head of the polyclinic in the family health, Dr.A.Alnaser suggested that the outpatients clinics have a lot of people coming from different parts of Saudi Arabia to accompany their parents and grandparents. Many of these people are themselves parents and they have plenty of time to be interviewed while they are waiting.

D) In both genetic and family health clinics, the researcher and trained nurse faced some difficulty to meet both parents at the same time, since most of the parents came to the clinic alone. Therefore, the researcher decided not to link the two parents.

E) In the qualitative part, the researcher and trained nurse could not use a tape recorder, Saudi parents do not like to record their voice in the tape recorder; Saudi females believe that nobody should listen to their voice except very close relatives, and Saudi males do not feel comfortable in recording their voice, because they are afraid that their voice will be used as a document against them. In addition, Saudi parents are not used to being interviewed with a tape recorder.

In planning the pilot, it had already been decided to use a semi-structured interview. An open ended method had been rejected because when given open questions, parents might not understand the researcher's point and might include irrelevant materials. In addition, the researcher could not use the grounded theory approach, as it needs training, unavailable in Arabic. Therefore, these reasons made it preferable for the researcher to use semi-structured, open-ended questions, and this technique proved successful in the pilot. Further, as a result of the experience in the pilot, it was planned to conduct the main study interviews without using a tape recorder, instead writing comments after asking each question separately. Parents were happy to give their views in this way in the pilot study.

5.7.1 Implications for the Main Study

Several important lessons were learned from the pilot study about the changes that enhanced the investigation, making it more useful and the results more generalizable. The pilot study was a trial of the research instruments. It was also intended to provide a broad look at the data in terms of the above two methods (quantitative and qualitative). In general, the data showed that the parents had no difficulty to answering the questionnaire. It indicated that the concepts and ideas were not too complex for them in answering the questionnaires. However, there were minor problems related to the questionnaire translation and using tape recorder. Accordingly, a few modifications were made.

5.8 THE MAIN STUDY

At the outset it is important to point out that parents were initially approached as individuals and were informed about the purpose of the study. The main study was conducted in July 2002 to February 2003. There was an overwhelming response and 94.8% (400/422) of those approached agreed to participate. The interview took from 20 to 25 minute for each individual and 15 minute extra for those parents who participated in both quantitative and qualitative interview. In the Leeds study were only women from West Yorkshire, white indigenous families and families of Pakistani origin, all recruited from local maternity services. The present study aimed to recruit Saudi parents with and without an affected child. Parents with an affected child were selected from different clinics (Hematology, Cystic Fibrosis, Metabolic, and Deafness). These four groups of different genetic disorders were selected to represent different levels of severity of the genetic condition. Furthermore, these different genetic conditions are autosomal recessive ones, which are common in the Saudi population because of the role of cousin marriage in over 57% of the Saudi population (El-Hazmi, 1995). Parents came from different regions in Saudi Arabia free of charge to use the services at KFSHRC because of the distinguished genetic department at KFSHRC and represented all sections of the Saudi society. If the parents were not Saudi or did not have an affected child with any of the four main conditions, they were not eligible to participate in the present study.

In the other group, parents without an affected child were drawn from visitors to the outpatient clinics, accompanying their father or mother to the hospital. They came from different regions in Saudi Arabia, because KFSHRC has sophisticated equipment to screen different diseases, which is not available in other hospitals.

In the waiting areas, there are separate places for men and women, where the patients wait for their appointment, and there is a digital electronic number to show one's turn. Usually, waiting time is lengthy. During this time, the researcher went to the men's section and the trained nurse went to the women's section, and targeted those parents in the waiting area with their father, in the men's section, or with their mother, in the women's section, If the parents were not Saudi, or if any of their children had one of the named conditions (or any other condition) they were not eligible to participate in this group.

The researcher and the trained nurse arranged with the geneticists and head nurses when to interview the parents, whether before or after their clinic appointments, depending on their waiting time. The nurses asked the parents if they would be willing to participate in the study before the clinic appointment and the geneticists asked the parents if they were willing to participate in the study after the clinic appointment. In the outpatient clinic, the researcher and trained nurse asked the parents if they wanted to participate in the study and found a convenient place, away from others, to make sure they were free to talk and nobody would interfere during the interview.

When parents agreed to participate in the study, the researcher interviewed fathers in one room, and the trained nurse interviewed mothers in another room. As mentioned earlier, in relation to the pilot study, the fathers and mothers were not usually a couple. The researcher and the trained nurse explained to the parents what the study was about, then provided the parents with an information booklet and a consent form, which were verbally explained to anyone who was unable to read, before they decided to take part in the study. The consent form had to be signed before starting with the interviews. The information sheet and consent form were approved by the hospital's local Research Ethics Committee.

The parents were assured of confidentiality and anonymity in order to enable them to participate freely without any fear that their comments might affect their care or reputation in the future. The parents were also informed that they did not have to answer any question that they found objectionable and that they could withdraw from the interview at any time without any explanation or permission.

The researcher and the trained nurse interviewed the parents face to face and read the questionnaire in a consistent tone, loudly and clearly for each scenario and parents were given three options for each scenario (no, yes, do not know). The researcher and trained nurse sat beside the parents to make sure they could read and look at the answer they were selecting. These were written in by the researcher and his trained nurse, as a means of helping the parents focus on each scenario in turn.

A sub-sample of parents completing the questionnaire were invited to participate with qualitative interview. To be eligible to take part in the qualitative interview, participants had to be prepared to speak openly about their life and people around them. The researcher is a counsellor and has experience with Saudi families from his counselling sessions. The researcher used his judgment, on the basis of parents' responsiveness during completion of the structured questionnaire, to select participants for the qualitative interview. However, participants to invite for the qualitative interview were not selected specifically on the basis of their detailed responses to the structured questionnaire. It is acknowledged that the recruitment procedure may have introduced some bias into the qualitative results, but since these were mainly intended to illustrate the quantitative findings, this limitation was considered to be acceptable. The same procedure was followed by the trained nurse, since she has two years experience with Prof Ozand in his clinic and knows much about Saudi families, and also the researcher had daily meetings with the trained nurse after she completing her interviews with mothers, to consider all the aspects discussed with the mothers and their comments. Therefore forty parents (20 males and 20 females) were selected to be interviewed in the main study, and all of them agreed to participate. The semi-structured questionnaire used in the qualitative part of the pilot study was clear to the participants; hence, the same questionnaire was used in the main study as follows;

1. Why do you think these conditions should be tested for or terminated and not others?

2. Some parents feel that having a disabled child in the family might change their life. What do you think?

3. Some parents feel that a disabled child might isolate the family from others. How do you see that?

4. According to the Fatwa, Islamic law allows termination only in severe cases and within the first three months of the pregnancy. What is your opinion?

All the selected parents were asked to participate in the qualitative part, after they had completed their questionnaires. The researcher and trained nurse wrote each answer separately after the parents replied to each question posed by the researcher for the males and by the trained nurse for the females. The qualitative data obtained were not restricted by the researcher's views and interests, and this was made clear to the nurse during her training.

Participants were encouraged to elaborate on the themes outlined in the interview with respect to open-ended questions. These responses were written down by the researcher during the interview as accurately as possible and later classified into four groups: kind of condition, effects on family life, shame, and religion, according to the questions above. Some of the parents did not answer a question directly but might answer it in cause of answering another question. For instance, when a parent was asked about the effect on the family life as a result of having an affected child in the family, he or she might not answer it, but when the researcher or his assistant asked about shame, the parent might raise the issue of effect on the family life.

5.8.1 Recruitment Rates in Main Study.

To make the statistical comparisons required by the study aims, a large number of parents needed to be recruited. Therefore, one hundred mothers with affected children, one hundred fathers with affected children, one hundred mothers without affected children, and one hundred fathers without affected children were recruited. In all, 422 Saudi parents were approached over a period of eight months, from July 2002 to February 2003. Of these, 22 refused to take part in the study for the following reasons (see tables 2 and 3).

NO.	REASON FOR REFUSING (MOTHERS)
1.	The mother does not want to feel depressed by the survey.
2.	The husband consulted his wife who refused.
3.	The father had a flight to catch, the mother said.
4.	Mother did not want to take the survey because she was unable to have more children.
5.	The mother was in a hurry.
6.	The mother did not want to disturb herself with reading about such diseases.
7.	The mother was sensitive and such a survey would upset her.
8.	The family had a flight to catch, so they refused to do the survey.
9.	The mother was in a hurry and did not have time to do the survey.
10.	The mother refused without explaining why.
11.	The mother started to answer the first two questions then stopped because it was a very sensitive and painful issue for her.
	Total 11

Table 2: Reason for refusing (mothers)

NO.	**REASON FOR REFUSING (FATHERS)**
1	The father had other appointments (N= 3)
2	Somebody called the father on his cell phone in the middle of the interview and he said that he had to go.
3	The father did not like to hear about this kind of abnormality (N= 2)
4	The father said that this question did not apply to him because all his children were normal. He had a previous problem when the doctors asked him to pull the plug on his father to let him die because he was suffering from cancer in the lung and he did not agree. He apologized and said he did not want to say anything.
5	The father said that he and his wife were not planning to have more children so they did not need to answer. (N= 2)
6	The father said that termination is against Islamic view so he did not need to continue. (N=2)
	Total 11

Table 3: Reason for refusing (Fathers)

Combining tables (2 and 3) it can be seen that reasons for refusing fell into three broad groups: 7 parents were "sensitive", 6 parents were "in a hurry", and 9 parents had other "practical" issues.

The final total number in the study was 400 parents, as follows:

1- 50 parents from the Metabolic clinic (25 fathers and 25 mothers)
2- 50 parents from the Hematology clinic (25 fathers and 25 mothers)
3- 50 parents from the Deaf clinic (25 fathers and 25 mothers)
4- 50 parents from the Cystic Fibrosis clinic (25 fathers and 25 mothers)
5- 200 parents from the Outpatient clinic (100 fathers and 100 mothers)

5.9 DATA ANALYSIS

Robson (1993:305) points out that analysis is necessary because data in their raw form are not meaningful. Their implications are hidden and need careful teasing out. The process and products of analysis provide the bases for interpretation. Data analysis (Bland, 1995; Seliger & Shohamy, 1989:201) refers to sifting, organising, summarising and synthesizing the data so as to arrive at the results and conclusions of the research. Thus, data analysis becomes the product of all the considerations involved in the design and planning of the research. However, the selection of a specific data analysis technique will depend mainly on the nature of the research questions, the design chosen to investigate it and the type of data collected. Data analysis is therefore valuable, only to the extent that there is a valid relationship between it and the other components of the research. As depicted in section 5.2.3, the current research was divided into two phases: quantitative and qualitative. The research paradigm of each phase is different. In each phase research problems determine different approaches to data collection and analysis. Thus, in the first phase data was collected for quantitative analyses using a structured questionnaire, and in the second phase, data was collected on parents' views using a semi-structured interview.

5.9.1 Quantitative Date Management

The questionnaire data was entered into the Statistical Package for the Social Sciences (SPSS) program. Data was initially summarized in the form of frequencies and percentages, then subjected to a series of statistical analyses, as described in the results chapter (See chapter 6 section 6.2)

5.9.2 Qualitative Data Management

According to Pope and Mays (Pope and Mays, 1995; Mays and Pope 1995) various strategies are available within qualitative research to protect against bias and enhance the reliability of the findings, such as using a tape recorder in order that another trained researcher could analyse the same data in the same way to see if they come to essentially the same conclusions. Unfortunately, the researcher could not use tape recordings in his interview because parents were not happy with it; therefore the researcher was concerned to ensure the validity of the data obtained. Instead of using a tape recorder, interviewers took extensive notes of what respondents said. With practice it was possible to do this without interrupting the flow of the interview.

The qualitative data was collected to address the fifth study aim, which was to explore factors influencing parents' attitudes. To do this, a semi-structured interview was built around four open-ended questions addressing topics which had been identified from the literature as potentially important influences on attitudes to prenatal testing in a Muslim population (see section 5.4.2). The same four questions were asked of all participants. All had been recruited on the basis of their willingness to speak openly about their lives. It is possible that people not eligible on these grounds would have held different views, but future work would be required to establish the extent of any bias of this kind.

The task of the qualitative analyses was to summarize the responses to these questions. For the reasons given earlier, an "analytical" approach to the qualitative data was rejected, and simple descriptive coding was undertaken instead, following methods devised for use in survey methodology (Moser and Kalton. 1993). This process is very similar to the "first level coding" identified by Miles and Huberman (1994). The process was conducted as follows.

1) After completing the interview with each parent the researcher reordered mothers and fathers comments under the relevant questions, and ensured that no relevant comments were overlooked.

2) The Coding system was established using an iterative process, and sought to identify labels for units of meaning in the accounts. In order to enhance the reliability of the coding an independent assessment of parents comments by an additional skilled researcher was incorporated into the coding process. The researcher and his colleague decided to establish coding for each question separately and split parents into two subgroups (parents without an affected child and parents with an affected child) because these parents had different comments according to their different experience.

5.9.2.1 Fathers and mothers without an affected child

The researcher and his colleague working separately looked at comments for the first question (about the kind of condition) for fathers and mothers without an affected child.

They each tried to develop a simple coding system for parents' comments and coded all the responses to this question. They then compared their results, made some amendments to the coding frame, and repeated the coding. A second comparison of results then took place, and the remaining small discrepancies were resolved by discussion. The final coding for the first question for both fathers and mothers was then as follows; A) against termination of the pregnancy in any condition. B) wanted to terminate severe learning disability and severe physical disability only. C) wanted to terminate severe learning disability and severe physical disability, plus other specific condition according to their individual experience.

For the second question, about the effect on family life, parents without an affected child had no relevant experience, and felt unable to answer a question about the effects on family life which could be created by an affected child in the family. There were therefore no comments from the parents without an affected child on this question, and no coding frame was established. For the third question about shame, only a few of the fathers and mothers without an affected child felt able to give comments, based on their experience with other parents with an affected child. However, a coding frame was devolved for these comments, based on the same iterative procedure descried above. The agreed coding was as follows; A) negative examples given of behaviour of a family with an affected child. B) positive examples given of behaviour of a family with an affected child.

The last question was about religious views. Following the procedure described earlier, a coding system was developed. The final coding was as follows; A) Islam law against termination of the pregnancy in any condition. B) agreed with the Fatwa. C) misunderstanding the Fatwa.

5.9.2.2 Fathers and mothers with an affected child

After the researcher and his colleague completed the coding for parents without an affected child, they followed the same procedures for parents with an affected child. Because parents with an affected child had a different experience, their comments were different, and a new coding system was required to capture these.

The final codes for question one were as follows; A) against termination of the pregnancy. B) not willing toward termination of the pregnancy in their conditions, but they were willing to terminate other conditions that they think were severe or against Islam law in their opinion. C) willing to terminate the pregnancy in their condition and similar condition that they thought were severe in their opinion.

For the second question, the final codes were as follows; A) an affected child did not change his parents life. B) parents were psychologically affected. C) parent's time was abused by their affected child. D) parents' marriage relationship was not stable because of their affected child.

For the third question about shame, the final codes were as follows; A) parents were not ashamed. B) parents were ashamed because of other people's questions. C) parents were ashamed because their children were criticized by others. D) parents were ashamed because of worries about their children's future marriage.

For the last question about religious views, the researcher and his colleague decided after looking at parents' comments that parent with and without an affected child had similar comments, therefore the researcher and his colleague used the same codes for both groups.

Following the coding process described above, the number of parents giving each type of response was calculated. To illustrate the content of each category, questions were abstracted from the transcripts and translated from Arabic into English, as described below.

5.9.2.3 Translating Arabic interviews into English

The interview transcripts were translated from Arabic into English. Reliability of the analysis may be affected by the quality of transcripts when translated into English. Twinn (1997) found differences between transcripts translated into English, when the original Chinese version had been translated by three different translators. She suggests that it is important to 'use one translator for all the interviews carried out in a study so that consistency in translation is obtained and reliability in the analysis of data can be maximized'. All non-English interviews in this thesis were translated into English by the researcher. During translation of the non-English interviews the researcher was constantly conscious of consistency in translating. To increase reliability of the translated transcripts, the researcher consulted a professional editor and an 'Arabic to English, English to Arabic' dictionary (Almord 2000) to clarify any translation he was uncertain about.

One of the first decisions faced by the researcher was whether to use 'literal' or 'free' translation in order to present an accurate translation of participants' narratives. Considering that there was no direct translation for many words or phrases and that there are differences in grammatical structure between English and Arabic, the researcher opted for free translation. This was to ensure that the meaning of participants' words was clearly presented. Literal translation (translating word-by-word) would have reduced the readability of the transcripts and the readers' ability to understand the participants' perspective. The researcher was aware of the dangers in using free translation, mainly the risk of misrepresenting the meaning of the conversation, and the risk of losing information from the non-English interviews (Birbili, 2000).

5.10 SUMMARY OF THE CHAPTER

This chapter has explained how the present study was designed and conducted in order to meet its aim of assessing parents' attitudes. In addition, this chapter has discussed two closely related ways of obtaining data. Both structured questionnaire and semi-structured interview require care and subtlety in questioning techniques. The questionnaire employed in the main study to assess parents' attitudes toward prenatal diagnosis and termination of the pregnancy was able to provide high quality data from parents with and without an affected child. Moreover, semi-structured interview which was used to supplement the questionnaire was successful in obtaining insight into parents' attitudes. The experience gained from the pilot study helped improve data collection in the main study. It suggested ways to improve data collection time management, to refine the instruments, to test the difficulty of the tasks and to improve the overall procedure. The refined procedures were used in the main study.

Having described the methodology adopted in both the structured questionnaire and semi-structured interview the next two chapters report the findings of the quantitative and qualitative data respectively.

CHAPTER 6: QUESTIONNAIRE: ANALYSIS AND RESULTS

6.1 INTRODUCTION

In an effort to gain an insight into attitudes to prenatal diagnosis (PND) and termination of the pregnancy (TOP) in different genetic conditions for Saudi parents with and without an affected child, this chapter reports on the analysis undertaken as the first phase of the current research. Data from the quantitative survey were analysed to investigate the following:

1) Rank ordering of conditions in which PND/TOP were considered acceptable;
2) Calculation and comparison of total scores for parents' attitudes to prenatal diagnosis and termination of the pregnancy;
3) Comparisons of the parents' attitudes for separate conditions towards prenatal diagnosis and termination of the pregnancy;
4) Associations between parents' attitudes to different conditions: specifically, how attitudes to the different conditions were associated with attitudes to thalassaemia. Thalassaemia was chosen as an example, because it is one of the most prevalent of the investigated conditions in Saudi Arabia, and it also emerged as one of the conditions that parents in this study collectively ranked as amongst those conditions that most justified prenatal diagnosis and termination of the pregnancy (see section 6.3.2.1 and 6.3.2.2)

The chapter is divided into two sections: firstly, the method used to analyse data will be described in section 6.2 and secondly, the results of the data analysis will be presented, in section 6.3.

6.2 DATA ANALYSIS

The term 'statistics' means numerical data. Statistical tests are a major aid to data interpretation. By statistical testing a researcher can compare groups of data to determine the probability that differences between them are based on chance, thereby providing evidence for judging the validity of a hypothesis or inference (Ritchi and Lewis, 2003).

In this study, there were two independent variables; each with two levels, i.e. four groups in all: fathers without an affected child, fathers with an affected child, mothers without an affected child, and mothers with an affected child. Parents' attitudes were the dependent variables, expressed as either attitudes to individual conditions or as total scores (See 6.5). If an attitude difference between parents was sufficiently large to be unlikely to have occurred by chance, the difference between groups can be considered as being significant ($p<.05$).

Responses were coded and data were subjected to statistical tests, using the Statistical Package for the Social Sciences (SPSS for Windows v.11.0.0). In order to address the study aims, the following analyses were conducted.

1. Preliminary comparisons of the demographic characteristics of the parents in the different groups were made by using the Mann-Whitney test. The exception was number of wives, where the chi-square test (x^2) was used.

2a. For attitudes toward PND and TOP: Simple descriptive statistics were calculated. These are reported, supplemented with a graphical presentation of the rank ordering of conditions. The chi-square test (X^2) was used to compare the outcomes with those of similar studies, and Bivariate correlations were carried out using Spearman's rank correlation test due to the non-normal distribution of many of the variables. Cochran tests for differences between correlated proportions were conducted to examine differences in attitudes between conditions.

2b. In addition to the above analyses which were designed to address the original study aims, the opportunity was taken at this point to conduct comparative analyses of attitudes in Saudi parents and UK parents, using Fisher Exact tests.

3. Comparisons of total scores were carried out using the non parametric Mann-Whitney test rather than the t-test, because the assumptions of normality and homogeneity of variance were not met, therefore the parametric t-test could not be used (See 6.5).

4. The effect of demographic differences on group comparisons of the parents' attitudes was analysed by using the Mann-Whitney test within demographic subgroups.

5. Group comparisons of attitudes to individual conditions were made using the Fisher exact test.

6. In addition to the analyses listed under point 2 above which addressed the original aim of comparing conditions, the extent of individual variation in attitudes to the different conditions was illustrated by cross- tabulating attitudes to thalassaemia with attitudes to the rest of the conditions.

6.3 THE RESULTS

This section presents the results from the analysis of the questionnaire in six parts: Part 1 concerns the demographic characteristics of the four groups. Part 2 considers the rank ordering of conditions and comparison with other studies. Part 3 provides an analysis of total scores. Part 4 analyses the effect of demographic characteristics on the parents' attitudes. Part 5 contains a comparison for separate conditions. Part 6 analyses the associations between parental attitudes to different conditions.

PART 1

6.3.1 Demographic characteristics:

In this study there were four different groups of Saudi parents (fathers with an affected child, fathers without an affected child, mothers with an affected child, and mothers without an affected child). These groups were found to have different demographic characteristics, as shown in the tables below:

6.3.1.1 Demographic characteristics of the fathers

Fathers	**Fathers with an affected child N = 100**			**Fathers without an affected child N = 100**			**Mann-Whitney**
Variables	**Range**	**Mean**	**SD**	**Range**	**Mean**	**SD**	**P value**
Age	24-50y	37.8	7.4	21-50y	35.2	6.5	.02
Education	1-6	4 (med)	1.2	1-6	4 (med)	1.1	NS
Children	1-10	5.1	2.4	1-10	3.3	2.4	$P<0.001$
Income	1000-25000	6920	4391	1000-25000	8170	4597	.026
More than one wife	20 (20%)			8 (8%)			NS (X^2)

Table 4: Demographic characteristics of fathers with and without an affected child

It is apparent from the above table (4) which compares fathers without affected children, and fathers with affected children, that fathers with affected children were significantly older, and had more children. Fathers without affected children had significantly higher income. However, there were no significant differences in the level of education or number of wives between the two groups of fathers.

6.3.1.2 Demographic characteristics of the mothers

Mothers	**Mothers with an affected child N = 100**			**Mothers without an affected child N = 100**			**Mann-Whitney**
Variables	**Range**	**Mean**	**SD**	**Range**	**Mean**	**SD**	**P value**
Age	21-46y	31.6	6.1	21-45y	30.9	5.9	NS
Education	1-6	3.5 (med)	1.4	1-6	5 (med)	1.2	NS
Children	1-10	5.17	2.6	1-10	3.2	2.1	$P<0.001$
Income	0-20000	5385 S.R	4387	0-30000	9780 S.R	6.6	$P<0.001$
More than one wife	12 (12%)			8 (8%)			NS (X^2)

Table 5: Demographic characteristics of mothers with and without an affected child

The table (5) above shows that mothers with an affected child had significantly more children than mothers without an affected child and had a significantly lower monthly income. There was no significant difference in their ages, level of education, and whether their husband had another wife or not. Furthermore, most of these women were providing new data, different from the men's data.

6.3.1.3 Number of affected children in families with an affected child

Number of affected children	**Fathers**	**Mothers**
One child	42 (42%)	46 (46%)
More than one child	58 (58%)	54 (54%)

Table 6: Number of affected children

It is apparent from the above table (6), that the majority of parents of affected children had more than one affected child.

PART 2

6.3.2 Attitudes to PND and TOP

One of the goals of this study was to get a better understanding of the parents' attitudes to prenatal diagnosis and termination of the pregnancy in different genetic conditions. Thus, this section will present in detail the results of the parents' attitudes to prenatal diagnosis and termination of the pregnancy in different genetic conditions. The genetic conditions will be ranked in order from the highest attitudes to the lowest, according to the proportion of parents who said yes for each condition. Possible correlation between attitudes toward prenatal diagnosis and termination of the pregnancy will be investigated. The findings from Saudi parents will then be compared with those from a similar survey of Leeds parents.

6.3.2.1 Parents' attitudes toward prenatal diagnosis in a range of different conditions

In order to assess parents' attitudes toward prenatal diagnosis in a range of different conditions that were presented in the questionnaire, responses are described based on the three categories of response in the questionnaires, namely No, Yes, and Not sure. Individual respondents gave their answers based on their views about the conditions. The views of all respondents were then summarized for each condition in terms of the percentage giving each reply, and the conditions were ranked according to the percentage of "yes" responses. These percentages are given in table (7). Figure (4) shows that there was a clear gradation in personal acceptance of prenatal testing, which was highest for severe learning difficulty and lowest for the child not being of the sex desired by the parents. Statistically, it is important to know if parents have significantly different views of prenatal diagnosis for different genetic conditions. The non-parametric Cochran Q test for the difference between correlated proportions was used because, in this study, there were thirty conditions to be compared. $Q = 1100.77$ and it is significant at $P<0.001$. This finding indicates that Saudi parents held very different attitudes to the different conditions in this study.

6.3.2.2 Parents' attitudes to termination of pregnancies in different genetic conditions

In order to assess parents' attitudes toward termination of the pregnancy in different genetic conditions that were presented in the questionnaire, responses are described, based on the three categories of response in the questionnaires, namely No, Yes , and Not sure. Individual respondents gave their answers based on their views about the conditions. The views of all respondents were then summarized for each condition in terms of the percentage giving each reply, and the conditions were ranked according to the percentage of "yes" responses. These percentages are given in table (8). Figure (5) shows that there was a clear gradation in personal acceptance of termination of pregnancy; running from child born without brain (anencephaly) to child is not of sex desired by parents. To find out if parents had different views towards termination of the pregnancy in various conditions, the non parametric Cochran Q test for the difference between correlated proportions was used, because in this study, there were thirty conditions to be compared Q = 1961.85 significant at P<0.001. This finding indicates that Saudi parents held very different attitudes to the different conditions in this study.

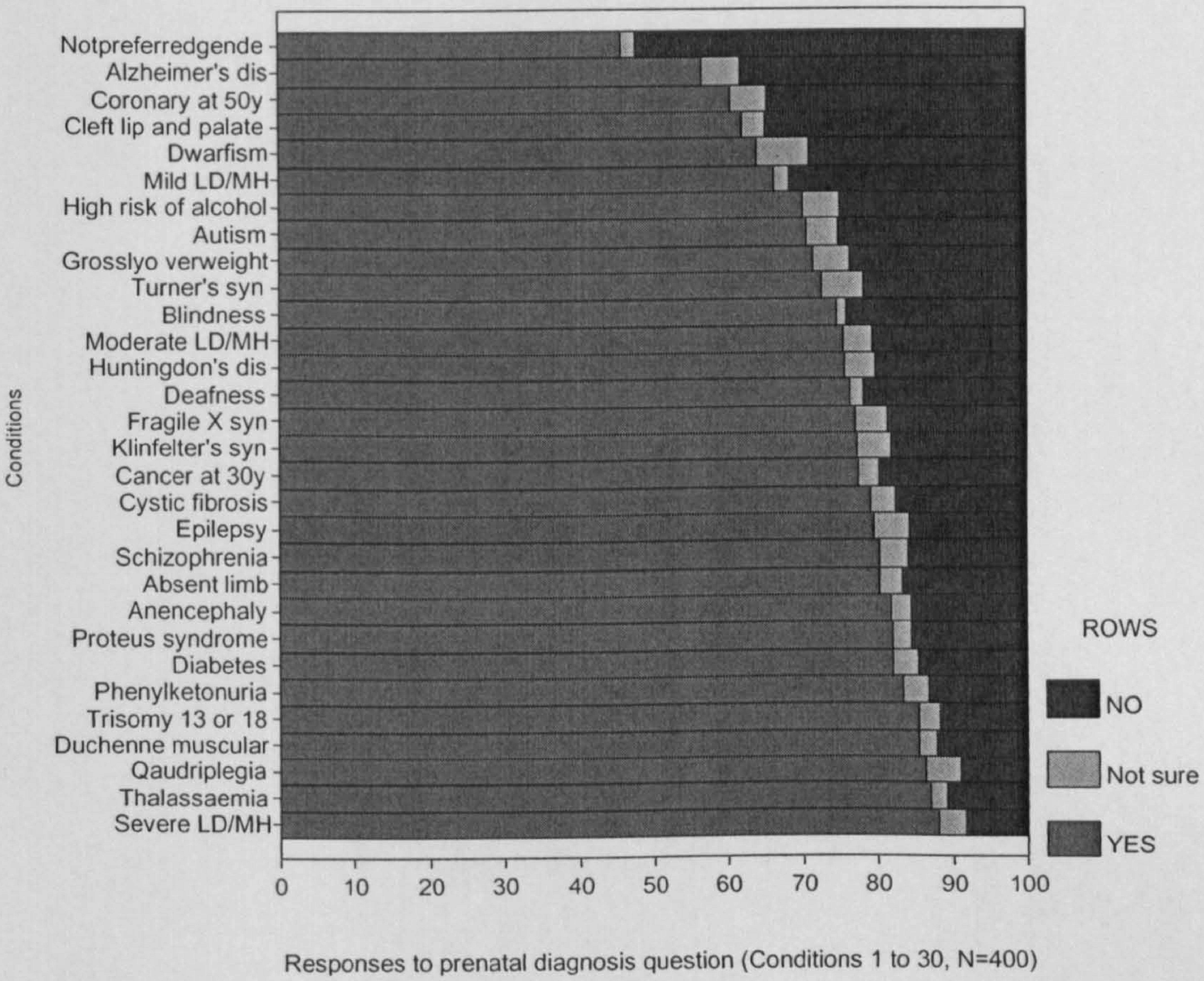


Figure 4: Parents' attitudes to prenatal diagnosis in different conditions

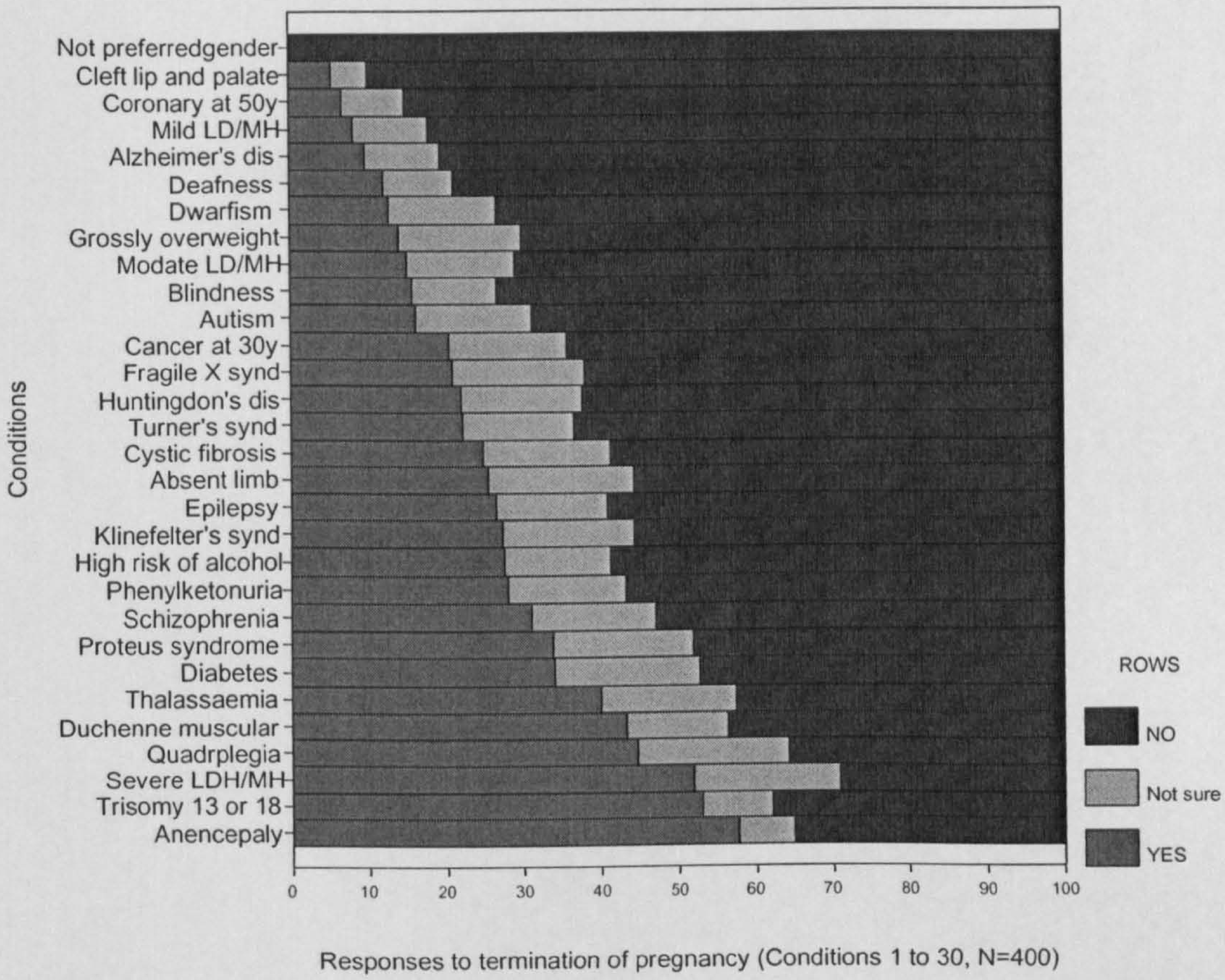


Figure 5: Parents' attitudes to termination of pregnancies in different genetic conditions

6.3.2.3 Saudi parents' attitudes toward PND and TOP: correlation

In order to find out if there is a relationship between parents' collective attitudes toward prenatal diagnosis and their collective attitudes towards termination of the pregnancy. Spearman's test was run to find the correlation between the two attitudes, based on the numbers saying 'yes' for each condition. It should be noted that some kind of positive relationship was anticipated, since at an individual level, people who said 'no' to prenatal diagnosis did not say 'yes' to termination of pregnancy. However, of those who wanted prenatal diagnosis (usually the majority), only a proportion wanted termination of pregnancy, so the relationship between the two attitudes at a collective level remains of interest.

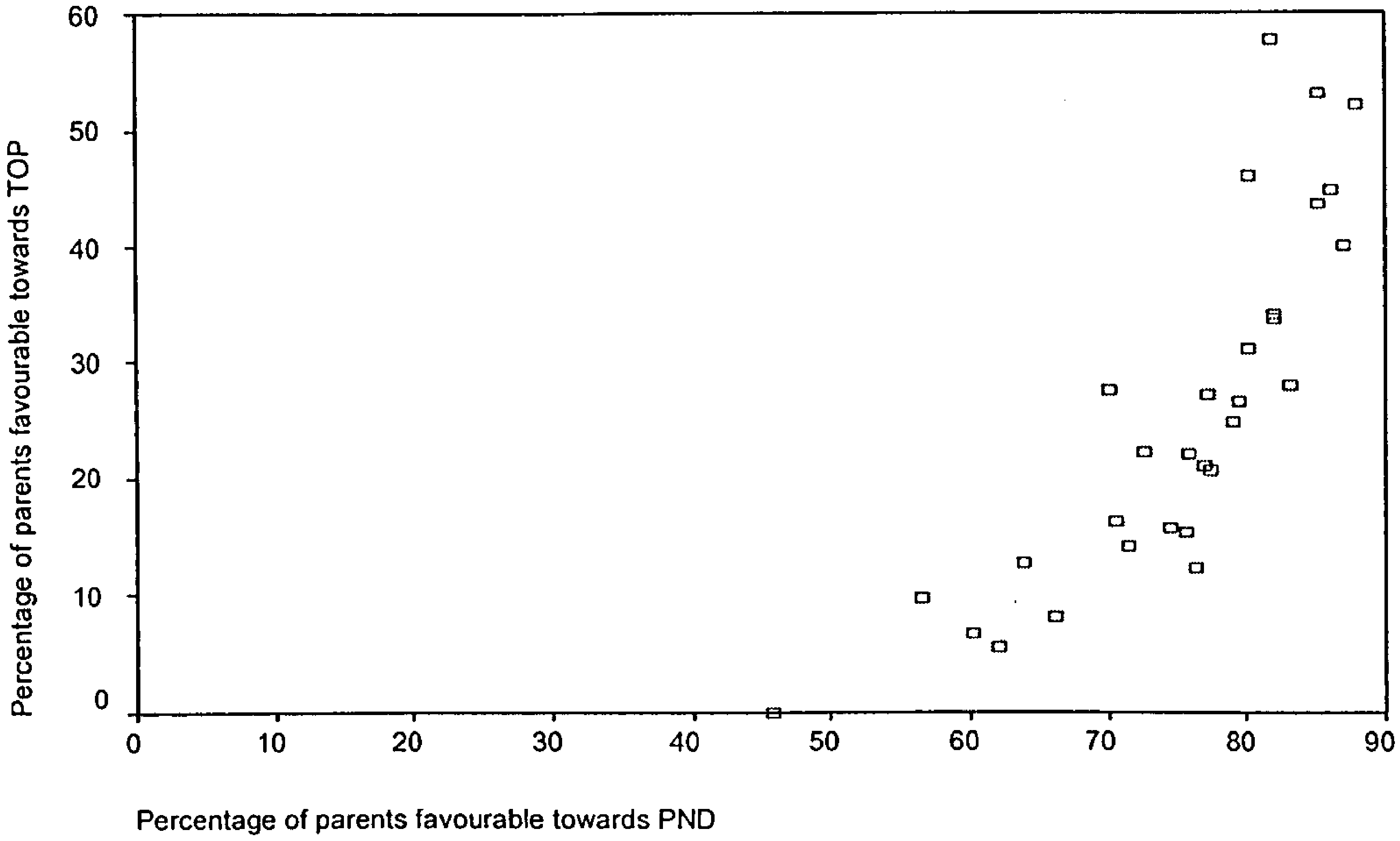


Figure 6: Saudi parents' attitudes toward PND and TOP.

It was found that the collective responses correlated significantly and positively with each other (prenatal diagnosis and termination of pregnancy in different conditions presented in the questionnaire, Spearman's *rho* = + 0.896, $p<0.001$), see the graph above. Figure (6) shows a strong tendency that conditions for which many people wanted prenatal diagnosis were also the conditions for which many people wanted termination of the pregnancy.

6.3.2.4 Comparison between Saudi parents and Leeds parents.

In the previous subsection. Saudi parents' attitudes to prenatal diagnosis and termination of pregnancy were examined for a range of genetic conditions that were presented in the questionnaire, and the conditions were ranked in order based on the parents' view in each of the genetic conditions. In this part, Saudi parents' attitudes to prenatal diagnosis and termination of pregnancy will be compared with those of parents in Leeds in the United Kingdom, toward the same genetic conditions, since the questionnaires were originally drawn from a Leeds study (See chapter 5 section 5.4). In order to compare the two studies, responses were recoded to binary variables (0= No and Not sure, and 2= Yes) for both prenatal diagnosis and termination of the pregnancy, and Fisher's exact test was used to compare the two populations. The genetic conditions are presented in table (7) below ordered on the basis of the Saudi parents' views of prenatal diagnosis, from the highest willingness to the lowest willingness, and the corresponding data from the Leeds study are placed alongside for each condition. Table (8) below shows the comparison between the two studies for attitudes to termination of the pregnancy in different conditions using the same methods as in table (7).

It must be stressed that the statistical comparisons reported in these tables were performed for exploratory purposes only, as no prior predictions had been made about the specific conditions likely to show a difference between the studies. Further research would be required to determine which, if any, of these differences could be confirmed.

6.3.2.5 Attitudes to PND in Saudi parents and Leeds parents

Table (7) below shows the number and the percentage of respondents who said yes for different genetic conditions and the results of the statistical comparisons. The genetic conditions have been listed in the table below from the highest to the lowest, according to the Saudi parents' attitudes towards prenatal diagnosis.

Genetic condition	**Present study N= 400**		**Leeds study N= 420**		**Fisher's Exact Test**
	N	%	N	%	
Severe LD/MH	**352**	**88**	**329**	**78**	**.000**
Thalassaemia	**348**	**87**	**309**	**73.2**	**.000**
Quadriplegia	**345**	**86.2**	**348**	**82.7**	**.178**
Duchenne muscular dyst	**341**	**85.2**	**341**	**81.8**	**.188**

Trisomy 13 or 18	341	85.2	348	82.5	.298
Phenylketonuria	333	83.2	294	70	.000
Diabetes	328	82	311	74.4	.009
Proteus syndrome	328	82	271	64.4	.000
Anencephaly	327	81.7	359	85.3	.188
Absent Limb	321	80.2	309	73.9	.038
Schizophrenia	321	80.2	287	68.5	.000
Epilepsy	318	79.5	302	72.1	.014
Cystic fibrosis	316	79	297	70.7	.008
Cancer	310	77.5	280	66.9	.001
Klinefelter's syndrome	309	77.2	273	65	.000
Fragile X	308	77	299	71.7	.093
Deafness	305	76.2	278	66.2	.002
Huntingdon's disease	303	75.7	293	69.9	.071
Moderate LD/MH	302	75.5	289	68.8	.036
Blindness	298	74.5	290	69.7	.138
Turner's syndrome	290	72.5	243	57.4	.000
Grossly overweight	286	71.5	212	50.59	.000

Autism	**282**	**70.5**	**269**	**64.2**	**.062**
High risk of alcoholism	**280**	**70**	**173**	**41.2**	**.000**
Mild LD/MH	**265**	**66.2**	**244**	**57.8**	**.015**
Dwarfism	**256**	**64**	**223**	**52.8**	**.001**
Cleft lip and palate	**248**	**62**	**268**	**63.4**	**.719**
Coronary at 50y	**241**	**60.2**	**217**	**51.5**	**.014**
Alzheimer's disease	**226**	**56.5**	**222**	**52.48**	**.263**
Not preferred gender	**183**	**45.7**	**144**	**34.4**	**.001**

Table 7: Attitudes to PND in Saudi parents and Leeds parents

For 20 of the genetic conditions shown in the above table (7) Saudi parents were significantly more favourable disposed than Leeds parents towards prenatal diagnosis.

6.3.2.6 Attitudes to TOP in Saudi parents and Leeds parents

Table (8) below shows the number and the percentage of respondents who said yes for different genetic conditions and the results of the statistical comparisons. The genetic conditions have been listed in the table below from the highest to the lowest according to the Saudi parents' attitudes towards termination of the pregnancy.

Genetic condition	Present study N= 400		Leeds study N= 420		Fisher's Exact Test
	N	%	N	%	
Anencephaly	231	57.7	274	65.4	.026
Trisomy 13 or 18	212	53	206	49.2	.294
Severe LD/MH	208	52	150	35.7	.000
Quadriplegia	179	44.7	158	37.9	.055
Duchenne muscular dystr	173	43.51	147	35.5	.026
Thalassaemia	160	40	59	14.1	.000
Diabetes	136	34	77	18.6	.000
Proteus syndrome	135	33.7	36	8.7	.000
Schizophrenia	124	31	73	17.72	.000
Phenylketonuria	112	28	17	4.1	.000
High risk of Alcoholism	110	27.5	15	3.6	.000
Klinefelter's syndrome	109	27.2	52	12.5	.000
Epilepsy	106	26.5	25	6	.000
Absent limb	102	25.5	46	11.1	.000
Cystic fibrosis	99	24.7	60	14.4	.000
Turner's syndrome	89	22.2	33	7.9	.000
Huntingdon's disease	88	22	82	19.7	.439

Fragile X syndrome	84	21	64	15.5	.046
Cancer	82	20.5	56	13.6	.009
Autism	65	16.2	37	8.9	.002
Blindness	63	15.7	34	8.2	.001
Moderate LD/MH	61	15.25	41	9.8	.02
Grossly overweight	56	14	21	5.1	.000
Dwarfism	51	12.7	23	5.5	.000
Deafness	49	12.2	14	3.4	.000
Alzheimer's disease	39	9.7	33	7.9	.39
Mild LD/MH	33	8.2	11	2.6	.001
Coronary at 50y	27	6.7	10	2.4	.004
Cleft lip and palate	22	5.5	13	3.1	.12
Not prefer gender	0	0	8	1.9	.008

Table 8: Attitudes to TOP in Saudi parents and Leeds parents

Table (8) above shows that the Saudi parents were significantly more favourably disposed towards termination of the pregnancy in 23 conditions. In only two conditions, the Leeds parents were significantly more favourably disposed towards termination of the pregnancy.

6.3.3 Comparison between Saudi women without an affected child and Leeds parents (white UK women, and UK Pakistani women).

In the previous section, Saudi and Leeds parents' attitudes to prenatal diagnosis and termination of the pregnancies were compared for the different genetic conditions that were presented in the questionnaire. When the two samples were compared, attitudes in the Saudi sample were found to be more favourable towards prenatal diagnosis and termination of the pregnancy for many conditions. This had not been anticipated. However, attitudes were subsequently shown (See section 6.9.5) to be more favorable in families with affected children in the Saudi sample, and this will have influenced the comparisons of countries. Further, the Leeds sample contained only women, and these were UK white indigenous women and UK Pakistani women. It was therefore decided to look more closely at the attitude differences between the studies by comparing only women without affected children. These comparisons minimise any bias between the two studies. Again, statistical comparisons were conducted in exploratory mode.

6.3.3.1 Attitudes to PND in two countries, Saudi women, and white UK women

Table (9) below shows the number of yes responses in each group of mothers, for each condition, with the results of the statistical comparisons. Conditions are listed in this table in rank order from most to least favoured (see table 7)

Genetic condition	**Saudi "healthy" women N= 100**		**Leeds white women N= 218-222**		**Fisher's Exact Test**
	N	**%**	**N**	**%**	
Severe LD/MH	82	82	170	76.9	.38
Thalassaemia	83	83	151	68.3	.007

Quadriplegia	83	83	179	81.4	.76
Duchenne muscular dyst	86	86	176	80.4	.27
Trisomy 13 or 18	82	82	191	86.4	.3
Phenylketonuria	84	84	136	61.5	.000
Diabetes	78	78	154	70	.18
Proteus syndrome	81	81	121	54.7	.000
Anencephaly	82	82	199	90.4	.04
Absent Limb	77	77	153	69.5	.18
Schizophrenia	80	80	131	59.3	.000
Epilepsy	75	75	142	64.2	.07
Cystic fibrosis	74	74	148	67.3	.24
Cancer	75	75	127	57.5	.003
Klinefelter's syndrome	77	77	131	59.5	.002
Fragile X	73	73	146	66.7	.3
Deafness	75	75	128	57.9	.004
Huntingdon's disease	77	77	146	66.1	.051

Moderate LD/MH	76	76	142	64.5	.052
Blindness	74	74	140	64.2	.09
Turner's syndrome	77	77	104	46.8	.000
Grossly overweight	72	72	85	38.6	.000
Autism	70	70	132	59.7	.08
High risk of alcoholism	68	68	56	25.3	.000
Mild LD/MH	65	65	111	50.2	.016
Dwarfism	66	66	93	42.7	.003
Cleft lip and palate	71	71	122	54.9	.007
Coronary at 50y	60	60	85	38.5	.000
Alzheimer's disease	58	58	86	38.7	.002
Not preferred gender	59	59	40	18.2	.000

Table 9: Attitudes to PND in two countries, Saudi women, and white UK women

In 16 of the genetic conditions shown in the above table (9) Saudi women's attitudes were significantly more favourable than Leeds white women's in the attitudes to prenatal diagnosis. In only 2 of the 30 conditions, attitudes were more favourable in Leeds' white women, but the difference was significant for only one condition. It may noted that the two conditions were trisomy 13 or 18 and anencephaly, in which the baby would die at or soon after birth.

6.3.3.2 Attitudes to PND in two countries, Saudi women, and UK Pakistani women

Table (10) below shows the number of yes responses in each group of mothers, for each condition, with the results of the statistical comparisons. Conditions are listed in this table in rank order from most to least favoured (see table 7)

Genetic condition	**Saudi women N= 100**		**Pakistani women N= 197-220**		**Fisher's Exact Test**
	N	%	N	%	
Severe LD/MH	82	82	159	79.5	.65
Thalassaemia	83	83	158	78.6	.4
Quadriplegia	83	83	169	84.1	.87
Duchenne muscular dyst	86	86	165	83.3	.6
Trisomy 13 or 18	82	82	157	78.1	.4
Phenylketonuria	84	84	158	79.4	.4
Diabetes	78	78	157	79.3	.9
Proteus syndrome	81	81	150	75	.3
Anencephaly	82	82	160	79.6	.65
Absent Limb	77	77	156	78.8	.8
Schizophrenia	80	80	156	78.8	.9

Epilepsy	75	75	160	80.8	.3
Cystic fibrosis	74	74	149	74.5	1
Cancer	75	75	153	77.7	.7
Klinefelter's syndrome	77	77	142	71	.3
Fragile X	73	73	153	77.3	.5
Deafness	75	75	150	75.4	1
Huntingdon's disease	77	77	147	74.2	.7
Moderate LD/MH	76	76	147	73.5	.7
Blindness	74	74	150	75.7	.8
Turner's syndrome	77	77	139	69.2	.17
Grossly overweight	72	72	127	63.8	.19
Autism	70	70	137	69.2	1
High risk of alcoholism	68	68	117	58.8	.13
Mild LD/MH	56	56	133	66.2	.9
Dwarfism	66	66	130	64.7	.5
Cleft lip and palate	71	71	146	72.6	.8

Coronary at 50y	60	60	132	66	.3
Alzheimer's disease	58	58	136	67.7	.1
Not preferred gender	59	59	104	52.5	.3

Table 10: Attitudes to PND in two countries, Saudi women, and UK Pakistani women

The table above (10) shows that Saudi women and UK Pakistani women have similar attitudes toward prenatal diagnosis

6.3.3.3 Attitudes to TOP in two countries, Saudi women, and white UK women

Table (11) below shows the number of yes responses in each group of mothers, for each condition, with the results of the statistical comparisons. Conditions are listed in this table in rank order from most to least favoured (see table 8)

Genetic condition	**Saudi women N= 100**		**Leeds white women N= 215-222**		**Fisher's Exact Test**
	N	**%**	**N**	**%**	
Anencephaly	56	56	189	85.1	.000
Trisomy 13 or 18	56	56	147	66.8	.08
Severe LD/MH	38	38	113	51.4	.03
Quadriplegia	38	38	106	48.6	.09
Duchenne muscular dystr	41	41	92	42.2	.9
Thalassaemia	40	40	30	13.7	.000

Diabetes	33	33	35	16	.001
Proteus syndrome	39	39	21	9.7	.000
Schizophrenia	33	33	43	19.8	.02
Phenylketonuria	33	33	5	2.3	.000
High risk of Alcoholism	26	26	2	0.9	.000
Klinefelter's syndrome	31	31	22	10	.000
Epilepsy	32	32	7	3.2	.000
Absent limb	25	25	17	7.8	.000
Cystic fibrosis	19	19	38	17.3	.75
Turner's syndrome	25	25	10	4.6	.000
Huntingdon's disease	23	23	51	23	1
Fragile X syndrome	20	20	39	17.9	1
Cancer	24	24	24	11	.004
Autism	12	12	27	12.4	1
Blindness	13	13	9	4.1	.007
Moderate LD/MH	18	18	29	13.2	.3
Grossly overweight	12	12	8	3.7	.01

Dwarfism	17	17	9	4.1	.000
Deafness	14	14	5	2.3	.000
Alzheimer's disease	12	12	13	6	.08
Mild LD/MH	8	8	3	3.7	.005
Coronary at 50y	9	9	4	1.8	.005
Cleft lip and palate	5	5	5	2.3	.3
Not prefer gender	0	0	2	0.9	1

Table 11: Attitudes to TOP in two countries, Saudi women, and white UK women

Table (11) above shows that Saudi women's attitudes toward termination of the pregnancies in a range of different conditions were significantly more favourable than those of white UK women in 16 of the 30 conditions. In only two conditions were white UK women significantly more favourable than Saudi women. It may be observed that these were the two conditions, anencephaly and trisomy 13 or 18, in which the baby would die at or soon after birth.

6.3.3.4 Attitudes to TOP in two countries, Saudi women, and UK Pakistani women

Table (12) below shows the number of yes responses in each group of mothers, for each condition, with the results of the statistical comparisons. Conditions are listed in this table in rank order from most to least favoured (see table 8)

Genetic condition	Saudi women N= 100		Pakistani women N= 194-200		Fisher's Exact Test
	N	%	N	%	
Anencephaly	56	56	85	43	.03
Trisomy 13 or 18	56	56	59	29.6	.000
Severe LD/MH	38	38	37	18.5	.000
Quadriplegia	38	38	52	26.3	.045
Duchenne muscular dystr	41	41	55	28.1	.03
Thalassaemia	40	40	29	14.6	.000
Diabetes	33	33	42	21.4	.03
Proteus syndrome	39	39	15	7.6	.000
Schizophrenia	33	33	30	15.4	.001
Phenylketonuria	33	33	9	4.6	.000
High risk of Alcoholism	26	26	13	6.6	.000
Klinefelter's syndrome	31	31	30	15.3	.002
Epilepsy	32	32	18	9.2	.000
Absent limb	25	25	29	14.9	.000

Cystic fibrosis	19	19	22	11.2	.08
Turner's syndrome	25	25	23	11.5	.004
Huntingdon's disease	23	23	31	15.9	.15
Fragile X syndrome	20	20	25	12.8	.12
Cancer	24	24	32	16.4	.1
Autism	12	12	10	5	.058
Blindness	13	13	25	12.8	1
Moderate LD/MH	18	18	12	6.1	.002
Grossly overweight	12	12	13	6.7	.13
Dwarfism	17	17	14	7.1	.015
Deafness	14	14	9	4.6	.000
Alzheimer's disease	12	12	20	10	.7
Mild LD/MH	8	8	8	4	.2
Coronary at 50y	9	9	6	3	.046
Cleft lip and palate	5	5	8	4	.8
Not prefer gender	0	0	6	3	.09

Table 12: Attitudes to TOP in two countries, Saudi women, and Pakistani women

Table (12) above shows that Saudi parents' attitudes towards termination of the pregnancies in a range of different conditions were significantly more favourable than those of Pakistani women in 19 of the 30 conditions.

6.3.3.5 Saudi and Leeds parents' attitudes towards PND: correlation

In the previous section, the proportions of parents expressing favourable attitudes towards prenatal diagnosis and termination of the pregnancy were compared between study groups. This section examines whether, at the level of the full samples, there is a relationship between Saudi parents' attitudes towards prenatal diagnosis for the different conditions and Leeds parents' attitudes to the same issue. Spearman's test was run to find the correlation between attitudes towards prenatal diagnosis in a range of different conditions between the two studies.

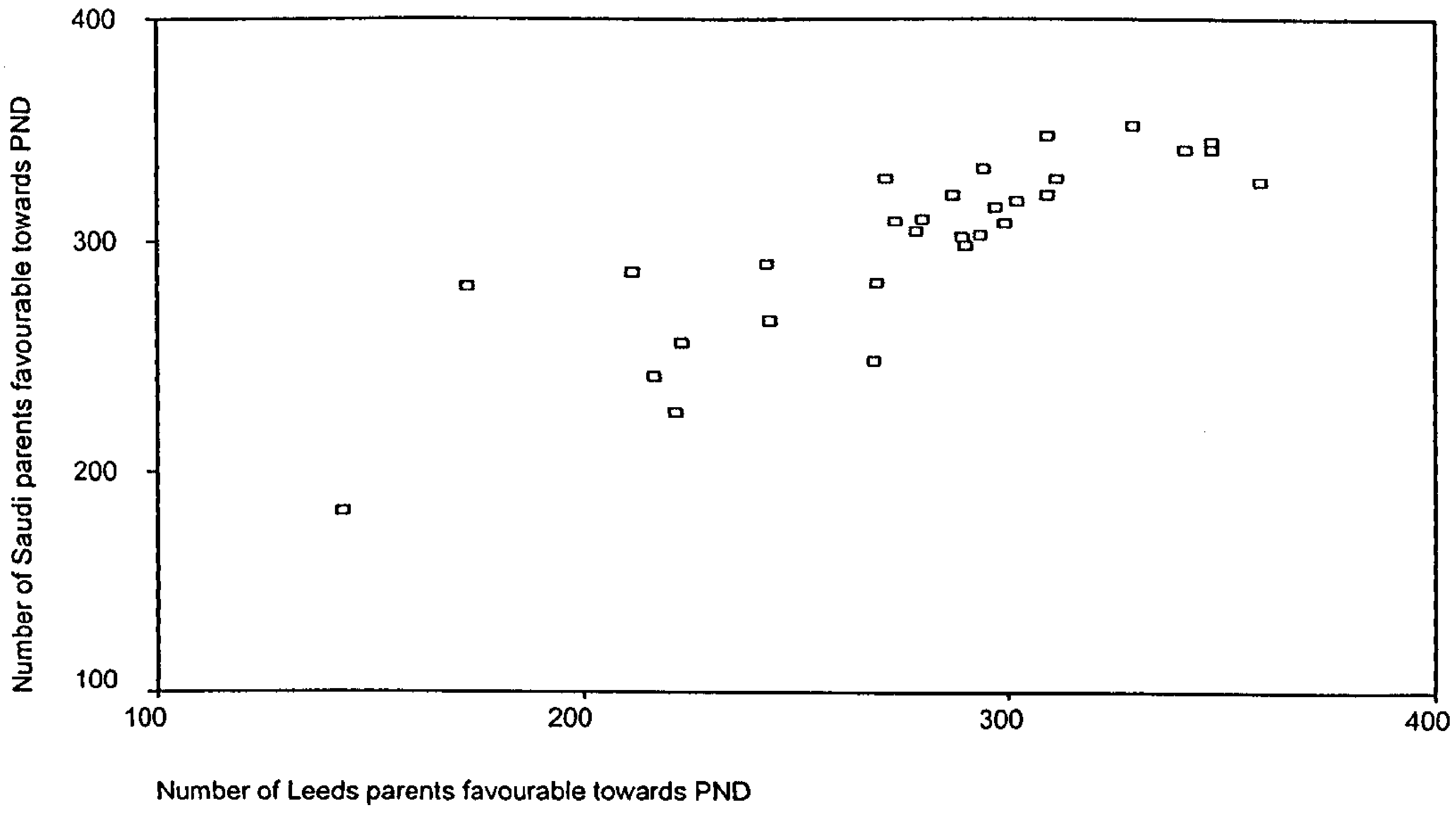


Figure 7: Saudi and Leeds parents' attitudes towards PND

It was found that the collective responses correlated significantly and positively with each other (Saudi parents' attitudes towards prenatal diagnosis and Leeds parents' attitudes towards prenatal diagnosis, Spearman's *rho* = + 0.863, p<0.001), see the graph above. Figure (7) shows a strong tendency that conditions for which many Saudi parents favoured prenatal diagnosis in the questionnaire were the same for which Leeds parents favoured it. There are strong relationships between parents' attitudes and kind of condition in both groups, which indicates that type of condition might influence parents' attitudes towards prenatal diagnosis within the same and different cultures.

6.3.3.6 Saudi and Leeds parents' attitudes towards TOP: correlation

The correlation between Saudi parents' attitudes and Leeds parents' attitudes towards termination of the pregnancy in different conditions presented in the questionnaire were analysed. The collective responses all correlated significantly and positively with each other (Saudi parents' and Leeds' parents attitudes towards termination of the pregnancies in different conditions, Spearman's *rho* = + 0.782, p<0.001).

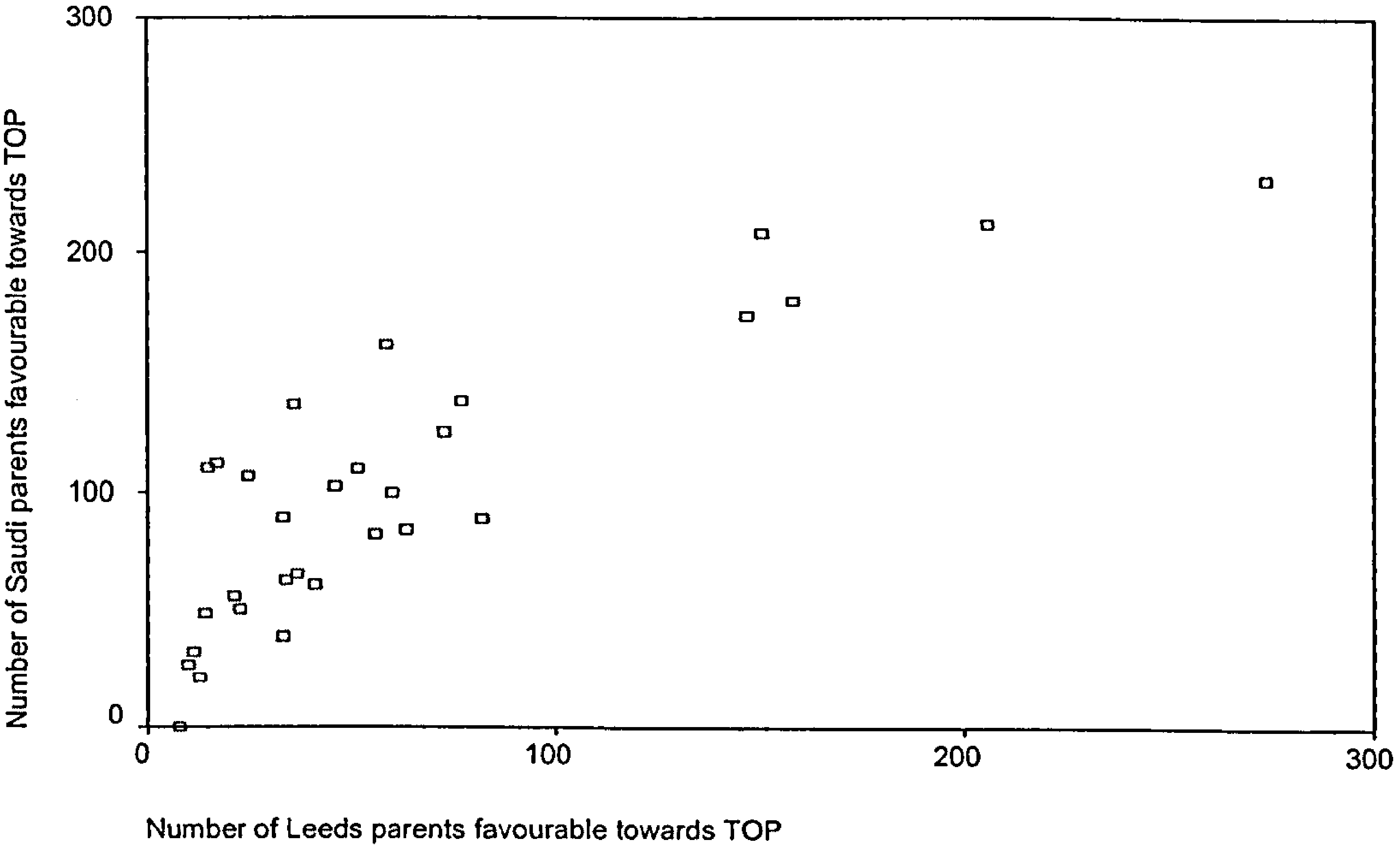


Figure 8: Saudi and Leeds parents' attitudes towards TOP

The graph above, figure (8) shows that there is a strong relationship between parents' collective attitudes to termination of pregnancy for the various conditions in two groups

6.4 SUMMARY

The findings in this section revealed favourable attitudes towards prenatal diagnosis and termination of the pregnancy among Saudi parents in a range of different conditions, attitudes varying according to the nature of the condition. There was a strong correlation between parents' attitudes towards prenatal diagnosis and their attitudes towards termination of the pregnancy. In addition, the comparison between Saudi parents and Leeds parents in attitudes towards prenatal diagnosis and termination of the pregnancy across a range of different conditions showed that Saudi parents had statistically significantly more favourable attitudes towards prenatal diagnosis and termination of the pregnancy for most of the genetic conditions. However, at a collective level, both studies had the same pattern of attitudes towards prenatal diagnosis and termination of the pregnancy across conditions, and the correlations between the two studies were strong.

PART 3

6.5 ANALYSIS OF SCORES ACROSS ALL CONDITIONS, BY POPULATION GROUP

In part 2, attitudes towards prenatal diagnosis and termination of the pregnancy were examined for each condition separately, and summarized for each of the survey population as a whole. In this section the total attitude scores for the Saudi parents towards prenatal diagnosis and termination of pregnancy for all the conditions will be presented in histograms and tables, to show Saudi parents' attitudes towards prenatal diagnosis and termination of pregnancy across all conditions. Comparisons will be made between the attitudes of fathers and mothers with and without an affected child, for prenatal diagnosis and termination of the pregnancy separately. The data were recoded as follows: 0= No, 1= Not sure, 2= Yes. A total score was then calculated by adding the values for each item. This total score had a maximum value of 60 points. The total scores were then used to compare the two sexes, and parents with or without an affected child. In order to compare two independent samples, it is necessary to select an appropriate statistical test, either parametric or non-parametric, based on the normality of data distribution and homogeneity of variance. All the figures in the section below clearly show that the normality and homogeneity of variance conditions for parametric tests were not met; therefore comparisons of total scores were carried out using the non-parametric Mann-Whitney test instead of the t-test. The histograms and tables below will show the results for each group separately. The analyses reported in sections 6.5.1 to 6.6.4 address study aims 2, 3, and 4.

6.5.1 Fathers' attitudes towards prenatal diagnosis in different conditions

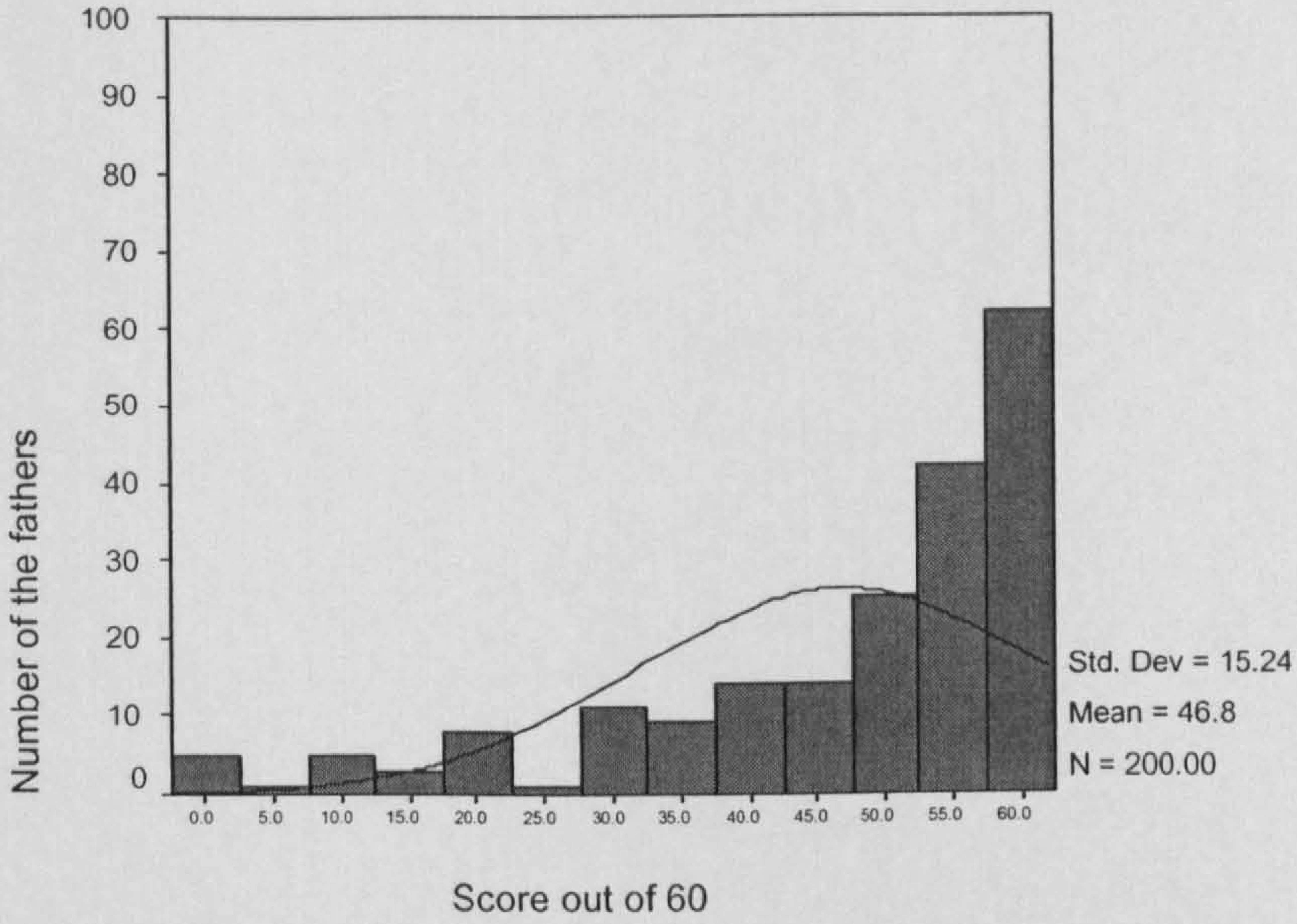


Figure 9: Fathers' attitudes towards PND

Figure (9) gives the distribution of the total scores for fathers' intentions towards prenatal diagnosis for the different conditions that were presented in this study. The frequency table (see Appendix 1) shows that 28 of 200 fathers (14%) were willing to have prenatal diagnosis in all conditions. Only four fathers (2%) were not willing to accept prenatal diagnosis in any kind of condition. This means that 98% of fathers would consider prenatal diagnosis for at least one condition.

Fathers	N	Mean	Std. Deviation	Median	IQR	MW Z-value	Sig
With an affected child	100	47.1	14.12	54	18	**- .59**	**.55**
Without an affected child	100	46.55	16.3	53	16.75		
All fathers	200	46.82	15.24	54	18		

Table 13: Fathers' attitudes to PND in different genetic conditions

The results presented in the table (13) above, present a comparison of attitudes towards prenatal diagnosis between two groups of fathers, i.e. those with and without an affected child. It shows favourable attitudes towards prenatal diagnosis for both groups, and the difference between them is not significant.

6.5.2 Mothers' attitudes towards prenatal diagnosis in different conditions

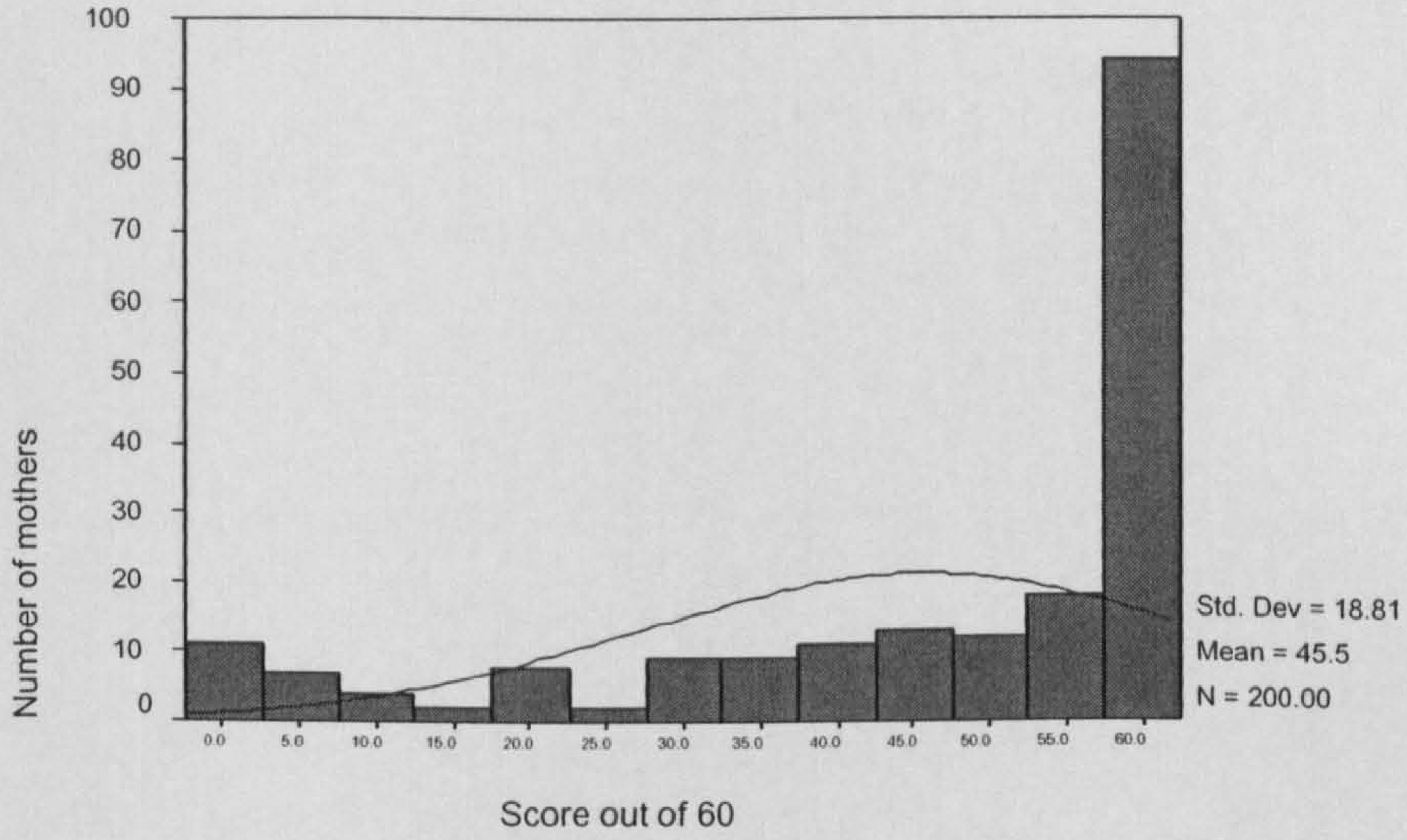


Figure 10: Mothers' attitudes to PND

Figure (10) and the frequency table (see Appendix 1) present the distribution of the total scores for mothers' intentions towards prenatal diagnosis for the range of different conditions that were presented in this study. They show that 56 of the 200 mothers (28%) were willing to have prenatal diagnosis in all the conditions, and 9 of the 200 mothers (4.5%) were not willing to have prenatal diagnosis in any of the different conditions. This means that 95.5% of mothers would consider prenatal diagnosis for at least one condition.

Mothers	N	Mean	Std. Deviation	Median	IQR	MW\ Z-value	Sig
With affected child	100	44.49	19.93	56	26	**- .99**	**.32**
Without affected child	100	46.48	17.66	56	22		
All mothers	200	45.48	18.81	56	23.75		

Table 14: Mothers' attitudes to PND in different conditions

The result presented in the table (14) above reveals a comparison between the two groups of mothers, with and without an affected child, towards prenatal diagnosis in all the conditions presented in the questionnaire. It shows favourable attitudes towards prenatal diagnosis in almost all the conditions. It can be seen that mothers with an affected child and mothers without an affected child have the same median score, and there is no significant difference between them.

6.5.3 Attitudes of fathers and mothers with an affected child towards prenatal diagnosis in different conditions

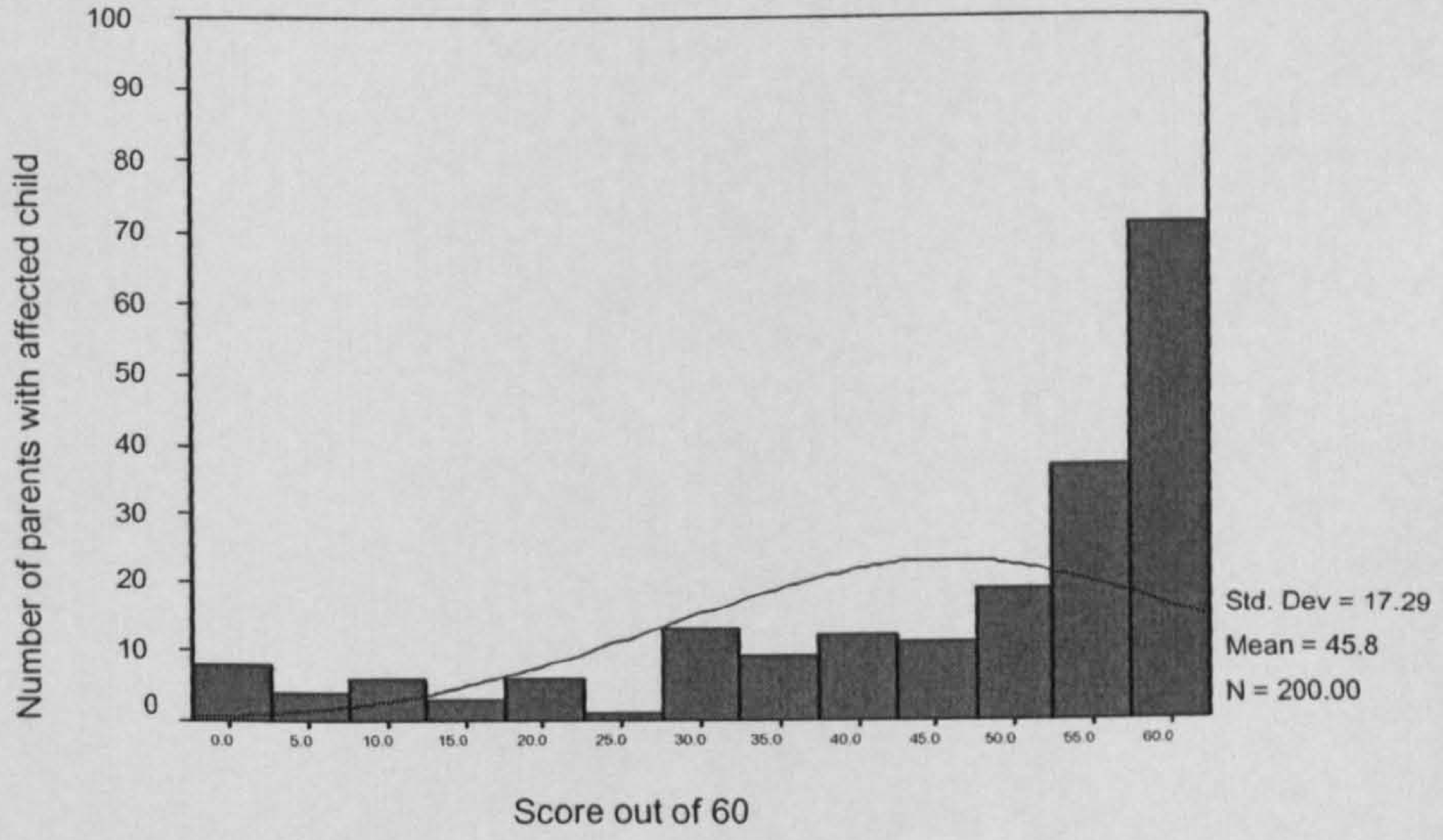


Figure 11: Attitudes of fathers and mothers with affected child, towards PND

The frequency table (Appendix 1) and figure (11) show the distribution of the total scores for fathers and mothers with an affected child regarding their intentions towards prenatal diagnosis in the different genetic conditions that were presented in this study. The results show that 33 of the 200 parents (16.5%) with an affected child were willing to have prenatal diagnosis in all of the different conditions and only 7 of 200 parents (3.5%) with an affected child were not willing to have prenatal diagnosis in any of these conditions. This means that 96.5% of these parents would consider prenatal diagnosis for at least one condition.

Parents	N	Mean	Std. Deviation	Median	IQR	MW\ Z-value	Sig
Fathers	100	47.1	14.13	54	18	**- 1.03**	**.30**
Mothers	100	44	19.93	56	26		
Fathers and Mothers	200	45.79	17.28	54	21.5		

Table 15: Comparison of fathers and mothers with an affected child in attitudes towards PND in different genetic conditions

The results presented in the table (15) above show a comparison between fathers and mothers with an affected child in terms of their willingness to accept prenatal diagnosis of the conditions presented in the questionnaire. It shows that fathers and mothers with an affected child had almost the same scores and the difference between them was not significant.

6.5.4 Attitudes of Fathers and Mothers without an affected child towards prenatal diagnosis in different conditions

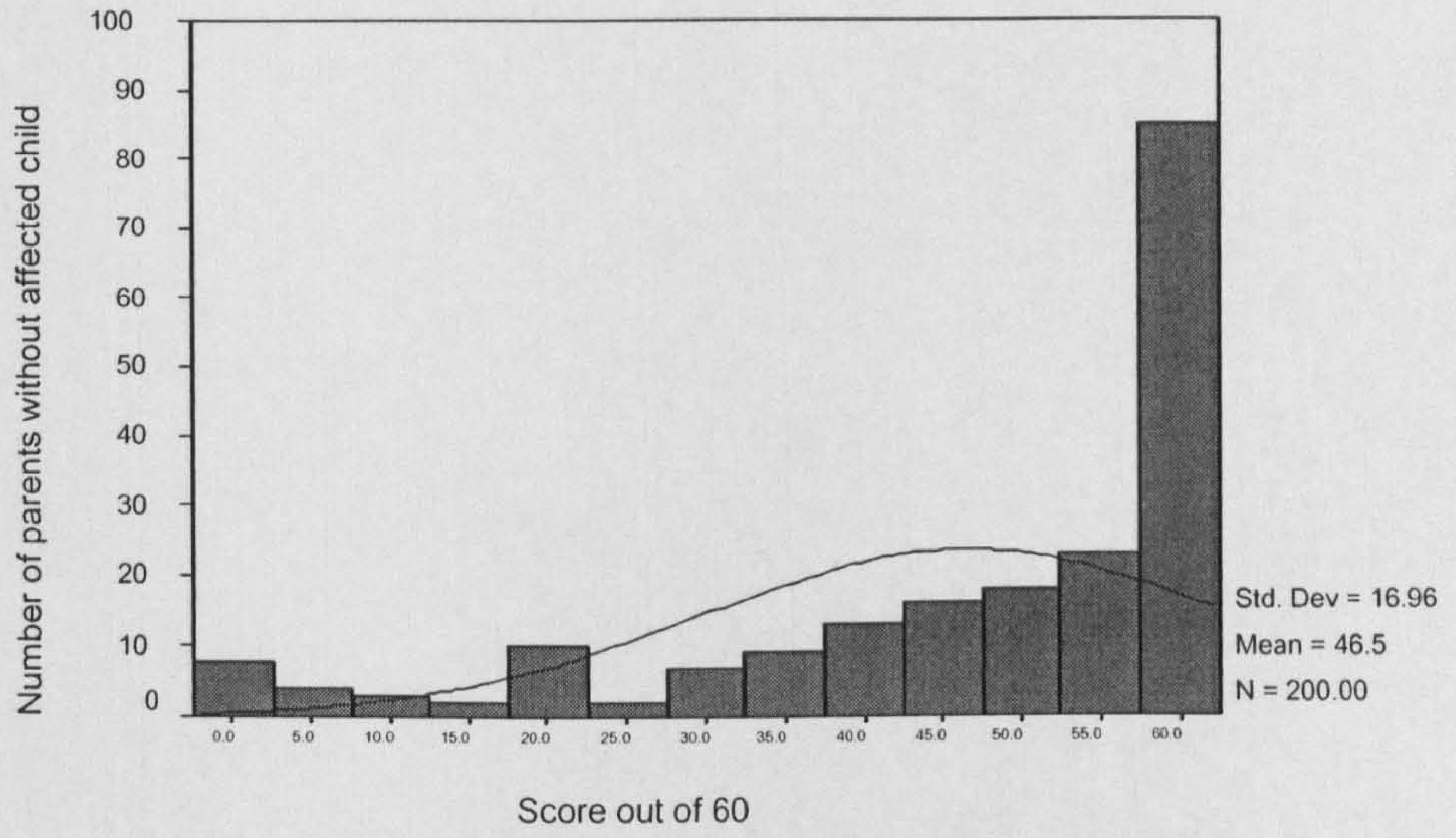


Figure 12: Fathers and Mothers without an affected child: attitude towards PND

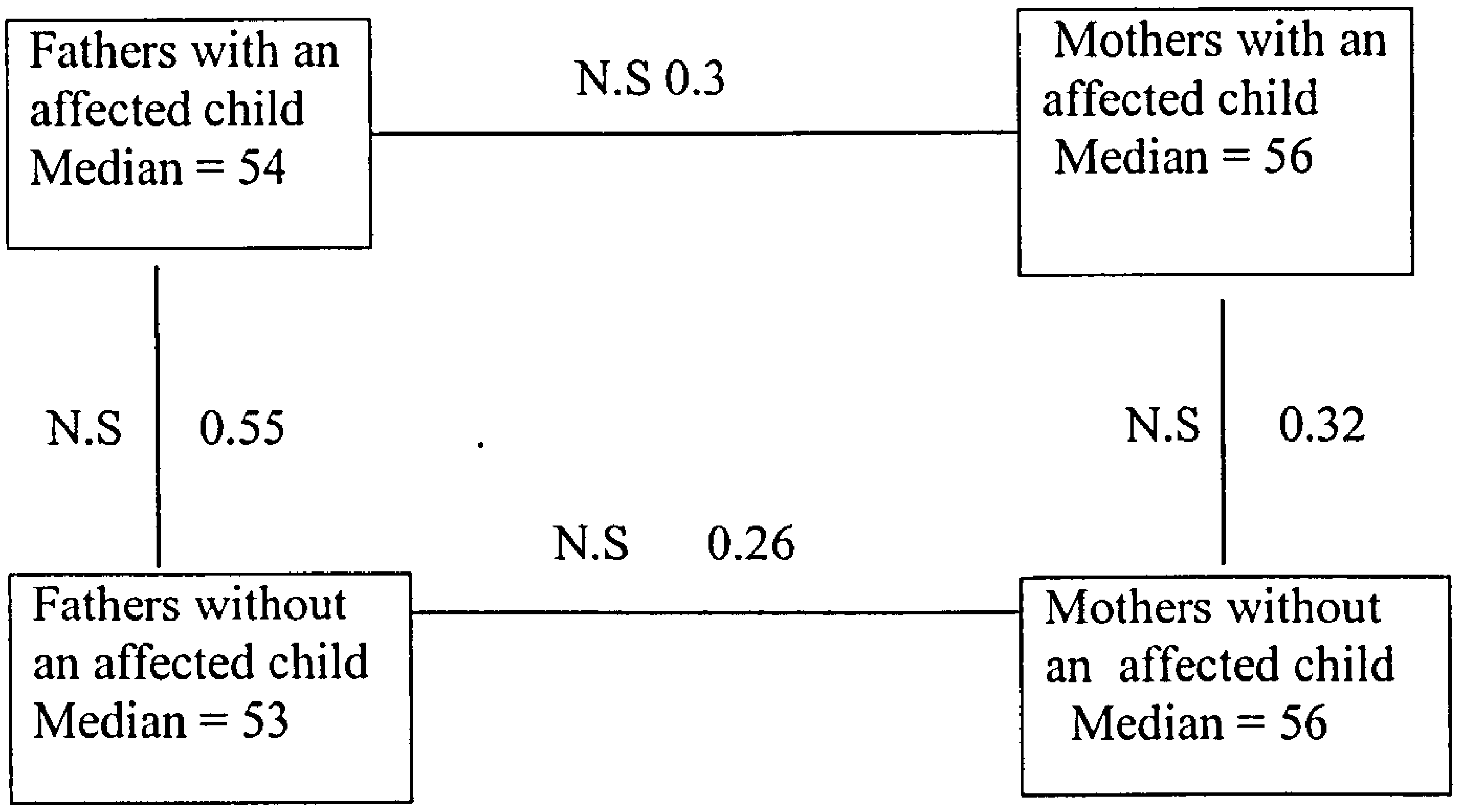
The frequency table (Appendix 1) and figure (12) show the distribution of the total scores for intentions towards prenatal diagnosis for fathers and mothers without an affected child in a range of different conditions presented in this study . It can be seen that 51 of the 200 parents (25.5%) without an affected child were willing to have prenatal diagnosis in all conditions, while only 6 of these parents (3%) were not willing to have prenatal diagnosis for any condition. This means 97% of the parents without an affected child would consider prenatal diagnosis in at least one condition.

Parents	N	Mean	Std. Deviation	Median	IQR	MW\ Z-value	Sig
Fathers	100	46.55	16.33	53	16.75	**- 1.13**	**.26**
Mothers	100	46.48	17.66	56	22		
Fathers and Mothers	200	46.5	16.96	54	20.75		

Table 16: Attitudes of Fathers and Mothers without an affected child towards PND in different genetic conditions

The result presented in the table (16) above reveals a comparison between fathers and mothers without an affected child, in willingness to consider prenatal diagnosis. It may be interpreted that fathers and mothers without an affected child both have favourable attitudes towards prenatal diagnosis and the difference between them is not significant.

6.6 SUMMARY: PARENTS' ATTITUDES TOWARDS PND



N.S= Not significant

Figure 13: Summary of parents' attitudes towards PND (Max score = 60)

Figure (13) above shows the median scores and comparison between all groups of Saudi parents. It may be interpreted that fathers and mothers with and without an affected child all have very favourable attitudes toward prenatal diagnosis and there are no significant differences between the groups. In the next section, 6.6.1, attitudes to termination of the pregnancy are presented.

6.6.1 Fathers' attitudes towards termination of the pregnancy in different conditions

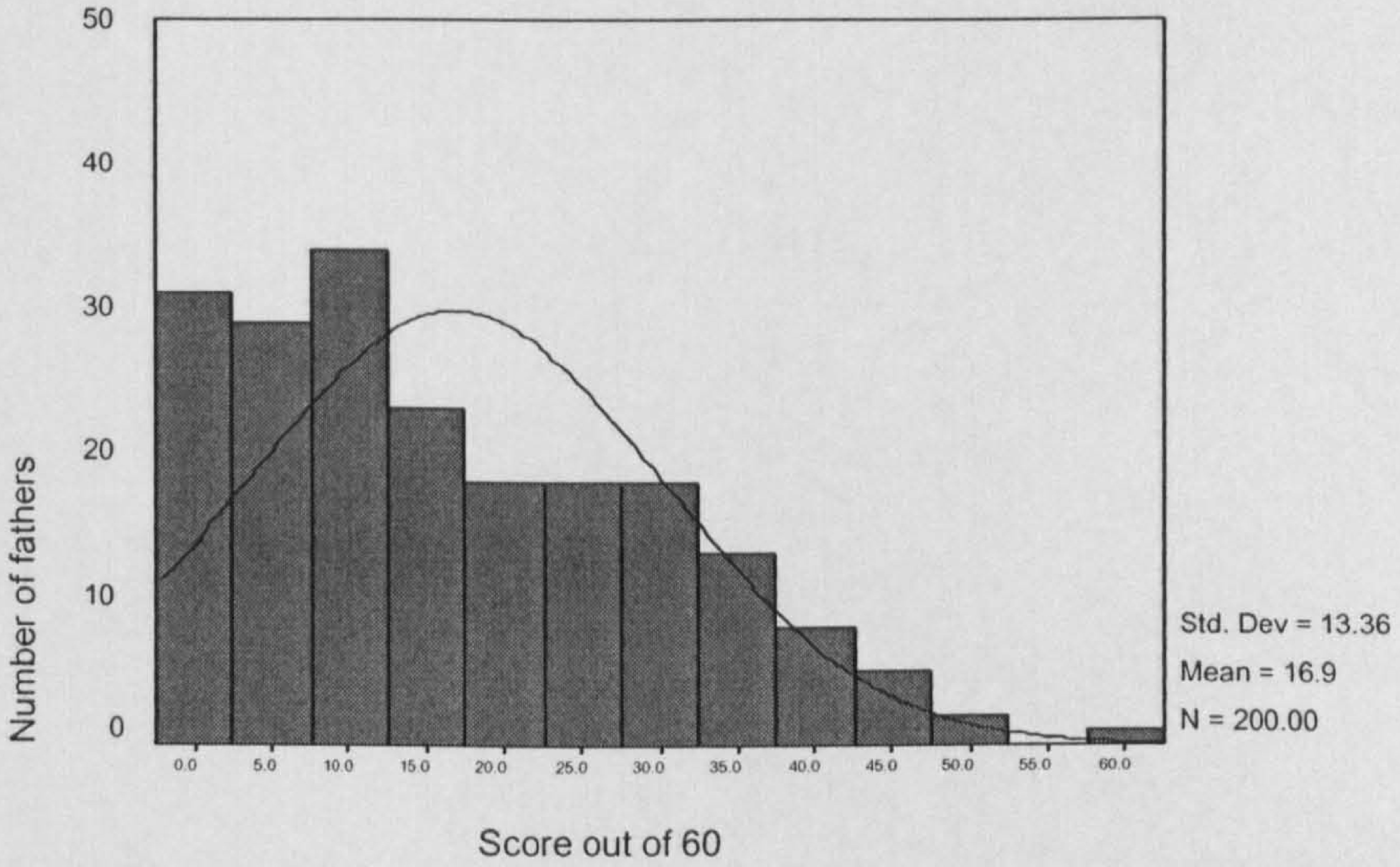


Figure 14: Fathers attitudes toward TOP in different conditions

Figure (14) and the frequency table (see Appendix 1) present the distribution of the total scores for fathers' intentions towards termination of the pregnancy for different conditions that were presented in this study. None of the 200 fathers (100%) were willing to accept termination of the pregnancy in all conditions and 20 fathers (10%) were not willing to accept termination of pregnancy in any kind of condition. This means 90% of the fathers would consider termination of the pregnancy in at least one condition.

Fathers	N	Mean	Std. Deviation	Median	IQR	MW Z-value	Sig
With an affected child	100	19.25	14.42	19	24	**-2.21**	**.027**
Without an affected child	100	14.47	11.81	12	17.75		
All fathers	200	16.86	13.36	14	22		

Table 17: Fathers' attitudes to termination in different conditions

The results presented in the table (17) above reveal that fathers with an affected child were significantly more likely to accept termination of the pregnancy than fathers without an affected child.

6.6.2 Mothers' attitudes towards termination of the pregnancy in different conditions

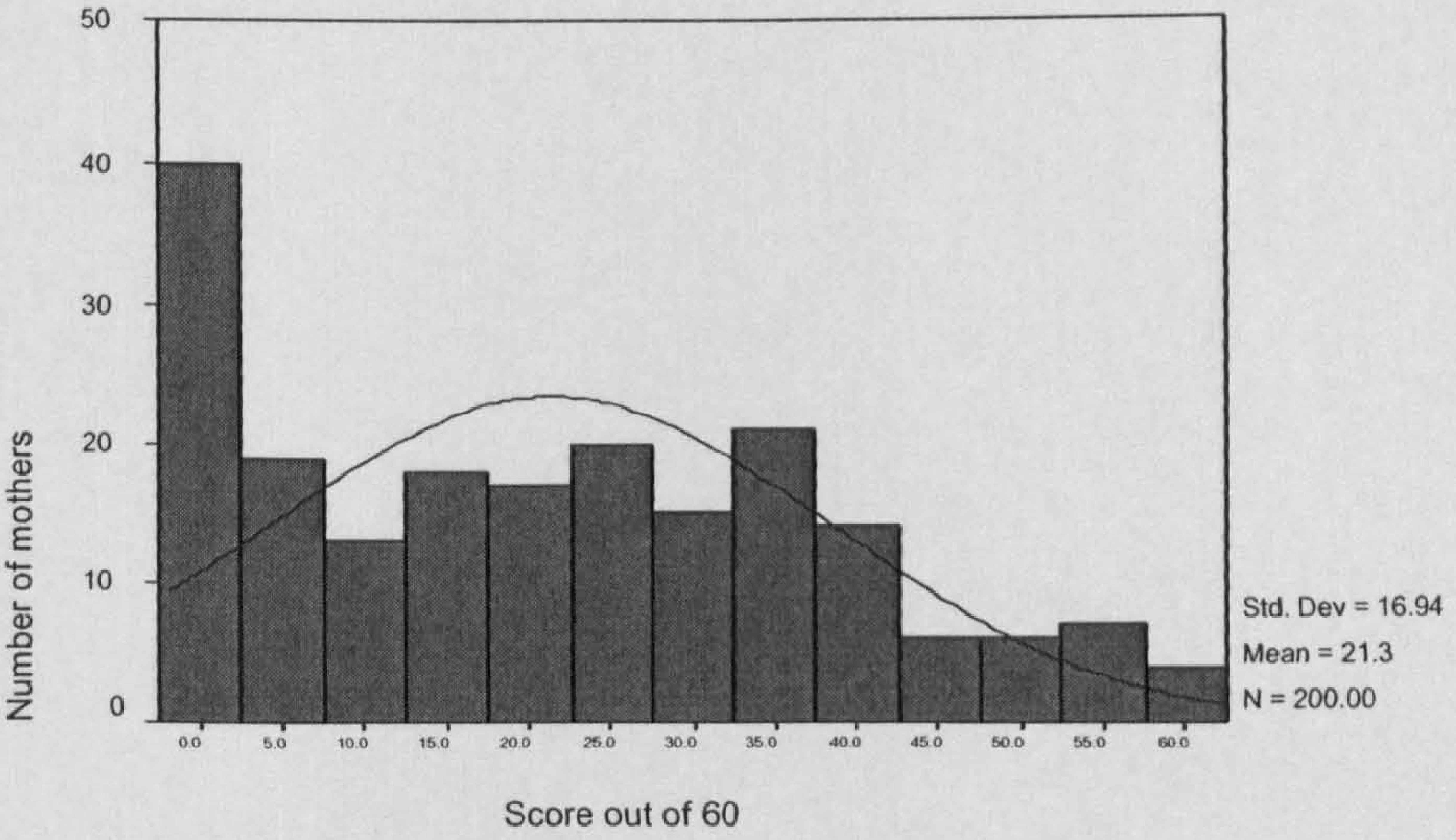


Figure 15: Mothers' attitudes towards TOP in different conditions

The distribution of the total scores in the histogram in figure (15) show mothers' intentions towards termination of the pregnancy for the different conditions that were presented in this study. None of the 200 mothers (100%) were willing to accept termination of the pregnancy in all conditions and 29 (14.5%) were not willing to have termination of the pregnancy in any of these conditions. This means 85.5% of the mothers would consider termination of the pregnancy in at least one condition.

Mothers	N	Mean	Std. Deviation	Median	IQR	MW\ Z-value	Sig
With an affected child	100	22.20	18.24	22.5	32.75	**- 0.491**	**.624**
Without an affected child	100	20.49	15.57	18.5	25.75		
All mothers	200	21.34	16.94	20	29		

Table 18: Mothers' attitudes to termination in different genetic conditions

The result presented in the table (18) above shows a comparison between mothers' with and without an affected child, towards termination of the pregnancy in different conditions that were presented in the study. The differences between the groups were not statistically significant.

6.6.3 Attitudes of fathers and mothers with an affected child towards termination of pregnancy in different conditions

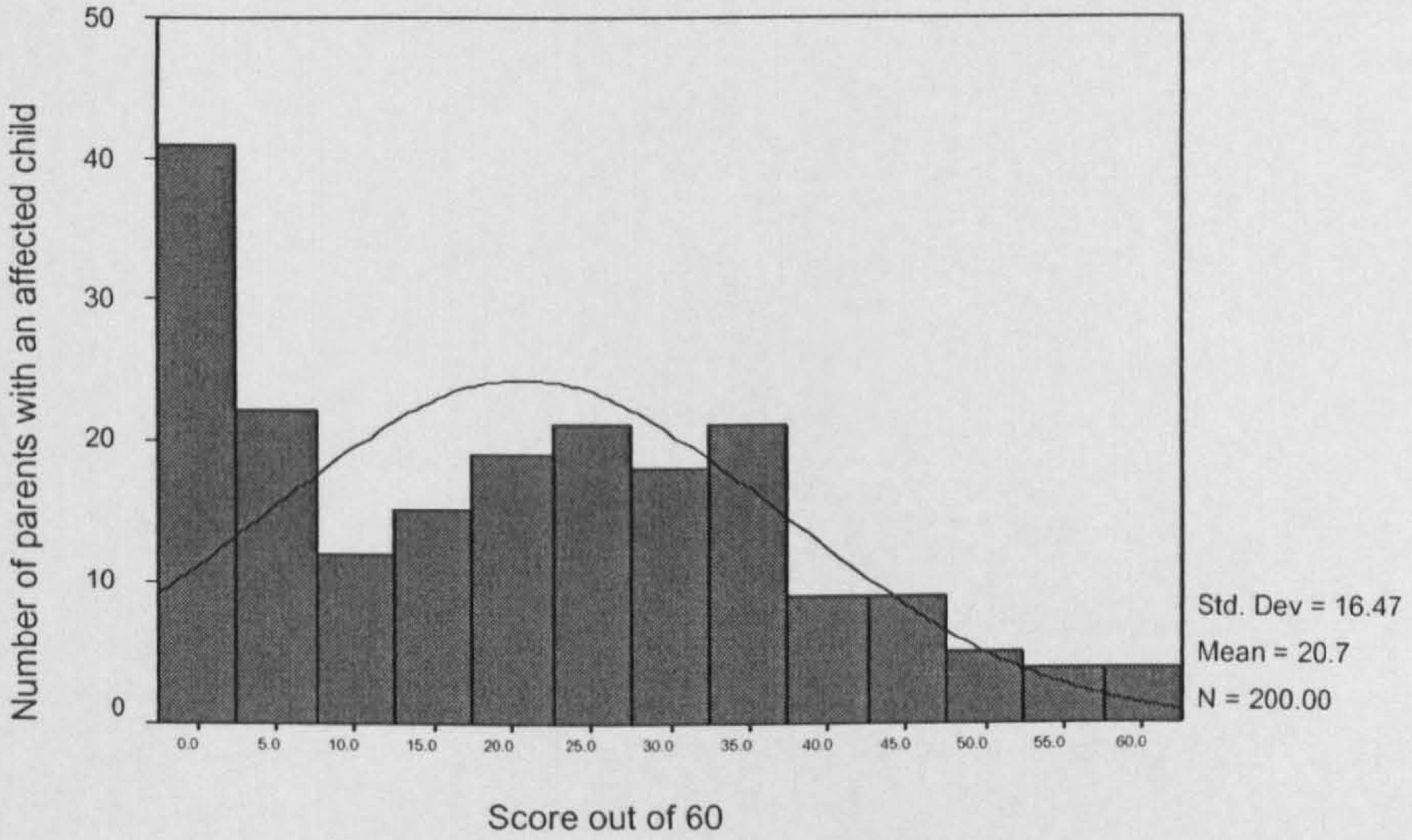


Figure 16: Parents with an affected child favourable towards TOP in different conditions

Figure (16) shows the distribution of the total scores for fathers and mothers with an affected child for intentions towards termination of the pregnancy for the different conditions that were presented in this study (for the frequency table see appendix 1). None of the 200 parents with an affected child were willing to accept termination of the pregnancy in all conditions and 29 (14.5%) were not willing to accept it in any of these conditions. This means 85.5% of the parents with an affected child would consider termination of the pregnancy in at least one condition.

Parents with an affected child	N	Mean	Std. Deviation	Median	IQR	MW Z-value	Sig
Fathers with an affected child	100	19.25	14.42	19	24	- .09	.37
Mothers with an affected child	100	22.2	18.24	22.5	32.75		
All fathers and mothers	200	20.72	16.47	20	28		

Table 19: Attitudes of fathers and mothers with an affected child to termination of different conditions

The results presented in the table (19) above show a comparison between fathers and mothers with an affected child. The difference was not significant. As the table indicates, mothers' scores on this measure were very variable, and this variability may have contributed to the lack of difference between the groups.

6.6.4 Attitudes of fathers and mothers without an affected child to termination of the pregnancy in different conditions

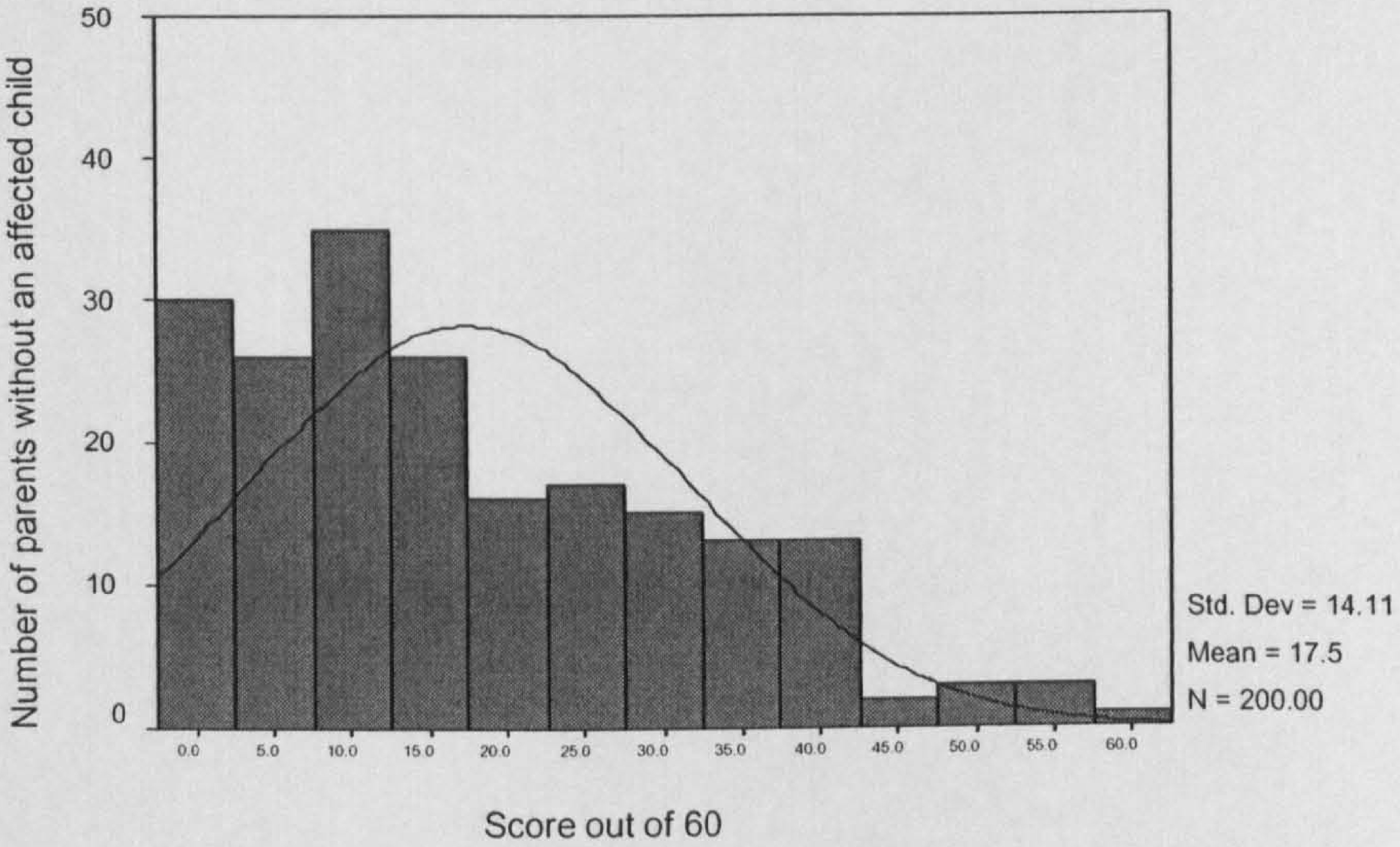


Figure 17: Attitudes of Parents without an affected child towards TOP in different conditions

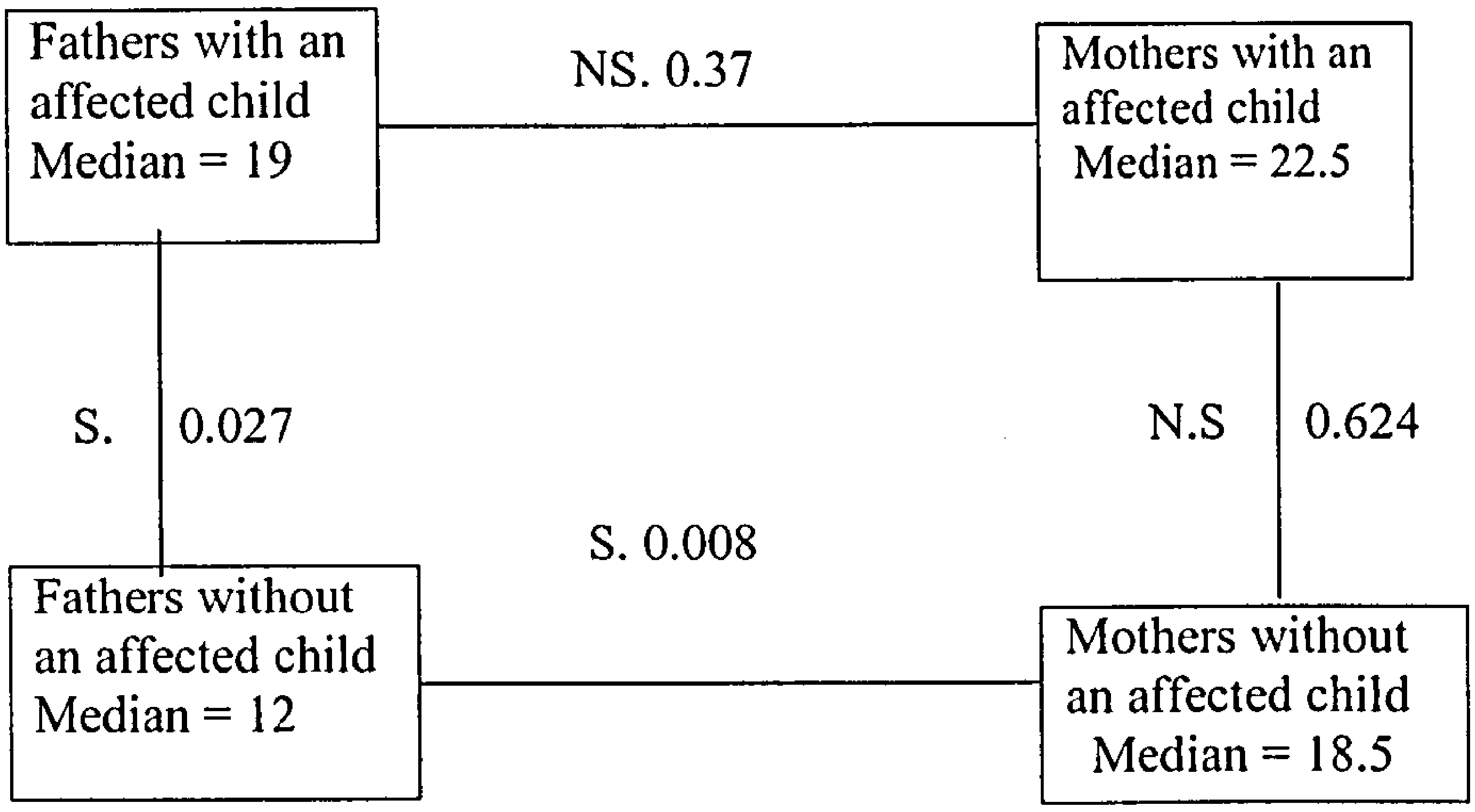
Figure (17) shows the distribution of total scores presented in a histogram, for intentions of fathers and mothers without an affected child towards termination of the pregnancy for different conditions that were presented in this study (for the frequency table see appendix 1). None of the 200 parents without an affected child were willing to accept termination of the pregnancy in all of these conditions and 20 (10%) were not willing to accept it for any of these conditions. This means 90% of the parents without an affected child would consider termination of the pregnancy in at least one condition.

Parents	N	Mean	Std. Deviation	Median	IQR	MW Z-value	Sig
Fathers without an affected child	100	14.47	11.81	12	17.75	**- 2.63**	**.008**
Mothers without an affected child	100	20.49	15.57	18.5	25.75		
Parents without an affected child	200	17.48	14.11	14	22.5		

Table 20: Attitudes of fathers and mothers without affected child to termination in different conditions

The results presented in the table (20) above, reveal a significant difference between fathers and mothers without an affected child in their attitude towards termination of the pregnancy in the different conditions presented in the questionnaire. It may be interpreted that mothers without an affected child were significantly more willing than fathers without an affected child to consider termination of pregnancy for the different conditions. As noted earlier, mothers' scores were very variable on this measure.

6.7 SUMMARY: PARENTS' ATTITUDES TOWARDS TOP



S= Significant

N.S= Not significant

Figure 18: Parents Summary finding toward TOP (Max score = 60)

Figure (18) above shows the median scores and comparisons between the groups of Saudi parents. It may be interpreted that the attitudes towards termination of the pregnancy of fathers without an affected child were significantly less favourable than those of the other three groups. Fathers and mothers with an affected child, and mothers without an affected child, all had very similar attitudes.

Part 4

6.8 RELATIONSHIP BETWEEN ATTITUDES TO PND AND TOP, AND DEMOGRAPHIC VARIABLES

In the foregoing sections, it was shown that there were some differences between fathers and mothers with and without an affected child in attitude towards termination of the pregnancy, though not in attitudes towards prenatal diagnosis. However, so far we have not considered the possible effects of demographic characteristics on the parents' attitudes. In this section, the effect of demographic characteristics on the parents' attitudes towards prenatal diagnosis and termination of the pregnancy will be presented. It was shown in section 6.3.1 that respondents in the four subgroups varied in demographic characteristics such as education. Such variables may have an impact on parents' ability and willingness to cope with a sick or disabled child, or on their awareness of health screening. Demographic differences between groups may also have influenced the group comparisons of attitudes to prenatal diagnosis and termination of the pregnancy. The analyses in this section were primarily conducted to see if group differences in attitudes were still seen, after allowance had been made for demographic differences.

6.8.1 Effect of the demographic data on the parents' attitudes to PND

In this section, the attitudes of respondents to prenatal diagnosis are analysed in relation to education, number of wives, age, number of children, monthly income. The Mann-Whitney test was used for this purpose. Attitudes to termination of the pregnancy are considered in section (6.8.3).

6.8.1.1 Level of Education and PND

Level of education was classified into two levels (see section 6.3.1), low education from level 1-4 and high education from level 5-6, and within each of the four subgroups of parents.

Total PND	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
High education	N= 52 M= 52.5	N= 50 M=54.5	N=47 M=54	N=51 M=58
Low education	N=48 M=54	N=50 M=56	N=53 M52	N=49 M=55

N= number of cases

M= median attitude score (Max score =60)

Table 21: Education and parents attitudes toward PND

The table (21) shows that in both education bands there were similarly high attitude scores towards prenatal diagnosis regardless of subgroup membership (maximum score was 60 and the median scores ranged from 52 to 58). These results indicate that the level of education did not influence the group comparisons.

6.8.1.2 Number of wives and PND

Total PND	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
One wife	N=20 M=55.5	N=12 M=58	N=8 M=52	N=8 M=54
More than one wife	N=80 M=53	N=88 M=54	N=92 M=53	N=92 M=56

Table 22: Number of wives and parents' attitudes towards PND

It was apparent from the table (22) above that all parents with and without an affected child had similarly favourable attitudes towards prenatal diagnosis (maximum score was 60 and the average toward prenatal diagnosis ranged from 52 to 58) regardless whether the husband had one or more wives. This indicates that the number of wives did not affect parents' attitudes towards prenatal diagnosis in the total scores for the different conditions presented in the questionnaire, and did not influence the group comparisons.

6.8.1.3 Parents' age and PND

Age was grouped in two categories (see section 6.3.1), younger age from 20y to 36y and older age from 37y-50y, and with each of the four subgroups of parents.

Tota PND	**Fathers with affected child**	**Mothers with affected child**	**Fathers without affected child**	**Mothers without affected child**
Yong age	N=43 M=50	N=77 M=55	N=60 M=52	N=77 M=55
Old age	N=57 M=54	N=23 M=56	N=40 M=54	N=23 M=58

Table 23: Parents' age and parents' attitudes towards PND

It is apparent from the table (23) above that in both age bands, there were similarly high attitude scores towards prenatal diagnosis regardless of subgroup membership (maximum score was 60 and the average towards prenatal diagnosis was from 52 to 58). This indicates that age did not influence the group comparisons.

6.8.1.4 Number of children and PND

Number of children was grouped in two categories: from 1 to 4 children and from 5-10 children (see section 6.3.1), for each of the four subgroups of parents.

Total PND	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
1-4 children	N=47 M=54	N=48 M=55	N=75 M=54	N=75 M=56
5-10 children	N=53 M=54	N=52 M=56	N=25 M=46	N= 25 M=58

Table 24: Number of children and parents' attitudes towards PND

It is apparent from the table (24) above that in both number of children bands there were similarly high attitude score towards prenatal diagnosis regardless of subgroup membership (maximum score was 60 and the average was from 46 to 58). The results indicate that number of children did not influence the group comparisons.

6.8.1.5 Parents' monthly income and PND

Monthly income was grouped into two categories (see section 6.3.1): low income from S.R.1000 to 6000 and high income from S.R. 7000 to 250000, within each of the four subgroups of parents.

Total PND	Fathers with an affected child	Mothers with an affected child	Fathers without an affected child	Mothers without an affected child
Low income	N=55 M=50	N=88 M=56	N=41 M=52	N=74 M=57
High income	N=45 M=54	N=12 M=44	N=59 M=53	N=26 M=56

Table 25: Monthly income and parents attitudes toward PND

It is apparent from the table (25) above that in both monthly income bands there were similarly high attitudes towards prenatal diagnosis regardless of subgroup membership (maximum score was 60 and the average was from 44 to 57). These results indicate that monthly income did not influence the group comparisons.

6.8.1.6 Number of affected children and PND

Number of affected children was classified in two levels (see section 6.3.1): one affected child and more than one affected child, and within each of the two subgroups of parents.

Number of affected children	Fathers	Mothers
One child	N=42 M=56	N=46 M=54
More than one child	N=58 M=51	N=54 M=56

Table 26: Number of affected children and PND

It is apparent from the table (26) above shows that both number of affected children bands, there were similar high attitudes scores towards prenatal diagnosis regardless of subgroup membership (maximum score was 60 and the average towards prenatal diagnosis from 51 to 56). These results indicate that number of affected children did not influence the group comparisons.

6.8.2 Summary: demographic data and attitudes to PND

It was previously found that the four study subgroups showed some differences in demographic characteristics, in terms of education, number of wives, age, number of children, number of affected children and monthly income (6.3.1). However, the analyses reported above show that these differences in demographic characteristics did not affect parents' attitudes towards prenatal diagnosis for a range of different conditions and all the parents had favourable attitudes. Further, differences in the demographic composition of groups did not contribute to the differences in attitudes between groups, reported in section (6.5). Overall, it can be observed that attitudes to prenatal diagnosis were highly favourable in all demographic and study groups, and this was probably the reason why no group difference were found.

6.8.3 Effect of the demographic data on the parents' attitudes to TOP

Having considered the relationship between demographic characteristics and attitudes towards prenatal diagnosis, we now turn to the effect of these variables on parents' attitudes towards termination of the pregnancy, to see if group differences are still seen, once allowance has been made for demographic factors.

As shown in the summary diagram figure (18), there were significant differences in attitudes toward termination of the pregnancy between a) fathers with and without an affected child and b) fathers and mothers without an affected child.

6.8.3.1 Level of education and TOP

Analyses reported earlier (tables 4 and 5) showed that fathers and mothers with and without an affected child were not significantly different in their education.

Total TOP	Fathers with an affected child	Mothers with an affected child	Fathers without an affected child	Mothers without an affected child
Highly educated	N=52 M=21.5	N=50 M=17	N=47 M=12	N=51 M=20
Low education	N=48 M=16	N=50 M=29	N=53 M=12	N=49 M15

N= number of cases

M= median attitude score (Max score =60)

Table 27: Education and parents' attitudes towards TOP

Overall, the pattern of results seen in the full sample was confirmed. In both education bands, 1) fathers with an affected child had more favourable attitudes than fathers without an affected child. The difference reached significance in the more educated fathers ($P< 0.027$). 2) mothers without an affected child were more in favour than fathers without an affected child. Again, this difference reached significance in the more educated group ($P<0.023$). In exploratory analyses, one other comparison was significant. In the less educated group, mothers with an affected child had more favourable attitudes than fathers with an affected child (P<0.026). In the more educated group, the non significant trend was in the opposite direction.

Looking at these figures another way, for mothers, although comparisons were not significant, the effect of education on attitudes seemed to be different in the two groups: in mothers without an affected child, more educated women tended to have more favourable attitudes towards termination of the pregnancy, whereas in mothers with an affected child, more educated women tended to have less favourable attitudes, as shown in the above table (27).

6.8.3.2 Number of wives and TOP

Analyses reported earlier (tables 4 and 5) showed that in families with and without an affected child there were no significant differences in the number of wives.

Total TOP	Fathers with an affected child	Mothers with an affected child	Fathers without an affected child	Mothers without an affected child
More than one wife	N=20 M=18	N=12 M=31.5	N=8 M=17	N=8 M=22
One wife	N=80 M=19	N=88 M=20	N=92 M=12	N=92 M=18

Table 28: Number of wives and parents' attitudes towards TOP

It is apparent from the above table (28) that the majority of fathers in families had only one wife. Attitudes towards termination of the pregnancy were more favourable among parents in families with more than one wife, except in the group of fathers with an affected child, where the medians were almost the same.

Overall, the pattern of results seen in the full sample was confirmed. In both "number of wives" bands, 1) fathers with an affected child had more favourable attitudes than fathers without an affected child. The difference reached significance in the fathers with one wife (P<0.017). 2) mothers without an affected child were more in favour than fathers without an affected child. Again this difference reached significance in the "one wife" group (P<0.012), possibly because of the large number in this group.

6.8.3.3 Parents' age and TOP

Analyses reported earlier (tables 4 and 5) showed that fathers with an affected child were significantly older than fathers without an affected child. There were no significant differences for mothers' age.

The previously noted differences in attitudes between groups were therefore re-examined taking age into account.

Total TOP	**Fathers with an affected child**	**Mothers with an affected child**	**Fathers without an affected child**	**Mothers without an affected child**
Younger age	N=43 M=16	N=77 M=20	N=60 M=12	N=77 M=20
Older age	N=57 M=22	N=23 M=29	N=40 M=12	N=23 M=14

Table 29: Parents' age and parents' attitudes towards TOP

As table (29) shows, the difference in attitudes previously noted between fathers with and without an affected child were observed within both age bands. This difference was significant in the older fathers (P<0.012), but did not reach significance in the younger fathers, in part because of the spread of attitudes within each subgroup.

The previously noted difference between fathers and mothers without an affected child was also re-examined taking age into account. Again, the effect was observed in both younger and older parents, but it only reached significance in the younger group. As may be noted from the above table, the effect of age on attitudes toward termination of the pregnancy seemed to vary between subgroups: in parents with an affected child, older parents had more favourable attitudes, but in parents without an affected child, the trend if anything, was in the opposite direction. Further research would be required to confirm this pattern.

6.8.3.4 Number of children and TOP

Analyses reported earlier (tables 4 and 5) showed that fathers with an affected child had significantly more children than fathers without an affected child. Also, mothers with an affected child had significantly more children than mothers without an affected child.

The previously noted differences in attitudes between groups were therefore re-examined taking number of children into account.

Total TOP	**Fathers with an affected child**	**Mothers with an affected child**	**Fathers without an affected child**	**Mothers without an affected child**
1-4 children	N=47 M=18	N=48 M=21	N=75 M=12	N=75 M=18
5-10 children	N=53 M=20	N=52 M=23	N=25 M=9	N= 25 M=20

Table 30: Number of children and parents attitudes' towards TOP

Once again, the pattern of results seen in the full sample was confirmed. The table (30) above shows that, within each "number of children" band, there were clear differences in the medians between the groups of parents with and without an affected child, as seen in the full sample, although the differences were not significant, because of the spread of the parents' attitudes within the different subgroups.

6.8.3.5 Parents' monthly income and TOP

Analyses reported earlier (tables 4 and 5) showed that fathers without an affected child were significantly higher in monthly income than fathers with an affected child. Also, mothers without an affected child were significantly higher in monthly income than mothers with an affected child.

The previously noted differences in attitudes between groups were therefore re-examined taking monthly income into account.

Total TOP	Fathers with affected child	Mothers with affected child	Fathers without affected child	Mothers without affected child
Low income	N=55 M=16	N=88 M=25	N=41 M=12	N=74 M=18
High income	N=45 M=21	N=12 M=17	N=59 M=12	N=26 M=19

Table 31: Monthly income and parents' attitudes toward TOP

Within income bands, there were clear differences in the medians between the groups of parents with and without an affected child, although some of these were not significant, because of the spread of the parents' attitudes within the different subgroups.

The previously noted effects were observed in both low income and high income parents, but only reached significance in the high income group. High income fathers with an affected child were significantly more likely than high income fathers without an affected child to consider termination of the pregnancy (P<0.003). For parents without an affected child, high income mothers were significantly more likely than high income fathers to consider termination of the pregnancy (P<0.001). As may be noted from the above table (31), the effect of income on attitudes towards termination of the pregnancy seemed to vary between subgroups. In parents with an affected child, higher income fathers had more favourable attitudes than lower income fathers, but for mothers the opposite was true. There were no clear patterns in parents without affected children.

6.8.3.6 Number of affected children and TOP

Analyses reported earlier (table 6) showed that fathers and mothers with an affected child had similar numbers of affected children.

Number of affected child	**Fathers**	**Mothers**
One child	N=42 M=22.5	N=46 M=23.5
More than one child	N=58 M=16	N=54 M=20

Table 32: Number of affected children and TOP

Within each demographic band, the attitudes of fathers and mothers were not significantly different. In exploratory analyses, fathers with only one affected child were significantly more likely to favour termination of the pregnancy than fathers with more than one affected child (P<0.019).

6.8.4 Summary: demographic data and attitudes to TOP

As previously noted, the four subgroups differed in some demographic characteristics. However, when these were taken into account, the differences between subgroups in attitudes to termination of the pregnancy identified earlier were still seen.

In exploratory analyses, some interesting effects of demographic variables on attitudes emerged. These effects sometimes varied from subgroup to subgroup. Further research would be required to investigate fully the relationships between the various demographic factors, and between demography, subgroups membership and parental attitudes.

PART 5

6.9 COMPARISON BETWEEN PARENTS WITH AND WITHOUT AN AFFECTED CHILD, FOR EACH CONDITION

In a previous section (results part 3) comparisons were made between groups of parents using the total scores for all conditions. Those analyses, which were designed to address the study aims, revealed that overall, there were no differences between groups in attitudes to prenatal diagnosis, but that fathers without an affected child had less favourable attitudes towards termination of the pregnancy than the other groups. In this section of the results comparisons are made between parents with and without an affected child for each condition. These analyses were conducted on an exploratory basis, to show how attitudes to the separate conditions contributed to the group comparisons previously performed using total scores. Statistical tests were performed to compare attitudes to the separate conditions, but it was recognized that performing multiple statistical comparisons makes interpretation of any particular comparison problematic. The interpretation offered at the end of each section, therefore, refers to the overall patterns emerging in the results, rather than to any specific differences found. In order to perform the necessary analyses, the coding of the data 0= No, 1= Not sure, 2= Yes was recoded back to 0= No and Not sure, 1= Yes (section 6.3.2) to show only the number of yes responses for each condition presented in the questionnaire. The proportions of yes responses in each group were compared using Fisher's exact tests.

6.9.1 Fathers' attitudes toward PND in each condition

Table (33) below shows the number of yes responses in each group of fathers, for each condition, with the results of the statistical comparisons. Conditions were listed in rank order from most to least favoured in this table see section (6.3.2.5)

Condition	Fathers with affected child N= 100	Fathers without affected child N= 100	Fisher's exact test 2. Sided
Severe LD/MH	94	90	.435
Thalassaemia	96	88	.065
Quadriplegia	96	87	.04
Duchenne muscular dyst	94	84	.04
Trisomy 13 or 18	93	85	.11
Phenylketonuria	92	77	.006
Diabetes	86	82	.56
Proteus syndrome	83	84	1
Anencephaly	86	84	.84
Absent Limb	83	82	1
Schizophrenia	83	77	.38

Epilepsy	**87**	**78**	**.14**
Cystic fibrosis	**92**	**80**	**.024**
Cancer	**83**	**75**	**.22**
Klinefelter's syndrome	**83**	**75**	**.22**
Fragile X	**79**	**80**	**1**
Deafness	**76**	**77**	**1**
Huntingdon's disease	**81**	**76**	**.5**
Moderate LD/MH	**81**	**72**	**.18**
Blindness	**78**	**74**	**.62**
Turner's syndrome	**73**	**68**	**.53**
Grossly overweight	**70**	**72**	**.88**
Autism	**71**	**73**	**.88**
High risk of alcoholism	**75**	**62**	**.067**
Mild LD/MH	**64**	**68**	**.65**

Dwarfism	**64**	**61**	**.77**
Cleft lip and palate	**50**	**63**	**.087**
Coronary at 50y	**56**	**67**	**.15**
Alzheimer's disease	**49**	**61**	**.12**
Not preferred gender	**35**	**47**	**.11**

Table 33: Fathers' attitudes to PND in each condition

The above table (33) shows that there were four significant differences between the groups, and in all cases, fathers of an affected child held more favourable attitudes towards prenatal diagnosis than did fathers without an affected child. The analysis of total scores reported in section (6.5.1) showed no significant differences between these groups of fathers. It may be that differences do exist for particular conditions, but this would need confirmation in other studies.

6.9.2 Mothers' attitudes toward PND in each condition.

Table (34) below shows the number of yes responses in each group of mothers, for each condition, with the results of the statistical comparisons.

Condition	Mothers with affected child N= 100	Mothers without affected child N= 100	Fisher exact test 2 sided
Severe LD/MH	86	82	.54
Thalassaemia	81	83	.85
Quadriplegia	79	83	.59
Duchenne muscular dyst	77	86	.14
Trisomy 13 or 18	81	82	1
Phenylketonuria	80	84	.58
Diabetes	82	78	.59
Proteus syndrome	80	81	1
Anencephaly	75	82	.3
Absent Limb	79	77	.86
Schizophrenia	81	80	1

Epilepsy	78	75	.74
Cystic fibrosis	70	74	.64
Cancer	77	75	.87
Klinefelter's syndrome	74	77	.74
Fragile X	76	73	.75
Deafness	77	75	.86
Huntingdon's disease	69	77	.26
Moderate LD/MH	73	76	.75
Blindness	72	74	.87
Turner's syndrome	72	77	.52
Grossly overweight	72	72	1
Autism	68	70	.88
High risk of alcoholism	75	68	.35
Mild LD/MH	68	65	.76

Dwarfism	**65**	**66**	**1**
Cleft lip and palate	**64**	**71**	**.36**
Coronary at 50y	**58**	**60**	**.89**
Alzheimer's disease	**58**	**58**	**1**
Not preferred gender	**42**	**59**	**.023**

Table 34: Mothers' attitudes towards PND each condition

The table (34) above shows the attitudes towards prenatal diagnosis between mothers with and without an affected child across thirty conditions. Only in preferred gender was a significant difference found: mothers without an affected child were significantly more likely than mothers with an affected child to favour prenatal diagnosis. This may have been a chance finding.

In the next section (6.9.3 and 6.9.4) comparisons between fathers and mothers with and without an affected child are presented.

6.9.3 Attitudes of fathers and mothers with an affected child toward PND in each condition.

Table (35) below shows the number of yes responses in each group of fathers and mothers with an affected child, for each conditions, with the results of the statistical comparisons.

Conditions	**Fathers with affected child N= 100**	**Mothers with affected child N= 100**	**Fisher exact test 2 sided**
Severe LD/MH	94	86	.097
Thalassaemia	96	81	.001
Quadriplegia	96	79	.000
Duchenne muscular dyst	94	77	.001
Trisomy 13 or 18	93	81	.019
Phenylketonuria	92	80	.024
Diabetes	86	86	.56
Proteus syndrome	83	80	.72
Anencephaly	86	75	.073
Absent Limb	83	79	.59
Schizophrenia	83	81	.854
Epilepsy	87	78	.146
Cystic fibrosis	92	70	.000

Cancer	83	77	.38
Klinefelter's syndrome	83	74	.168
Fragile X	79	76	.735
Deafness	76	77	1
Huntingdon's disease	81	69	.072
Moderate LD/MH	81	73	.24
Blindness	78	72	.41
Turner's syndrome	83	77	.38
Grossly overweight	70	72	.88
Autism	71	68	.76
High risk of alcoholism	75	75	1
Mild LD/MH	64	68	.654
Dwarfism	64	65	1
Cleft lip and palate	50	64	.063
Coronary at 50y	56	58	.87
Alzheimer's disease	49	58	.26
Not preferred gender	35	42	.38

Table 35: Attitudes of fathers and mothers with an affected child toward PND in each condition

The above table (35) shows that fathers with an affected child were significantly more likely than mothers with an affected child to favour prenatal diagnosis in six conditions. There were no significant differences in the other direction. The analysis of total scores reported in section (6.5.3) showed no significant difference between fathers and mothers with an affected child. It may be that differences do exist for particular conditions, but this would need confirmation in other studies.

6.9.4 Attitudes of fathers and mothers without an affected child towards PND in each condition.

Table (36) below shows the number of yes responses in each group of fathers and mothers without an affected child, for each condition, with the results of the statistical comparisons.

Condition	Fathers without affected child N= 100	Mothers without affected child N= 100	Fisher exact test 2 sided
Severe LD/MH	90	82	.53
Thalassaemia	88	83	.42
Quadriplegia	87	83	.55
Duchenne muscular dyst	84	86	.84
Trisomy 13 or 18	85	82	.7
Phenylketon u-ria	77	84	.28
Diabetes	82	78	.59
Proteus syndrome	84	81	.7
Anencephaly	84	82	.85

Absent Limb	82	77	.49
Schizophrenia	77	80	.73
Epilepsy	78	75	.74
Cystic fibrosis	80	74	.4
Cancer	75	75	1
Klinefelter's syndrome	75	77	.87
Fragile X	80	73	.32
Deafness	77	75	.87
Huntingdon's disease	76	77	1
Moderate LD/MH	72	76	.63
Blindness	74	74	1
Turner's syndrome	68	77	.2
Grossly overweight	72	72	1
Autism	73	70	.75
High risk of alcoholism	62	68	.46
Mild LD/MH	68	65	.76
Dwarfism	61	66	.56

Cleft lip and palate	**63**	**71**	**.23**
Coronary at 50y	**67**	**60**	**.38**
Alzheimer's disease	**61**	**58**	**.77**
Not preferred gender	**47**	**59**	**.12**

Table 36: Attitudes of fathers and mothers without an affected child towards PND in each condition

There was no significant difference in total score between fathers and mothers without an affected child in section (6.5.4). Further, as table (36) above reveals, there were no statically significant differences between fathers without an affected child and mothers without an affected child in attitudes to prenatal diagnosis for any of the thirty conditions.

* * * * * * * * * * * * * * * * *

The analyses reported in sections 6.9.1 to 6.9.4 above present the detailed findings of the comparisons between sample groups in attitudes to prenatal diagnosis for each of the thirty conditions on the questionnaire. These data on prenatal diagnosis are presented in summary in Figure (19) below. In the figure, conditions are ranked according to the results presented in section 6.3.2.5.

In the next section (6.9.5), attitudes towards termination of the pregnancy are examined.

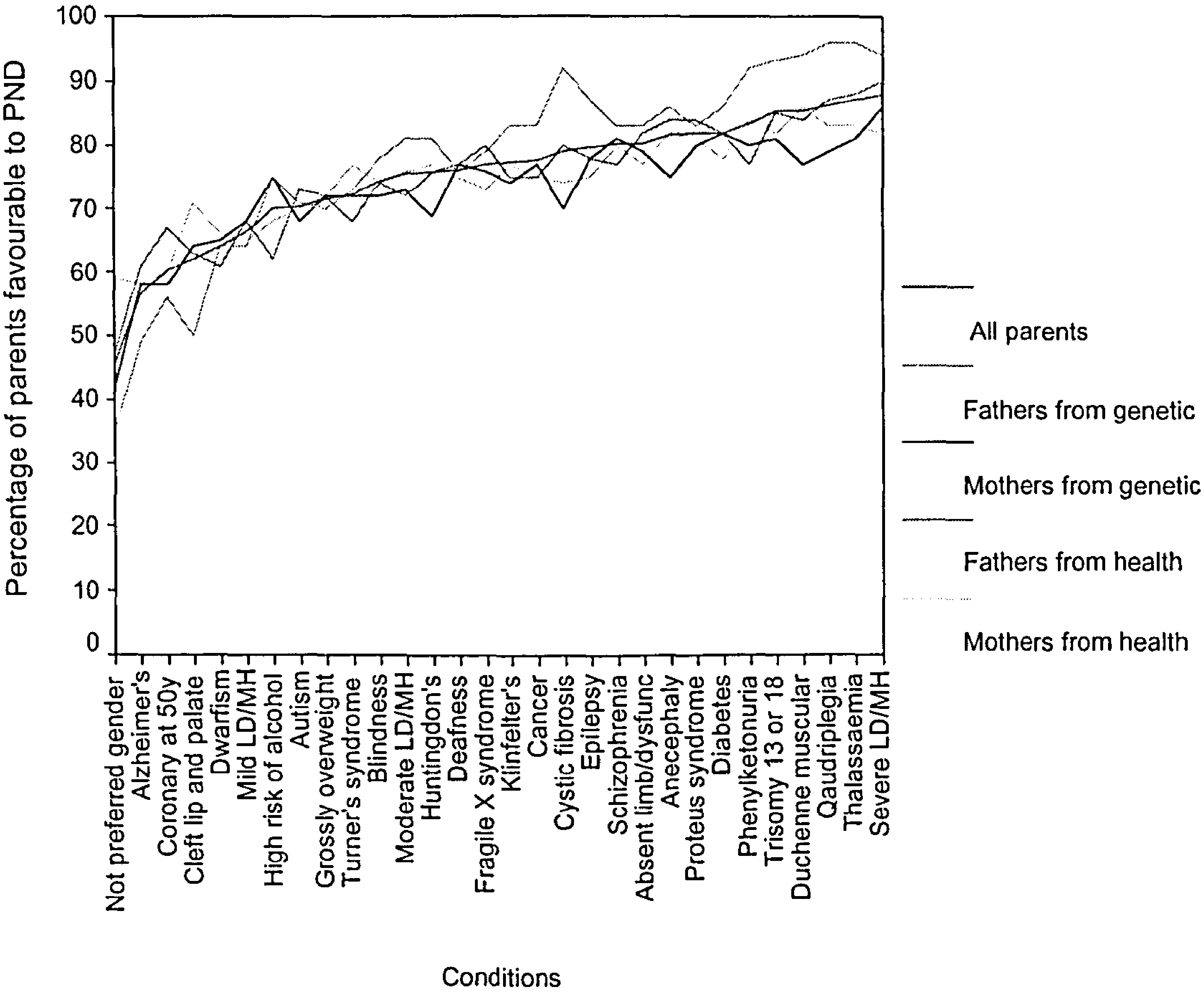


Figure 19: Parents' attitudes towards parental diagnosis

6.9.5 Fathers' attitudes towards TOP in each condition

Table (37) below shows the number of yes responses in each group of fathers, with and without an affected child, for each condition, with the results of the statistical comparisons. Conditions are listed in this table in rank order from most to least favoured see (section 6.3.2.6)

Condition	Fathers with an affected child N= 100	Fathers without an affected child N= 100	Fisher exact test 2. Sided
Anencephaly	**60**	**64**	**.66**
Trisomy 13 or 18	**56**	**49**	**.396**
Severe LD/MH	**63**	**55**	**.31**
Quadriplegia	**53**	**38**	**.047**
Duchenne muscular dystr	**50**	**31**	**.009**
Thalassaemia	**43**	**36**	**.39**
Diabetes	**35**	**20**	**.026**
Proteus syndrome	**28**	**24**	**.63**
Schizophrenia	**39**	**19**	**.003**
Phenylketonuria	**28**	**16**	**.06**
High risk of Alcoholism	**34**	**15**	**.003**
Klinefelter's syndrome	**36**	**14**	**.001**

Epilepsy	**29**	**13**	**.009**
Absent limb	**29**	**18**	**.095**
Cystic fibrosis	**31**	**17**	**.03**
Turner's syndrome	**20**	**13**	**.25**
Huntingdon's disease	**27**	**11**	**.006**
Fragile X syndrome	**19**	**15**	**.57**
Cancer	**20**	**10**	**.073**
Autism	**19**	**12**	**.24**
Blindness	**17**	**11**	**.31**
Moderate LD/MH	**14**	**6**	**.097**
Grossly overweight	**16**	**10**	**.29**
Dwarfism	**8**	**8**	**1**
Deafness	**12**	**4**	**.065**
Alzheimer's disease	**5**	**6**	**1**
Mild LD/MH	**4**	**5**	**1**
Coronary at 50y	**3**	**5**	**.72**

Cleft lip and palate	**1**	**5**	**.21**
Not preferred gender	**0**	**0**	

Table 37: Fathers' attitudes towards TOP in each condition

Table (37) above shows that in nine conditions, fathers with an affected child were significantly more likely than fathers without an affected child to accept termination of the pregnancy, (although none of the fathers were willing to terminate for non-preferred gender). There were no significant differences in the other direction. The analysis of total scores reported in section 6.3.3.6 showed that these was a significant difference between these groups of fathers, in the same direction as seen for the individual conditions.

6.9.6 Mothers' attitudes towards TOP in each condition

Table (38) below shows the number of yes responses in each group of mothers with and without an affected child, for each condition, with the results of the statistical comparisons.

Condition	Mothers with affected child N= 100	Mothers without affected child N= 100	Fisher's exact test 2. Sided
Anencephaly	**51**	**56**	**.57**
Trisomy 13 or 18	**51**	**56**	**.57**
Severe LD/MH	**52**	**38**	**.064**
Quadriplegia	**50**	**38**	**.12**
Duchenne muscular dystr	**51**	**41**	**.2**

Thalassaemia	**41**	**40**	**1**
Diabetes	**48**	**33**	**.04**
Proteus syndrome	**44**	**39**	**.57**
Schizophrenia	**33**	**33**	**1**
Phenylketonuria	**35**	**33**	**.88**
High risk of Alcoholism	**35**	**26**	**.22**
Klinefelter's syndrome	**28**	**31**	**.76**
Epilepsy	**32**	**32**	**1**
Absent limb	**30**	**25**	**.53**
Cystic fibrosis	**32**	**19**	**.05**
Turner's syndrome	**31**	**25**	**.43**
Huntingdon's disease	**27**	**23**	**.62**
Fragile X syndrome	**30**	**20**	**.14**
Cancer	**28**	**24**	**.63**
Autism	**22**	**12**	**.089**
Blindness	**22**	**13**	**.14**

Moderate LD/MH	**23**	**18**	**.48**
Grossly overweight	**18**	**12**	**.32**
Dwarfism	**18**	**17**	**1**
Deafness	**19**	**14**	**.45**
Alzheimer's disease	**16**	**12**	**.54**
Mild LD/MH	**16**	**8**	**.13**
Coronary at 50y	**10**	**9**	**1**
Cleft lip and palate	**11**	**5**	**.2**
Not preferred gender	**0**	**0**	

Table 38: Mothers' attitudes towards TOP in each condition

The results in table (38) above show that in two conditions, mothers with an affected child were significantly more likely than mothers without an affected child to accept termination of the pregnancy (although none of the mothers, with or without an affected child, were willing to terminate for reasons of gender preference). The analysis of total scores reported in section 6.6.2 showed no significant difference between these groups of mothers. It may be that differences do exist for particular conditions, but this would need confirmation in other studies.

6.9.7 Attitudes of Fathers and Mothers with an affected child towards TOP in each condition

Table (39) below shows the number of yes responses in each group of fathers and mothers with an affected child, for each conditions with the results of the statistical comparisons.

Condition	Fathers with affected child N= 100	Mothers with affected child N= 100	Fisher exact test 2. Sided
Anencephaly	60	51	.25
Trisomy 13 or 18	56	51	.57
Severe LD/MH	63	52	.15
Quadriplegia	53	50	.78
Duchenne muscular dystr	50	51	1
Thalassaemia	43	41	.89
Diabetes	35	48	.085
Proteus syndrome	28	44	.027
Schizophrenia	39	33	.46
Phenylketonuria	28	35	.36
High risk of Alcoholism	34	35	1
Klinefelter's syndrome	36	28	.29

Epilepsy	**29**	**32**	**.76**
Absent limb	**29**	**30**	**1**
Cystic fibrosis	**31**	**32**	**1**
Turner's syndrome	**20**	**31**	**.1**
Huntingdon's disease	**27**	**27**	**1**
Fragile X syndrome	**19**	**30**	**.1**
Cancer	**20**	**28**	**.25**
Autism	**19**	**22**	**.73**
Blindness	**17**	**22**	**.48**
Moderate LD/MH	**14**	**23**	**.14**
Grossly overweight	**16**	**18**	**.85**
Dwarfism	**8**	**18**	**.057**
Deafness	**12**	**19**	**.24**
Alzheimer's disease	**5**	**16**	**.019**
Mild LD/MH	**4**	**16**	**.008**
Coronary at 50y	**3**	**10**	**.082**

Cleft lip and palate	**1**	**11**	**.005**
Not Preferred gender	**0**	**0**	

Table 39: Attitudes of Fathers and Mothers with an affected child towards TOP in each condition

The results in table (39) above show that in four conditions, mothers with an affected child were significantly more likely than fathers with an affected child to favour termination of the pregnancy. There were no significant differences in the opposite direction. The analysis of total scores reported in section 6.6.3 showed no significant difference between fathers and mothers with an affected child. It may be that differences do exist for particular conditions, but this would need confirmation in other studies.

6.9.8 Attitudes of Fathers and Mothers without an affected child towards TOP in each condition

Table (40) below shows the number of yes responses in each group of fathers and mothers without an affected child, for each condition, with the results of the statistical comparisons.

Condition	Fathers without affected child N= 100	Mothers without affected child N= 100	Fisher exact test 2. Sided
Anencephaly	**64**	**56**	**.13**
Trisomy 13 or 18	**49**	**56**	**.39**
Severe LD/MH	**55**	**38**	**.023**
Quadriplegia	**38**	**38**	**1**
Duchenne muscular dystr	**31**	**41**	**.18**

Thalassaemia	36	40	.66
Diabetes	20	33	.054
Proteus syndrome	24	39	.033
Schizophrenia	19	33	.036
Phenylketonuria	16	33	.008
High risk of Alcoholism	15	26	.079
Klinefelter's syndrome	14	31	.006
Epilepsy	13	32	.002
Absent limb	18	25	.3
Cystic fibrosis	17	19	.85
Turner's syndrome	13	25	.046
Huntingdon's disease	11	23	.037
Fragile X syndrome	15	20	.46
Cancer	10	24	.014
Autism	12	12	1
Blindness	11	13	.83

Moderate LD/MH	**6**	**18**	**.015**
Grossly overweight	**10**	**12**	**.82**
Dwarfism	**8**	**17**	**.086**
Deafness	**4**	**14**	**.024**
Alzheimer's disease	**6**	**12**	**.22**
Mild LD/MH	**5**	**8**	**.57**
Coronary at 50y	**5**	**9**	**.14**
Cleft lip and palate	**5**	**5**	**1**
Not Preferred gender	**0**	**0**	

Table 40: Attitudes of Fathers and Mothers without an affected child towards TOP in each condition

The results above in table (40) show that for ten conditions, mothers without an affected child were significantly more likely than fathers without an affected child to favour termination of the pregnancy and there was one condition in which the opposite was true. The analysis of total scores reported in section 6.6.4 showed that this was a significant difference between fathers and mothers without an affected child, in the same direction as seen for the majority of the individual conditions.

* * * * * * * * * * * * * * * *

The analyses reported in sections 6.9.5 to 6.9.8 above present the detailed findings of the comparisons between study groups in attitudes to termination of the pregnancy for each of the thirty conditions on the questionnaire. These data on termination of the pregnancy are presented in summary in Figure (20) below. In the figure, conditions are ranked according to the results presented in section 6.3.2.6.

In concluding this section, which contributed to addressing study aims 2, 3, and 4, it may be noted that a clear pattern emerged from comparisons of parents with and without an affected child. Parents with an affected child had more favourable attitudes to prenatal diagnosis and termination of pregnancy than parents without an affected child. However, no simple pattern emerged from comparisons of fathers and mothers, where differences depended on the measure used and the specific comparison made.

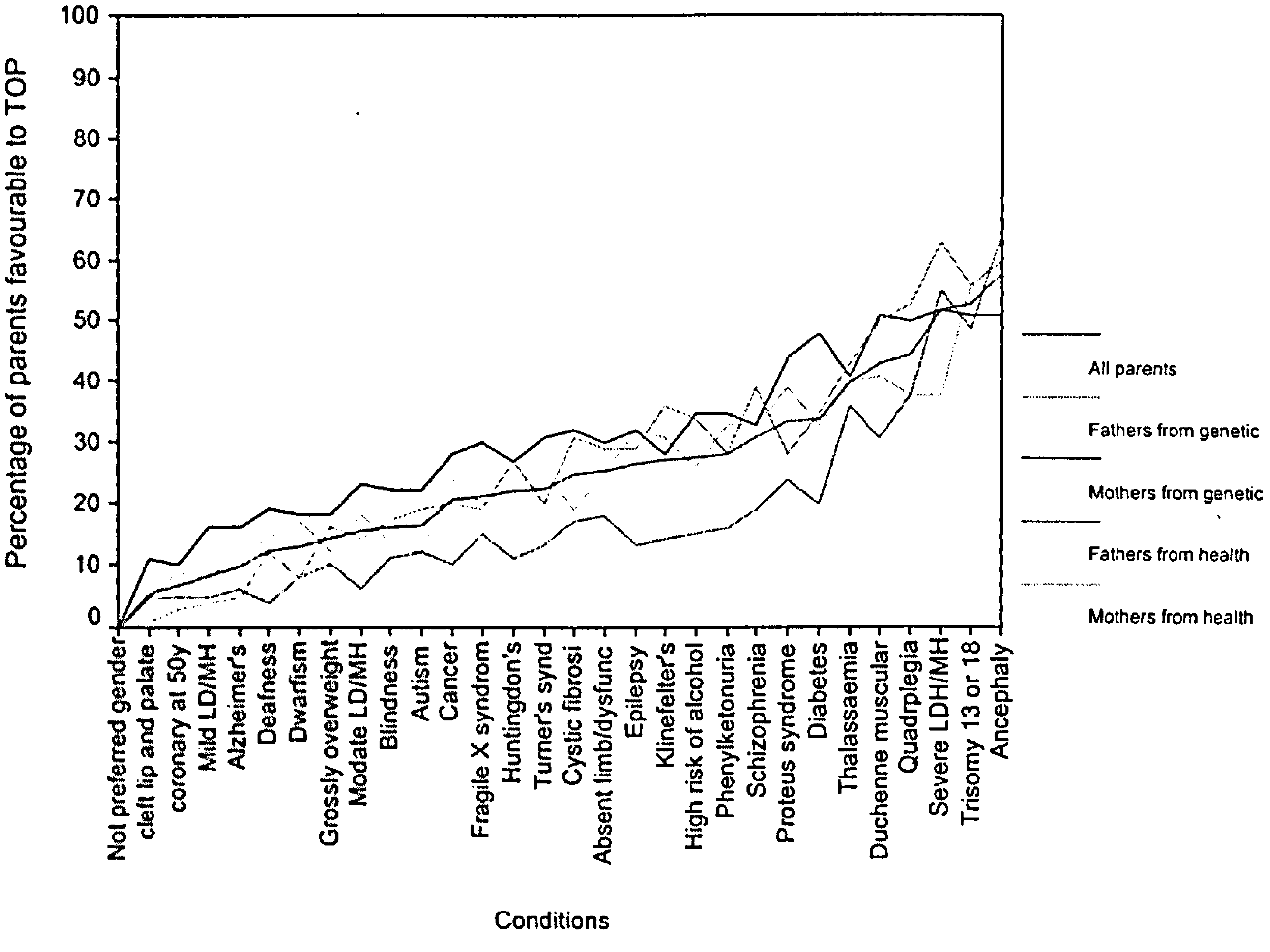


Figure 20: Parents' attitudes toward TOP

Part 6

6.10 ATTITUDES TOWARDS PND AND TOP FOR SPECIFIC CONDITIONS

The previous sections of the results showed similarities and differences between parents with and without an affected child in their attitudes towards prenatal diagnosis and termination of pregnancy across a range of conditions presented in the questionnaire. It was not clear from the previous sections, however, whether the same parents were favourable towards prenatal diagnosis and termination of pregnancy for different conditions. It would not have been feasible to examine how each condition related to every other condition, so instead, an illustrative example was chosen and investigated. The tables and analysis in this section examine the association between parents' attitudes toward prenatal diagnosis and termination of the pregnancy for thalassaemia and their attitudes towards the other conditions presented in the questionnaire. Thalassaemia was selected among the thirty conditions, because thalassaemia is one of the commonest diseases in Saudi Arabia, and also, it was one of the conditions for which parents in this study held the most favourable attitudes towards prenatal diagnosis and termination of the pregnancy.

			Severe LD		
			No	Yes	Total
Thal	No	Count	29	23	52
		% of Total	7.3%	5.8%	13.0%
	Yes	Count	19	329	348
		% of Total	4.8%	82.3%	87.0%
Total		Count	48	352	400
		% of Total	12.0%	88.0%	100.0%

Table 41: Attitudes to PND for thalassaemia and severe learning disability (% are of total sample)

Table (41) above is presented as an example to illustrate the cross tabulation between thalassaemia and another condition, namely, severe learning disability. It shows a strong association between the two conditions, but a large number of individual exceptions to each rule. A Fisher's exact test confirmed there was a significant association between attitudes to the two conditions ($P<0.01$). In each condition, nearly 90% of parents held favourable attitudes to prenatal diagnosis, but the minority who rejected prenatal diagnosis consisted of slightly different people on the two occasions. The results of the rest of the cross tabulations with thalassaemia are presented in a more condensed format in the tables below. In all cases, Fisher's exact test showed that attitudes to the two conditions in question were significantly associated (at P<0.01).

6.10.1 Parents' attitudes towards PND in thalassaemia and other conditions

Table (42) below shows the percentage of responses in each combination of attitudes. Conditions are listed in this table in rank order from most to least favoured (see section 6.3.2.5).

Condition	No to thalassaemia and other condition %	No to thalassaemia but Yes to other condition %	Yes to thalassaemia and other condition %	Yes to thalassaemia but No to other condition %
Severe LD/MH	7.3	5.8	82.3	4.8
Quadriplegia	8.5	4.5	81.8	5.3
Duchenne muscular dyst	10.8	2.3	83	4
Trisomy 13 or 18	9.3	3.8	81.5	5.5
Phenylketonuria	9.5	3.5	79.8	7.3
Diabetes	10.5	2.5	79.5	7.5
Proteus syndrome	10	3	79	8
Anencephaly	10.3	2.8	79	8
Absent Limb	10.5	2.5	77.8	9.3
Schizophrenia	10	3	77.3	9.8
Epilepsy	11	2	77.5	9.5
Cystic fibrosis	10.8	2.3	76.8	10.3
Cancer	10.8	2.3	75.3	11.8

Klinefelter's syndrome	10.8	2.3	75	12
Fragile X	10.3	2.8	74.3	12.8
Deafness	10.8	2.3	74	13
Huntingdon's disease	10.3	2.8	73	14
Moderate LD/MH	10	3	72.5	14.5
Blindness	10.8	2.3	72.3	14.8
Turner's syndrome	10.8	2.3	70.3	16.8
Grossly overweight	11.3	1.8	69.8	17.3
Autism	10.3	2.8	67.8	19.3
High risk of alcoholism	9.8	3.3	66.8	20.3
Mild LD/MH	11.3	1.8	64.5	22.5
Dwarfism	11.8	1.3	62.8	24.3
Cleft lip and palate	11.3	1.8	60.3	26.8
Coronary at 50y	11.5	1.5	58.8	28.3
Alzheimer's disease	12	1	55.5	31.5
Not preferred gender	11	2	43.8	43.3

Table 42: Parents' attitudes towards PND in thalassaemia and other conditions

6.10.2 Parents' attitudes towards TOP in thalassaemia and other conditions

Table (43) below shows the percentage of responses in each combination of attitudes. Conditions are listed in this table in rank order from most to least favoured (see section 6.3.2.6).

Condition	No to thalassaemia and other condition %	No to thalassaemia but Yes to other conditions %	Yes to thalassaemia and other condition %	Yes to thalassaemia but No to other condition %
Anencephaly	**36.8**	**23.3**	**34.5**	**5.5**
Trisomy 13 or 18	**41**	**19**	**34**	**6**
Severe LD/MH	**39.8**	**20.3**	**31.8**	**8.3**
Quadriplegia	**43**	**17**	**27.8**	**12.3**
Duchenne muscular dystr	**48.3**	**11.8**	**31.5**	**8.5**
Diabetes	**50.3**	**9.8**	**24.3**	**15.8**
Proteus syndrome	**50.8**	**9.3**	**24.5**	**15.5**
Schizophrenia	**52.8**	**7.3**	**23.8**	**16.3**
Phenylketonuria	**54**	**6**	**22**	**18**
High risk of Alcoholism	**49.5**	**10.5**	**17**	**23**
Klinefelter's syndrome	**54.8**	**5.3**	**22**	**18**
Epilepsy	**54**	**6**	**20.5**	**19.5**
Absent limb	**54.8**	**5.3**	**20.3**	**19.8**
Cystic fibrosis	**55.5**	**4.5**	**19.8**	**20.3**
Turner's syndrome	**54.8**	**5.3**	**17**	**23**
Huntingdon's disease	**55.3**	**4.8**	**17.3**	**22.8**

Fragile X syndrome	55.5	4.5	16.5	23.5
Cancer	55	5	15.5	24.5
Autism	57.3	2.8	13.5	26.5
Blindness	57.5	2.5	13.3	26.8
Moderate LD/MH	57.5	2.5	12.8	27.3
Grossly overweight	57.5	2.5	11.5	28.5
Dwarfism	57	2.8	10	30
Deafness	57.5	2.5	9.8	30
Alzheimer's disease	57.3	2.8	7	33
Mild LD/MH	58.5	1.5	6.8	33.3
Coronary at 50y	59	1	5.8	34.3
Cleft lip and palate	58.8	1.3	4.3	35.8
Not preferred gender	60	0	0	40

Table 43: Parents' attitudes towards TOP in thalassaemia and other conditions

Tables (42 and 43) above show that parents' attitudes towards prenatal diagnosis and termination of the pregnancy for thalassaemia are significantly associated with their attitudes in relation to all of the other conditions (Fisher's exact P<0.01 in all cases). However, for all conditions except non-preferred gender, parents were identified who held all combinations of attitudes, namely favourable for both conditions, for neither condition, for thalassaemia but not the other condition, and vice versa. So, for example, even though cleft lip and palate had a very low ranking overall, and thalassaemia a much higher ranking, there were still some parents who rejected termination for thalassaemia but accepted it for cleft lip and palate. In the next chapter, results from the qualitative study are presented, which help to explain both similarities and differences in the attitudes people held to the 30 conditions investigated.

CHAPTER 7: QUALITATIVE INTERVIEW

7.1 INTRODUCTION

The results presented in the previous chapter showed that the Saudi parents surveyed had generally very favourable attitudes toward prenatal diagnosis and varying attitudes towards termination of the pregnancy across the range of conditions presented in the questionnaire. In the light of those findings, in-depth interviews were requested in order to find out why parents held different views. According to the literature review and the researcher's previous experience as a Saudi counsellor (see section 5.4.2 in the methodology chapter), there were many factors which it was thought might influence parents' attitudes toward prenatal diagnosis and termination of pregnancy. This chapter presents the responses of forty parents (twenty parents with an affected child and twenty parents without an affected child) to interviews (see section 5.8 in the methodology chapter) about the factors that influenced their attitudes toward prenatal diagnosis and termination of the pregnancy. The interviews were carried out to provide answers to the following questions:

1. Why do you think these conditions should be tested or terminated, and not others?

2. Some parents feel that having a disabled child in the family might change their life. What do you think?

3. Some parents feel that a disabled child might isolate the family from others. How do you see that?

4. According to the Fatwa, Islamic law allows termination only in severe cases and within the first three months of the pregnancy. What is your opinion?

All of the 40 parents were asked, individually, to express their views after they had completed their questionnaire. This approach has the strength of capturing the uniqueness and individuality of each participant, and the circumstances in depth.

The researcher and his nurse assistant asked the parents the questions above in order, to allow the parents to give their comments in order. However, some parents had no comments in regard to the question, and for some parents their comments might not match the question that was given, and might match another question. Therefore, before analysis the researcher reordered parents' comments according to the question (See methodology chapter, section 5.9.2).

The findings are presented in two sections, for parents with and without an affected child respectively and in the following chapters (Chapter 8 and 9) we will compare and discuss these findings.

7.2 VIEWS OF PARENTS WITHOUT AN AFFECTED CHILD TOWARDS PND AND TOP

7.2.1 The Nature of the Condition

The first question was: Why do you think these conditions should be tested or terminated and not others?

7.2.1.1 Fathers' comments

It was found that three fathers were against termination of the pregnancy in any condition, one father wanted to terminate severe learning disability and severe physical disability only, and six fathers wanted to terminate severe learning disability and severe physical disability, plus other specific conditions according to their individual experience. In addition, none of the fathers from the interview made any comments about prenatal diagnosis.

Adel (34 year Saudi male, low education with two children)

Nobody should terminate any kind of genetic abnormality, as you can see some of the genetic conditions such as blindness, deafness, shortness, and late affected are normal and you can see them everywhere and some of them are in high positions in the government. My uncle is blind and we give him all due respect....

Naji (30 year Saudi male, low education with four children)

...I know a poor family that became rich after having a disabled child...

Some parents believed a disabled person could make the family rich, which indicates that different beliefs might influence parents' attitudes toward prenatal diagnosis and termination of pregnancy.

Samir (22 year Saudi male, low education with one child)

...My mother told me that having a disabled child in the house prevents the evil eye and protects all other family members from envy...

Obaid (44 year old Saudi male, low education with eight children)

... I am really keen about my children's needs and their future so I have to sacrifice for them, but I can't imagine one of my children being disabled. My situation will be very difficult, I can't solve the problem and I will be biased towards his brothers and sisters. Any kind of abnormality means his life will be different. I can't help him or her and they can't help themselves ...

This father was worried about his family's expenses and thought life was already very difficult, with many demands such as education, medical treatment, and entertainment. A disabled child needs more care and effort and could create discrimination between siblings, in the father's view.

Jaber (36 year old Saudi male, low education with two children)

...Nobody should terminate other conditions except if the test confirms that the foetus is missing one of its body parts...

Mamdoh (34 year old Saudi male, highly educated with two children)

... Regarding the late onset dying in adulthood or having problems, I have not seen that yet. But if I was sure, then I would terminate the pregnancy because I do not want to inform him or wait for his sickness and death, and I would blame myself if that happened. I would be cheating his or her partner if I hid the secret from them and this is not allowed in Islamic Law...

Ali (40 year old Saudi male, highly educated with five children)

...I see my 70 year old uncle giving his sons and daughters a very difficult time in looking after him as a result of difficult behavior that looks like Alzheimer's disease. I feel they can't get away from him. Such kind of abnormality causes lots of problems for the family. I would terminate the pregnancy if it is confirmed...

In the father's experience, his uncle's family could not enjoy their life like other families, because their father restricted their movement and made their life more difficult. This influenced the father's attitudes toward termination of the pregnancy in case of such a condition. This indicates the importance of the experience that parents without an affected child are exposed to.

Zakki (37 year old Saudi male, low education with three children)

... My nephew died six months after birth as a result of a breathing difficulty. My sister still remembers him. If I knew that my wife would have a case in which the baby would die early then I would terminate the pregnancy..

Parents without an affected child such as Zakki did not have a disabled child of their own, but their views were influenced by seeing how close relatives are having a difficult time and psychological problems after losing their child because of a genetic condition. Hence, the father decided not to have a disabled child and agreed to terminate this kind of condition.

Sayyed (38 year old Saudi male, low education with three children)

...Cancer: cancer chemotherapy is only a temporary treatment. Losing hair, weight, appetite, and family disruption . I would terminate the pregnancy if I knew the baby would be affected with cancer...

Sultan (45 year old Saudi male, highly educated with six children)

...I am always keen on maintaining my weight in order to avoid heart problems resulting from cholesterol and diabetes. Obesity is one of the main problems of most diseases. I would terminate the pregnancy for a fat baby. As the saying goes, I would close the door that brings me wind...

7.2.1.2 Mothers' comments

It was found that three mothers were against termination of the pregnancy in any condition, four mothers favoured terminating conditions where the child would have severe learning disability and severe physically disability and four mothers would agree to terminate conditions where the child would have severe learning disability and severe physically disability and other conditions according to their experience.

Salwa (36 year old Saudi female, low education with four healthy children)

None of the conditions should be terminated

Fadwa (30 year old Saudi female, highly educated with two children)

None of the conditions should be terminated

Lamia (28 year old Saudi female, highly educated with two children)

... I would do the prenatal diagnosis so that I could be prepared psychologically and educate myself about the disease that the child might have, but I would never abort any kind of genetic condition unless it would affect my life...

Having a prenatal test, does not mean that the parents plan to terminate the pregnancy. Some parents still wanted to assure themselves about the condition of the foetus without terminating any kind of abnormality. The test results would help the parents prepare themselves with all the necessary requirements before the baby is due as Lamia mentioned. This finding supports the quantitative finding that many parents without affected children were more favourable towards prenatal diagnosis than termination of the pregnancy.

Ahad (24 Saudi female, low education with one child)

...If the child will be severely disabled or mentally handicapped, these kinds of conditions should be terminated...

Israa (30 year old Saudi female, low education with six healthy children)

...Children who cannot help themselves, like those with severe learning difficulty and physically disabled should be terminated...

Nora (31 year old Saudi female, highly educated with four children)

...There is no point in having a child who cannot enjoy his life...

Arrowa (32 Saudi female, high educated with tow children)

Conditions that make mother and child suffer lifelong should be terminated...

Reem (33 year old Saudi female, highly educated with one child)

...My mother died as a result of cancer after chemotherapy treatment, I don't want to have a child with cancer because I know he will die...

Majedah (43 year old Saudi female, low education with three children)

...Ladies usually spend most of their time in front of the mirror for makeup purposes. I feel that if a lady is short, fat, deaf, blind, or missing a part of her body she will suffer a lot, so termination of such an abnormality would be better.

This comment from this mother may help to explain why women tended to be more favourably disposed than men in the quantitative analysis towards termination of the pregnancy in case of the cosmetic conditions presented in the questionnaire.

May (31 year old Saudi female, low education with seven children)

...Those who will suffer late in life will be a heavy burden to their family and cause many problems; such conditions should be terminated...

Saudi families expect their children to stay around and not leave them alone, which makes the parents worried about their children's future. Therefore, tradition might influence parents' attitudes toward prenatal diagnosis and termination of the pregnancy.

7.2.2 Effects on Family Life

The second question was: Some parents feel that disabled child might change their life. What do you think?

Parents without an affected child felt unable to answer this question. Since they did not have an affected child to change their life, they lacked experience of the impact a disabled child could have.

7.2.3 Shame

The third question was: Some parents feel that a disabled child might isolate the family from others. How do you see that?

7.2.3.1 Fathers' comments

Only two fathers felt able to narrate different examples according to their experience. One father had a negative example of behaviour of a family with an affected child and one father had a positive example of behaviour of a family with an affected child.

Obaid (44 year old Saudi male, low education with eight children)

...My brother in law does not bring his two affected children to my house, and he allows them to shout at my children when they visit his house...

Mamdoh (34 year old Saudi male, highly educated with two children)

...I have a cousin with Down's syndrome, his family encourages him to play with us and we are happy playing a football with him...

7.2.3.2 Mothers' comments

Only six mothers without an affected child felt able to narrate different stories according to their experience. Four mothers had negative examples of behaviour of a family with an affected child and two mothers had a positive behaviour of a family with an affected child.

Salwa (36 year old Saudi female, low education with four children)

...I know a family with a disabled child, the family does not allow him to go outside and they also didn't enrol him in a school for the disabled.

Zeenab (33 Saudi female, highly educated with three children)

One of my relatives has a child with Down's syndrome. His mother never has him with her. At family parties, when we ask her" why didn't you bring him with you she says," He does not want to come".

Israa (30 year old Saudi female, low education with six children)

...One of my relatives has a child with Cleft Lip and Palate; the mother isolates herself from society because of how people look at her child...

The mother said that even the smallest things could induce parents not to leave the house, and to hide their disabled children from others.

Arrowa (32 Saudi female, high educated with tow children)

...When I have visited my friend, she tells her adult daughter with mild disability to go inside her room and not sit with us. I believe the daughter is very nice but I do not know why her mother wants to isolate her from others...

Ahad (24 Saudi female, low education with one child)

My aunty has a daughter with Down's syndrome. Everybody in the family likes her especially when she dances. Sometimes she does something strange, but we still love her.

The mother narrated her aunt's daughter's story, which indicates that family support plays an important role in helping parents with an affected child to live their life in the society.

Fadwa (30 year old Saudi female, highly educated with two children)

...My nephew is physically challenged; society treats him with pity, his peers with cruelty, and his family with love...

This mother wanted to indicate that everybody should treat a disabled child with full respect and not look at him from a different angle. This indicates again how important it is for society to treat parents with a disabled child with full respect and not create any kind of barriers which would isolate parents with an affected child from the society and increase their burden.

7.2.4 Religious Perspective

The fourth question was: According to the Fatwa, Islam allows termination only in severe case and within the first three months of the pregnancy. What is your opinion?

The researcher and his nurse assistant had read the Fatwa to all parents before the parents answered the questionnaire. All the parents were Muslims but some parents had heard about the Fatwa and agreed with it, and some parents had other opinions.

7.2.4.1 Fathers' comments

It was found that three fathers still thought that Islamic law was against termination of the pregnancy in any condition, five fathers agreed with the Fatwa, and two fathers misunderstood the Fatwa.

Adel (34 year Saudi male, low education with two children)

Nobody should terminate any kind of disability, because Islam does not allow that.

From the interviews we found that some parents recited the Fatwa but still did not agree with it. They had asked various religious individuals about the abortion issue and they were given different Fatwa, which they followed according to their own feelings.

Samir (22 year Saudi male, low education with one child)

...I believe that Islamic law allows terminating the pregnancy before the foetus moves inside the uterus. In addition, scholars have different Fatwa regarding termination of pregnancy, I personally agree with scholars who suggest that termination is against Islam law...

Naji (30 year Saudi male, low education with four children)

...I have no clear picture whether Islamic law allows termination or not in these kinds of genetic conditions. Most of them, I have never heard about, but as far as I know, Islam is against termination of pregnancy...

Zakki (37 year old Saudi male, low education with three children)

... I would terminate any kind of abnormality under the Fatwa conditions...

Ali (40 year old Saudi male, highly educated with five children)

...I would do termination of the pregnancy if it is not against Islam law...

Obaid (44 year old Saudi male, low education with eight children)

...Islamic law has a very clear Fatwa toward termination of pregnancy and, myself, I would follow the Fatwa...

Mamdoh (34 year old Saudi male, highly educated with two children)

...Islam is not against termination of pregnancy under certain conditions, as mentioned in the Fatwa...

Parents without an affected child lacked experience with any other condition and therefore, tended to agree with the religious authority's Fatwa, that only severe genetic conditions should be terminated.

Jaber (36 year old Saudi male, low education with two children)

...Before we do any kind of termination of the pregnancy we should ask the religious authority...

Despite the fact that the researcher had read the Fatwa to him, the father still did not trust the authority's view on testing during pregnancy and termination, and wanted to ask other people whom he trusted.

Sultan (45 year old Saudi male, highly educated with six children

...I think we should terminate any kind of genetic condition which might affect our life, and that is not against the Fatwa...

Despite the fact that the father was Moslem and had heard about the Fatwa, he was still concerned about his quality of life and understood how an affected child might change his life satisfaction.

Sayyed (38 year old Saudi male, low education with three children)

I believe that abortion is permitted as long as the diagnosis is done within the first 3 months of pregnancy.

According to the Fatwa, not all genetic conditions can be terminated in the first three months, as this father believes. This indicates that some parents might understand part of the Fatwa, but when they have an affected child in the future they might face some conflict due to incomplete understanding of the Fatwa.

7.2.4.2 Mothers' comments

It was found that three mothers still thought that Islam law was against termination of the pregnancy in any condition, three mothers agreed with the Fatwa, and four mothers misunderstood the Fatwa.

Salwa (36 year old Saudi female, low education with four healthy children)

...I am convinced that Islam is against abortion, even if the Fatwa states differently...

This mother would not abort any kind of disability, even if the religious authority permitted abortion of severe genetic conditions, which indicates that some parents opposed termination, even it is allowed by Islamic law.

Lamia (28 year old Saudi female, highly educated with two children)

... I would never abort any kind of genetic condition because it is against Islamic law, unless it would affect my life, because Islam allows that...

The religious authority allows prenatal diagnosis in all genetic conditions and termination of the pregnancy not only if the child will affect his mother's life but also under certain other conditions. However, this mother would follow half of the Fatwa and disagree with the other half, according to her belief.

Fadwa (30 year old Saudi female, highly educated with two children)

...I believe that Islam law does not allow terminate any kind of abnormality, except if the mother's life will be affected....

The mother has recited the old Fatwa, made before development in the technology and the possibility of discovering genetic abnormality before the child is born. Religious scholars reached a consensus about the new Fatwa on termination, after a new Fatwa was requested regarding genetic abnormality in society.

Ahad (24 Saudi female, low education with one child)

I believe that abortion is permitted based on the disability of the child and as long as the diagnosis is done within the first 3 months of pregnancy.

Israa (30 year old Saudi female, low education with six healthy children)

The Islamic authority allows termination of the pregnancy before 12 weeks of the pregnancy if it is severe.

Nora (31 year old Saudi female, highly educated with four children)

...I believe that abortion is permitted as long as the diagnosis is done within the first 3 months of pregnancy...

May (31 year old Saudi female, low education with seven children)

...I am really convinced that Islamic law allows termination of any disability, before three months of gestation...

Majedah (43 year old Saudi female, low education with three children)

...Islamic law is not against termination, before three months of the pregnancy, that's what I know.

Ahad, Israa, Nora, May, and Majedah recited the Fatwa, agreed with it, and did not mind terminating any sort of disability if diagnosed within the first three months of pregnancy. But they did not remember the other half of the Fatwa, that termination is allowed only in severe conditions which cannot be treated.

Arrowa (32 Saudi female, high educated with two children)

Islamic authorities have different opinions on termination of the pregnancy, which makes it easy sometimes to choose what you like.

The mother believed it was good to have different Fatwa toward the termination of the pregnancy, as it enabled parents to decide to follow the Fatwa that accorded with their own inclinations..

Reem (33 year old Saudi female, highly educated with one child)

I have heard many Fatwa about termination in the media. Myself I do not know which one is right.

According to the findings, not only this mother was confused about the Fatwa. Many people had heard different Fatwa about termination, even through the media.

7.3 VIEWS OF PARENTS WITH AN AFFECTED CHILD TOWARDS PND AND TOP

7.3.1 The Nature of the Condition

The first question posed to the parents after the questionnaire had been completed was: Why do you think these conditions should be tested or terminated and not others?

7.3.1.1 Fathers' comments

It was found that fathers had varied comments toward termination of the pregnancy. Two fathers were against termination of the pregnancy in any condition, two fathers were not inclined towards termination in their condition, but agreed to terminate other conditions they thought were severe or were against Islamic law, and six fathers agreed to terminate their condition and similar conditions that they thought severe.

Musaad (34 year old Saudi male, highly educated with three children, one with a severe metabolic disease and one who died of the same condition)

...Any child that needs special care will be considered a burden on himself and his parents, regardless of the kind of the abnormality, but nobody should terminate any kind genetic abnormality...

The father's comments indicate that the level of care demanded of the parents determines the perceived severity of the condition; it is seen as severe if it increases parents' responsibility. Hence, any kind of genetic condition that requires extra care from the parents is considered a severe condition, according to the father's experience, and conditions that do not require care such as Klinefelter's, Turners', ...etc. are not severe. Therefore, some parents have different attitudes toward prenatal diagnosis and termination of the pregnancy according to the level of care that the affected child needs from the parents. However, this father was against termination in any kind of genetic abnormality.

Mazen (34 year old Saudi male, highly educated with three healthy children and two deaf children)

In my view boys and girls are equal; but I think most of the Saudi society is concerned about the gender. Therefore, gender is important to the parents in relation to termination of the pregnancy in these conditions.

Mazen was a student counsellor and knew much about what Saudi parents prefer according to his experience in the school from the stories of different parents. Therefore, in his perception, conditions that have a gender effect play an important role in influencing parents' attitudes toward prenatal diagnosis and termination of the pregnancy. However, Mazen was opposed to termination in any kind of genetic condition.

Majed (35 year old Saudi male, highly educated with two normal children and one deaf child)

We should not terminate any kind of abnormality because it's all from God and we can't do anything against God's creatures, but for the alcoholic condition we should terminate the pregnancy because it is against Islamic Law....

This father of three children, one of whom was deaf, was happy with what God gave him. He appeared to be a very conservative Muslim who believed that since alcohol is banned in Islamic Law then pregnancy in case of a genetic predisposition to alcoholism should be terminated. Furthermore, he wanted others to follow his example according to his belief. The father's comment shows that the perceived severity of the condition depends on the parents' belief rather than the impairment itself.

Mohib (29 year old Saudi male, highly educated with five healthy children and two deaf children)

With disabilities such as mentally handicapped and physically handicapped, I feel that a child with this disability will suffer a lot even if he doesn't speak or complain, and his parents will be hopeless about his future. In other kinds of disabilities such as feature disorder or losing a part of the body, this will be more complicated for the disabled himself and girls will be worse than boys in these disabilities...

The interview illustrates the view of some fathers that disabled girls will be more difficult to handle than disabled boys, especially as regards future marriage, because in Saudi culture, the man finds out about his bride by researching her family. Therefore, culture plays an important role in parents' attitudes.

Faraj (30 year old Saudi male, low education with one healthy child and three thalassaemic children)

A *child with a blood transfusion in the society, is considered a problem to himself and to society. It is better for him not to come to this life. If he will not do anything and make other people tired with him all the time, we should terminate this kind of genetic condition, and any condition that makes the family suffer.*

From the interview we gather that the father still loved his child but he perceived the blood transfusion process as very difficult and painful and, as a result, thought that not only would his child suffer, but also his spouse and relatives. This made the father think of terminating the pregnancy if the child would be affected by a blood condition, which illustrates how the kind of genetic condition influences parents' attitudes towards prenatal diagnosis and termination of pregnancy.

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven healthy children and one child with sickle cell anemia)

...conditions that make the parents busy with the disabled child and ignore the healthy children should be terminated. When my wife is willing to get pregnant again, I will ask for the test and if the test shows that the foetus is affected, I will terminate the pregnancy because I think that it is not fair to his brothers and sisters, they can't enjoy their life....

Dr. Hussein was highly educated and keen on having his family living in a comfortable way and not being broken up by brothers or sisters having any kind of disability that would make their life difficult, especially as he had already experienced an affected child and felt that he gave him more attention than his brothers and sisters. Dr. Hussein wanted to be fair and non-discriminative to his family by not having more disabled children.

Abdullatif (40 year old Saudi male, low education with three healthy children and two with cystic fibrosis)

> *...Any kind of genetic condition that can be detected by prenatal diagnosis before three months of gestation should be terminated; otherwise parents and the child will face problems as a result of the severe illness...*

The father considered that all kinds of the genetic conditions create problem to the family and to the disabled child him/herself. The father considered all the genetic conditions are severe and should be terminated.

Salim (35 year old Saudi male, low education with one healthy child and two with cystic fibrosis)

> *I am not against God's will or His creatures, but in certain disabilities, such as you have mentioned, such as a child without a brain who will die in the uterus or soon after birth, such a child will be useless and he cannot live. In this case, termination will be better. Blood transfusion is time consuming and it is too much work for the parents, like cystic fibrosis as in my case I need to go to hospital from time to time.*

The father was concerned about his expected child and was willing to terminate the pregnancy under certain genetic conditions such as when the infant would die early in the uterus or soon after birth or when the child would need of blood transfusions or medication, like his own children. The father revered God's creatures but he could not tolerate the outcome of such genetic conditions. Not all the parents would follow the Fatwa; it depends how strongly they believe and on the kind of genetic condition, which would influence their attitudes toward prenatal diagnosis and termination of pregnancy.

Sami (37 year Saudi male, highly educated with two healthy children and two with metabolic disease)

> *It is good to know and it prepares you for the next child but I will not terminate the pregnancy if the foetus has mild abnormality. I feel God will help and not leave him alone. But in other kinds of abnormalities such as mental or physical handicap and metabolic disease I think we should terminate the pregnancy in this case, because it will be very*

difficult for both the parents and the disabled child himself or herself, and parents feel[children with] these kinds of abnormality will be hopeless in the future...

The father believed that severe conditions such as his child's condition and mental or physical handicap should be terminated, since such conditions cannot be treated, but he would not terminate a pregnancy if the medical test showed that the child would be affected by a mild condition. He believed that God would help the child and not forsake him. Again, in different ways the kind of condition plays an important role in parents' attitudes.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

> *.... I feel we should terminate only severe mentally and physical handicapped, because they will be hopeless, but for those who will be late affected in his or her age should not be terminated at all because he or she should live their lives. Nobody knows when he or she will die, as that is unseen...*

This interview shows that some parents do not feel the late onset condition should be terminated because, as a Muslim community, that God has "written" the person's day (time of his death). Therefore, they believe that such a person might die before forty years of age. Furthermore, the prophet Mohammed said, "my nation's age is 60-65 years old" which means that such an affected person would have lived three quarters of his/her life and they believe that that is enough.

7.3.1.2 Mothers' comments

It was found that none of the mothers were totally against termination of the pregnancy for all scenarios that were presented in the questionnaire except for one condition (not the preferred gender). However, mothers had distinctive opinions toward termination of the pregnancy. Three mothers were not willing toward termination of the pregnancy in their conditions, but they were willing to terminate other conditions that they thought were severe or against Islamic law, while seven mothers were willing to terminate the pregnancy in their condition and similar conditions that they thought were severe.

Lama (30 year old Saudi female, highly educated with three healthy and two deaf children)

... I would not abort in any of the survey cases except for the alcoholic case. An alcoholic would be a burden on the family and society; also an alcoholic would bring shame to the family...

The mother was not ashamed of her deaf children, but she felt that an alcoholic would bring shame to the family. Lama was from a very conservative family who try to avoid any kind of action contrary to their religion. That indicates that perceived severity of the condition depends on parents' belief.

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)

...I would consider aborting in hopeless untreated cases such as a brainless foetus or a newly born whose lifespan won't exceed a couple of months...

Dina felt that a short lifespan and a brainless foetus were cases that should be terminated because they are hopeless and cannot be treated; whereas the rest of the genetic conditions, including deafness, which affected one of her two children, should not be terminated.

Iqbal (36 year old Saudi female low education, who have 4 PKU children and two normal children)

...I would consider abortion if [the condition] is hard to deal with, as in severe mental retardation, and in cases in which the patient would be dependant on others as in a physical disability...

The mother felt that severe mental retardation and physical disability are severe conditions and should be terminated. However, she felt that her daughters' conditions are not as severe as mental or physical handicap. Therefore, parents' experience plays an important role to influence their attitudes toward prenatal diagnosis and termination of the pregnancy.

Asma (34 year old Saudi female, highly educated with three healthy children and three with cystic fibrosis)

> *...I would abort in the case of severe mental retardation because it would be difficult to handle such an individual. I would also abort in fatal cases such as when a child will eventually die within a couple of months or with a brainless foetus because I feel I would suffer emotionally. I would experience motherhood then suffer the loss. I would also abort in the case where the child would suffer physically from the disease itself...*

Asma was one of the mothers who had a child with a cystic fibrosis and who did not want to have another child with the same condition, because she did not like the daily routine treatment. She also did not want to have a child with a severe mental and physical handicap or one who would die soon after birth. All of these conditions made her uncomfortable and she seemed sensitive towards most genetic conditions.

Rasha (26 year old Saudi female, highly educated with one healthy child and one deaf child)

> *... I would abort in the case where the child would suffer physically or mentally from the disease itself. In milder cases such as deafness or blindness, a girl would suffer more than a boy because a boy, in my opinion, can depend on himself, unlike a girl; girls are weaker and more sensitive by nature. Another point in the gender issue is marriage; I believe the chance of a disabled male getting married is greater than the chance of a disabled female getting married.*

Gender was a very important issue to Rasha and it made her willing to terminate a deaf female, but not a deaf male. This was because her deaf child was a girl and she is worried about her future, especially in Saudi culture, where the tradition is for the girl to marry through the male's family; they decide which girl is to marry their son and they would see the girl first and make the necessary arrangements. This made Rasha feel unhappy and want to terminate any future pregnancy in which the baby would be a deaf female. This mother's concern indicates that culture plays an important role to influence parents' attitudes.

Fahdah (35 year old Saudi female, low education with three healthy children and two with a metabolic disease)

....I would abort in cases in which the child suffers physically or mentally. But in cases in which the disease shows after 40, I wouldn't abort because the patient would have had a normal childhood, and he might die before that age...

According to the mother's experience, she felt that any kind of abnormality would cause a heavy burden to the family, and should be terminated. However, the mother thought that late onset conditions should not be terminated, because the child would spend most of his life in comfort, and might die before that age.

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

I am counting on benefiting from my sons and daughters who are expected to cooperate with me in social affairs so any kind of genetic condition should be terminated if it is hopeless...

Saudi society has different traditions from other societies. Most Saudi parents expect their male children to stay with them for most of their lives; even after marriage they are expected to stay in the same house and help their parents. These traditions are compulsory under Islamic Law; the prophet Mohamed said that if you treat your parents nicely then your children will, in the future, do the same to you. Wasmih expected her children to be healthy and help her in her old age, as she did to her parents so she felt sorry for her two disabled children who were unable to help her but needed help themselves. She would terminate any kind of genetic condition in which her children were unable to help her in her future. In western society, by contrast, children leave their parents after they become independent and might go to another country, depending on their school or the job they are looking for, and might not see their parents for a long time or forever. In case of a late onset condition, children might not know whether their parents have got the condition or not after they leave their parents, and similarly for the parents, their children might be exposed to a late onset condition without the parents knowing. Therefore, cultural differences might influence parents' attitudes toward prenatal diagnosis and termination of the pregnancy.

Leila (22 year old Saudi female, low education with one healthy child and one with cystic fibrosis; she is currently pregnant)

...I would abort out of sympathy for a child who would suffer physically or mentally in any way in his life...

Conditions for which mothers were most likely to want termination of the pregnancy were mainly those in which they considered the child would have a poor quality of life. However, some parents were worried about their own quality of life.

Fatma (35 year old Saudi female, low education, lost two children to thyrosinemia and has 7 living children 2 of them with the disease. She is currently pregnant)

I would abort any condition that would break the family life.

Fatma was a mother whose life was broken after she had an affected child, because her husband took another wife to give him a normal child. Hence, she wanted to terminate any kind of abnormality that would break up family life, as happened to her. This indicates that individual experience might influence parents' attitudes.

Maha (24 year old Saudi female, highly educated with two healthy children and one child with thalassaemia)

Anyone in this life wants a healthy child, therefore any abnormality which would cause the child and his parents to suffer should be terminated.

Maha was one of the parents who had both healthy and affected children and knew the difference between them, and how difficult it is to have an affected child in the family, as it makes the parents discriminate in treatment between children. She described how any kind of abnormality could be considered severe if the affected child would need special care, according to her experience.

7.3.2 Effects on Family Life

The second question was: Some parents feel that a disabled child in the family might change their life. What do you think?

7.3.2.1 Fathers' comments

It was found that one father of an affected child experienced no change in his life, six fathers were psychologically affected, two fathers thought their time was excessively taken up by their affected child, and one father's marriage was not stable.

Mazen (34 year old Saudi male, highly educated with three healthy children and two deaf children)

...I am a high school counsellor and I have a business in the afternoon. I don't have problems with my two disabled daughters and I have enough money to cover all their needs. My wife also works and my two daughters have a private teacher...

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven healthy children and one child with sickle cell anemia)

...Any kind of condition that makes the parents busy with the disabled child and ignore the healthy children should be terminated...

Majed (35 year old Saudi male, highly educated with two normal children and one deaf child)

I saw my child play alone and I felt she was isolated from others...

The father did not complain about his deaf child at home, but he felt that his child was isolated from friends and relatives. In his perception nobody could understand the deaf child and they could not communicate with her and she cannot communicate with others. The deaf child would not feel happy when she went outside and her parents could not stay home with her all the time, and they did not wish to see her isolated from others.

Abdullatif (40 year old Saudi male, low education with three healthy children and two with cystic fibrosis)

...Look at my hair turning white as a result of losing one of my children and having another one suffering now. I think he will die as well. The problem is that there are no tests during the pregnancy because the doctor said, 'We couldn't identify your C.F gene for it is different from the common one'...

The father expressed his feelings through the colour of his hair; it was black and turned to white. He had lost one of his affected children and the second one was on his way to dying. He did not do anything but maintain the appointments for pain killers and sputum suction, hopeless of any kind of treatment, even for future pregnancies.

Parents face difficult times when there are no treatments and when they are unable to have prenatal tests because the gene that causes the disease is unidentifiable. Saudi parents are Muslim and cannot use artificial insemination or third party donors. Their options are limited to not having children or remarrying if they have enough money.

Musaad (34 year old Saudi male, highly educated with three children one with a severe metabolic disease and one who died of the same condition)

... One thing that bothers me is when they are crying. I can't understand what are they complaining of because they can't explain what is the matter...

The father felt deep pain inside, watching his children cry and complain day and night and being unable to help them. He could not understand what they are complaining of, in order to help them. This is one of the major issues that Musaad complained about. It is a nightmare for parents to watch their disabled children suffer while they are unable to do anything for them. Despite the fact that the father narrated a nightmare story about his affected children, he was still against termination of the pregnancy.

Sami (37 year Saudi male, highly educated with two healthy children and two with metabolic disease)

A disabled child in the family causes a lot of change such as psychological problems in the family. My wife and I are no longer thinking of ourselves. Before having disabled children, we were thinking of our future and we used to go out from time to time and I was so happy at work. Now, all I think about is going to the hospital and the pharmacy and making excuses to my manager every time I have to go to the hospital.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

...Any person in this life wishes for a healthy child. My sister has two daughters whose ages are similar to my two affected daughters' age, but when you compare their speech and behaviour abilities you would find a big difference and this makes me feel unhappy.. I have to hide my healthy children at meal time in a locked room as a jail like criminal people, because I do not want the affected daughters to be upset by looking at their brothers and sisters eating what they want to eat. I am sleeping in a different room because my two daughters wake up every hour. I cannot sleep with my wife because she takes care of our daughters...

Salim (35 year old Saudi male, low education with one healthy child and two with cystic fibrosis)

I was a wealthy man and I had a lot of business. Since my child was born I have lost all my business and now I don't have enough money. I think a disabled child in the family would break any kind of business and the future's dreams ...

Salim was one of those parents who had lost their money and dreams after they had a disabled child. He was a rich man and had lots of things to do and many dreams to fulfil, but after two of his sons were born with cystic fibrosis, he spent all his money on treating them and all his dreams slowly disappeared.

Mohib (29 year old Saudi male, highly educated with five healthy children and two deaf children)

...I am not from Riyadh. I am travelling and spending lots of time and money on hearing aids and high tuition fees for speech therapy. A disabled child demands a lot of care from the parents...

Only a few institutes in Saudi Arabia deal with disabled children and they do not cover the whole country, so many parents have to pay for travelling costs. In addition, speech therapy and hearing aids are expensive and cost around 25,000 SAR (3571. UK Pounds). Parents with deaf children, like Mohib, who reside in villages, are unable to find a specialized institute nearby and thus have to travel to the city and pay large sums of money for treatment and education.

Faraj (30 year old Saudi male, low education with one healthy child and three thalassaemic children)

I am from a tribe where marriage with a very close cousin is compulsory. My father forced me to marry my cousin; I could not say no. After the marriage, I had an affected child and the second child was affected as well. The problem still goes on, for the third one was healthy, but the last one was affected. My father told me that I should marry another to have a normal child because the physicians suggest not to marry a close cousin. I married a woman from far away but she is not pregnant yet. I told my first wife,' No more kids,' because I have enough problems; she did not listen to me and she is now pregnant.

7.3.2.2 Mothers' comments

It was found that one mother thought her affected child did not change her life, five mothers were psychologically affected, three mothers felt their time was consumed by their affected child, and one mother's marriage relationship was not stable.

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)

My affected boy did not change my life.

Dina was happy with her deaf son, and she feels that he had not changed her life. This reminds us that, parents' views of the disabled children are different according to the parents' experience.

Rasha (26 year old Saudi female, highly educated with one healthy child and one deaf child)

...I become more sensitive to others after I knew that my second child not be able to hear...

Fahdah (35 year old Saudi female, low education with three healthy children and two with a metabolic disease)

...I have lost a child and have a living child who is severely affected. I am suffering with the living child who is completely crippled. I don't want to put him in a rehabilitation centre for I believe that God will reward me for the care giving. If prenatal diagnosis was available, it would prevent a lot of the pain and suffering for both the parents and the child...

Most Muslim women ask Allah, subhana ta'ala, to reward them on the Day of Judgment for all their suffering in this life. They refer to the prophet Mohamed's saying, "Almomen mobtala" which means that God gives people suffering in this life to test their belief. Fahdah hopes that Allah will reward her on the Day of Judgment, but also wishes that prenatal diagnosis and pregnancy termination were available at the time to prevent all this pain.

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

..I am dreaming of the day when prenatal diagnosis is available for cystic fibrosis. I have suffered a lot and lived through losing my daughter to this illness. When my daughter was in ICU, I prayed that God would end her pain and suffering by taking her soul. The eldest of my children is a boy who is a 1 ½ years older than my dead daughter and he also has cystic fibrosis. He has nightmares about his late sister whom he was very attached to...

Having more than one affected child creates more pain for the parents, especially if they have the same genetic condition and their lifespan is short. The dilemma is worse when the second child sees his brother or sister dying as a result of the severity of the disease. He will go through the same severity and wait for his turn to die, while his parents are unable to do anything for him. Wasmih wanted her daughter to die, not because she did not love her, but because she was suffering so much. Her son will suffer in the same way from the disease and she could not prevent it. She therefore wished for prenatal diagnosis and termination of pregnancy.

Fatma (35 year old Saudi female, low education, who lost two children to thyrosinemia and has 7 living children, 2 of them with the disease and she is currently pregnant)

...The diet is the main problem for me, I see my two boys craving food that they cannot eat it makes me sad and in pain. My husband's family thinks that I am the cause of their son having sick children and they have always caused me stress and pressured my husband to get another wife. He gave in to them 4 years ago, he got married just to have a normal child, but his wife hasn't got pregnant yet...

Number of healthy and affected children and the special diet for the affected children, as well as interference of the husbands' family in her life, affected the mother and put her under pressure, which has made her attitudes more favourable toward prenatal diagnosis and termination of pregnancy.

Maha (24 year old Saudi female, highly educated with two healthy children and one child with thalassaemia)

...I have graduated from the science college and I know how the viruses' transfer through blood transfusion. Therefore, every time I go to the hospital, I feel worried about my child's health as a result of the blood transfusion...

This mother was worried about her affected child incurring further health risks from blood transfusions. Therefore, education plays an important role to influence parents' attitudes toward prenatal diagnosis and termination of the pregnancy.

Asma (34 year old Saudi female, highly educated with three healthy children and three with cystic fibrosis)

...My husband and I are suffering mainly because the appointments are in Riyadh and we live in a distant city. My husband has problems getting excuses from work to take his children to their appointments and getting supplies. We lead a miserable life...

This mother had a big family with half of her children healthy and the other half affected. She was very concerned about her husband's job because his manager was not flexible with him. She was worried that her husband might be fired from his job and that they would lose their source of income. Lack of health services in the villages might influence parents' attitudes toward termination of the pregnancy.

Leila (22 year old Saudi female, low education with one healthy child and one with cystic fibrosis; she is currently pregnant)

...I have a daughter with cystic fibrosis and I am pregnant in the fourth month. I wanted to do prenatal diagnosis in order to abort if the result came out positive, but the doctor told me that abortion is prohibited and I was devastated and depressed. I don't want to have another child with the same disease. I have no social life because my life is centered on taking care of my affected child. I feel cursed and that life is unfair...

Iqbal (36 year old Saudi female low education, who has 4 PKU children and two normal children)

I have 4 children with PKU but thank God, it's not that bad a disease; I mean they can clean and feed themselves and that is important to me. My main problem is giving them the medication. I have a very hard time doing that because of timing and because each one has his own dose.

Despite the fact that the mother had four children with PKU which consumed her time, she still would not terminate such an abnormality in any future pregnancy.

Lama (30 year old Saudi female, highly educated with three healthy and two deaf children)

...My husband's family wants my husband to take another wife to avoid having more deaf children...

7.3.3 Shame

The third question was: Some parents feel that a disabled child might isolate the family from others. How do you see that?

7.3.3.1 Fathers comments

It was found that two fathers were not ashamed, three fathers were ashamed because of people's questions, three fathers were ashamed because their affected children were criticized by others, and two fathers were ashamed because their children's marriage prospects were adversely affected.

Musaad (34 year old Saudi male, highly educated with three healthy children and one with a severe metabolic disease and one who died of the same condition)

..I feel happy when I take my child out to the shopping mall. I feel people look at me like I am doing something good to the disabled child...

This father was very happy with other people's treatment and proud of the way he took care of his disabled children, which indicates that different parents have different views about how others look at them or it might be that the kind of disability affects others' reactions. This could influence parents' attitudes towards prenatal diagnosis and termination of the pregnancy, based on the kind of disability.

Mazen (34 year old Saudi male, highly educated with three healthy children and two deaf children)

... I can relate a story a student told me at school about his family and how they are treating their disabled child. The father has a disabled child who can't move so he isolated him from other people and for about 17 years nobody knew anything about him. The boy was left alone in a separate room in the house on the top floor. After 17 years, the father took him to the doctor to request surgery because he couldn't move any part of his body.

Another story involves two daughters, one is disabled and one is healthy. The parents discriminate between them. The disabled daughter is allowed only to go to school and then come back to the house without anybody seeing her, not even guests, whereas the healthy daughter can do anything she wants.

The stories narrated by the student counsellor indicated that some parents worried about their disabled children's reputation and some worried about their own reputation and that of their healthy children. They were ashamed of showing their disabled children to people and they were afraid that if people knew about their children's disability no one would marry their healthy children in the future.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

...I have not told anyone in my family, even my parents, that my children have a genetic disorder. I told them that they have a difficulty digesting their food and that is why, from time to time, when I go to the hospital I do not like people looking at me and my daughters in a different angle or with pity or mercy. If my family knew they would not stop telling me that they have a lot of suggestions such as why this happened, why don't you go to other hospitals, why don't you marry another wife, and you should use this kind of herbs. Also, if I tell anybody that I have affected daughters, nobody will marry my healthy children. That is why I have decided with my wife that nobody should know anything about the genetic diseases, not even our children. The procedure of having a healthy child will open hope for me again without waiting nine months knowing nothing about the result. When I plan to use this method (prenatal diagnosis and termination of pregnancy) I will not tell anybody...

Culture influenced this father in hiding the fact that his two daughters were affected by a genetic condition, because he did not want to be stigmatized by people or have the chances of marriage for his healthy children jeopardised. This influenced him towards prenatal diagnosis and termination of pregnancy.

Salim (35 year old Saudi male, low education with one healthy child and two with cystic fibrosis)

... People have lots of questions about my children's treatment and the methods of treatment (tell me how he uses the breathing aid and so on). I am not happy about people's questions ...

Some people inquire about a disabled child's aids and parents do not like to answer questions about their child's aids. Parents feel uncomfortable about other people's concern because they are not always happy to answer such questions, especially when they are occupied with many disabled children as was the case with Salim. If the parents have uneducated family and friends around them, that might influence their attitudes toward prenatal diagnosis and termination of pregnancy.

Sami (37 year Saudi male, highly educated with two healthy children and two with metabolic disease)

...Everybody in town knows that I have affected children; some of them understand the situation and others keep asking me all the time what kind of disease, is it a virus and can it affect others, especially at meal time. If somebody invites me, my affected children do not eat meat because it causes them problems, but uneducated people think that they have hepatitis. They are really difficult and they think that all of my children, healthy or affected, are affected. It is very difficult to convince them and my children's future will be stigmatized...

This father faced a major problem with his relatives as their constant questions made him feel unhappy. He would be obliged go to their house if they invited him; otherwise nobody would come to his house, which was considered shameful in his relatives' view and his parents as well. Therefore, culture and misunderstanding of the genetic disease might affect parents with an affected child.

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven healthy children and one child with sickle cell anemia)

...Our population is not educated enough; people should respect the handicapped and not criticize them...

This father was a highly educated wealthy man with a big family. His children were very intelligent and quiet and they could communicate and play together, but he feels that his relatives and neighbours were not educated enough to overlook his disabled child and to leave them alone. The way society looks on a disabled child might influence parents' attitudes toward prenatal diagnosis and termination of pregnancy

Majed (35 year old Saudi male, highly educated with two healthy children and one deaf child)

... When my daughter was a child she was socially accepted by family and friends, but when she reached adulthood she became unsociable. She does not like to mix with people because of their unhelpful attitudes...

This father was worried about his daughter's future. He felt that her friends changed their attitudes, for when they were children they spent most of the time playing with their toys and doing homework together, but after they grew into adulthood, their attitudes as friends to her changed. This made his daughter feel different, so she isolated herself from others.

Mohib (29 year old Saudi male, highly educated with five healthy children and two deaf children)

..I am living in a small town where you know everybody there and they know of my situation. Some of them criticize my two daughter's future and their behaviour. I plan to move to a capital city where nobody will know me there. But the difficulty is when my daughters want to marry, who will marry them? I think nobody wants a deaf woman. If I was in this situation, I would not marry a deaf woman. I think it is very important that the government encourages marrying a disabled woman by providing money or housing or any kind of assistance to anyone who marries a disabled woman...

Abdullatif (40 year old Saudi male, low education with three healthy children and two with cystic fibrosis)

Two of my sisters-in-law have carrier children and they knew about the disease before my marriage but they did not tell me the truth. Now I have two carrier daughters. Shall I hide the truth like my wife's family did? I am really confused about their marriage.

The father criticized his wife's family for not telling him that his wife was a carrier and he felt that they cheated him by hiding the truth from him. He now faced the same situation with his carrier daughters. His wife's family hid the secret, because if they had made the situation clear, other people might not understand what is meant by carrier and they would believe they are sick in some way and would not want to marry them; they might look for another family free from any kind of disease for their son.

Faraj (30 year old Saudi male, low education with one healthy child and three thalassaemic children)

... I became very worried when I heard the news that premarital medical tests will become compulsory and my daughters didn't like this news. They have bad feelings about their future and know that no one will marry them. Their lives have become very complicated and this complication is affecting their health...

Despite the fact that premarital tests are very important for the population in preventing many genetic diseases, some parents with affected children think that these tests will make their children's lives more complicated and stigmatize them, because of the way marriage is arranged in Saudi society which might influence parents' attitude toward prenatal diagnosis and termination of pregnancy.

7.3.3.2 Mothers' comments

It was found that three mothers were not ashamed, three mothers were ashamed because of people's questions, three mothers were ashamed because their affected children were criticized by others, and one mother was ashamed because of the impact on her children's marriage prospects.

Iqbal (36 year old Saudi female low education, who have 4 PKU children and two normal children)

...My family and my husband family are praying for me, because of the massive care that I give to my four affected children, and I feel I am not isolated from others...

The mother was happy with her family and her husbands' family, regarding their support and prayers for her. Thus, social support plays an important role for the family with an affected child.

Fatma (35 year old Saudi female, of low education, who lost two children to thyrosinemia and has 7 living children; 2 of them have the disease and she is currently pregnant)

...I am socially active and I take my 2 boys with me wherever I go, but it bothers me a bit when people ask me questions like "Why do you have to be with them while they eat?"" or" Why do you let the poor thing eat that?" but that doesn't prevent me from socializing...

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

...I don't feel alone...

Leila (22 year old Saudi female, highly educated with one healthy child and one child with cystic fibrosis, she is currently pregnant)

...My family has a lot of questions regarding my child condition...

Asma (34 year old Saudi female, highly educated with three healthy children and three with cystic fibrosis)

...My children friends keep asking them, 'What's wrong with your brothers?' This kind of question upsets them, because they cannot give the right answer...

Fahdah (35 year old Saudi female, low education with three healthy children and two with a metabolic disease)

...My relatives keep saying, I should not prevent my affected children from having any kind of food they want, because they do not know what the reason is, and this kind of comments irritates me and isolates me from others...

As a result of the mother hiding the truth from her relatives, she received many comments about the kind of food that she gave her affected children. The mother is in a difficult situation. If she told the truth about the fact that her children are affected by a genetic disease, her relatives might criticize her and damage her relations with her husband and her children's future marriage prospects; if she kept hiding the truth, she would receive more suggestions.

Rasha (26 year old Saudi female, highly educated with one healthy child and one deaf child)

..A deaf girl would draw people's attention because the child and the parents will feel uncomfortable or even ashamed....

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)

...When I discovered that my daughter couldn't hear, I didn't tell my mother for six months. She said I should have told her that before and that it is God's Will and it is not a shame. After the first appointment, I told everybody about my daughter but my mother said that I shouldn't tell one of the ladies because she will tell everybody in town...

Lama (30 year old Saudi female, highly educated with three healthy and two deaf children)

...My husband's family has lapelled me, as a mother with deaf children...

Maha (24 year old Saudi female, highly educated with two healthy children and one child with thalassaemia)

.... I come from a remote small area where most people are illiterate and where a word would spread around and where people will never consider marrying a carrier.

7.3.4 Religious Perspective

The fourth question was: According to the Fatwa, Islam law allows termination only in severe case and in the first three months of the pregnancy. What is your opinion?

7.3.4.1 Fathers' comments

It was found that three fathers were against termination, four fathers agreed with the Fatwa, and three fathers misunderstood the Fatwa.

Mazen (34 year old Saudi male, highly educated with three healthy children and two deaf children)

....I am discouraging termination of pregnancy because it is against the Islamic Law of killing innocent people and maybe there is a chance in the future for treatment...

Majed (35 year old Saudi male, highly educated with two normal children and one deaf child)

When the sperm and ova meet in the uterus this is the beginning of a human being and nobody can kill him in any stage of his life as this is against Islamic Law...

Islam looks at the developing embryo and foetus as passing through diverse stages of purity as written in The Holy Book. The inception of life occurs with the union of a sperm and an ovum, thus forming a zygote, but the breathing stage of the spirit starts after 120 days. Despite the fact that this father was a Moslem who knew all the stages from the beginning until the end, he was unable to distinguish between the different stages and he felt that nobody should touch the zygote in any stage of its life. This shows how different beliefs influence parents' attitude toward prenatal diagnosis and termination of pregnancy.

Musaad (34 year old Saudi male, highly educated with three children, one with a severe metabolic disease and one who died of the same condition)

...When we were in the UK the physicians suggested taking a sample from the child to see if the foetus was affected. They found that he would be affected with the same condition and they asked if we wanted to terminate this pregnancy. I told them "No way, do you want me to kill? This is a big crime and God will punish me if I do so. 'I am against the termination of pregnancy at any stage because termination is not allowed by Islamic law....

Despite the fact that the father was in the UK and given the opportunity to terminate the affected foetus, he did not take the opportunity and he said Islamic law would not allow termination of pregnancy in any genetic condition. Even after hearing the Fatwa from the researcher, he still thinks that Islam law is against termination, which indicates that some parents oppose termination under any circumstances, even if it is allowed by Islamic law.

Sami (37 year Saudi male, highly educated with two healthy children and two with metabolic disease)

... I think my children's condition is considered one of the severe conditions that should be terminated but, my wife is against termination...

Mohib (29 year old Saudi male, highly educated with five healthy children and two deaf children)

We should not terminate because of deafness, it's all from God and we can't do anything against God's creatures.

The father was not willing to terminate on the ground of this condition and he does not want anybody else to terminate either, because he thought that Islamic law does not allow termination of a deaf child, because it is not a severe condition in his experience.

Faraj (30 year old Saudi male, low education with two thalassaemic children)
I don't mind terminating any kind of genetic abnormality if it is permissible in Islamic Law.

The interview shows that most of the parents did not know whether termination of pregnancy is acceptable in Islamic Law or not. Hence, parents had various views regarding termination of pregnancy, based on what they had heard from various religious authorities.

Salim (35 year old Saudi male, low education with one healthy child and two with cystic fibrosis)
...Myself agree with the Fatwa and am willing for termination, but my wife totally against termination, because she thinks that Islamic law is against termination...

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven children and one child with sickle cell anemia)
...I don't know about religious opinion in the different genetic conditions, they should make it clear as to what can be terminated and what cannot, and make it clear also as to when to terminate . These documents (Fatwa) should be available in each clinic.

This father was not content, because the Fatwa is not clear and easily obtainable and hence no one can be certain. Furthermore, the Fatwa does not precisely state which genetic conditions may be terminated and which may not. This had left the father making inquiries on his own and in total confusion when he was given dissimilar Fatwa. This kind of confusion is considered as one of the main factors that affect parents' attitude towards prenatal diagnosis and termination of pregnancy.

Abdullatif (40 year old Saudi male, low education with three healthy children and two with cystic fibrosis)
The Fatwa is clear, therefore termination is allowed by Islamic law in the first three months of the pregnancy in any kind of genetic condition.

This father has recited half of the Fatwa correctly, but the other half is not correct, because Islamic law allows termination only for severe conditions which cannot be treated.

Therefore, misunderstanding of the Fatwa causes parents surprise when they ask about the test and termination of the pregnancy in any condition.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

...I think my case is one of the severe conditions, which is allowed by Islamic law to be terminate but I do not know if the hospital terminates this kind of condition ore not...

PKU can be treated. This means Islam would oppose termination for this kind of abnormality, according to the Fatwa.

7.3.4.2 Mothers' comments

It was found that none of the mothers with an affected child were totally against termination of the pregnancy; four mothers agreed with Fatwa, and six mothers misunderstood the Fatwa.

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

..I think that if a child will suffer physically or socially then it is better to know and abort. In addition, the parents will suffer if the child is mentally challenged so it is better to know and abort as the Fatwa state.

Rasha (26 year old Saudi female, highly educated with one healthy child and one deaf child)

The Fatwa is clear, but I am not quite sure about my condition, and I would follow the Fatwa.

Fahdah (35 year old Saudi female, low education with three healthy children and two with a metabolic disease)

...Prenatal diagnosis should be done only for the diseases which Islam allows abortion for...

This mother would not have prenatal diagnosis, nor abort the baby, unless it is permissible according to Islamic Law. She made a link between prenatal diagnosis and the termination of pregnancy if the test is positive.

The interview shows that some parents link prenatal diagnosis with termination of pregnancy. Nevertheless, some parents say that Islam encourages the use of prenatal testing if it does not jeopardize the life of the mother or the baby, so that parents will be informed about their baby's future and be prepared for it.

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)

...I believe that prenatal diagnosis might come out positive but maybe, by the will of Allah, it might change later on, but I don't mind what the Fatwa stated, which might support parents if they want to terminate...

The mother wanted to do prenatal diagnosis and terminate the pregnancy if the result was a clear positive diagnosis, but at the same time she believed in God's infinite power to change anything at any time and she bowed to God's will.

The interviews show that parents had varied attitudes regarding the termination of pregnancy. Some parents emphasized that a defect in the baby is a test from God and that they must accept what is "written". Some parents emphasized that humans have some knowledge of what is inside the uterus but that they cannot rely completely on technological advances, for only God knows the unseen.

Lama (30 year old Saudi female, highly educated with three healthy and two deaf children)

... I would not abort in any of the survey cases because it is against Islamic law as far as I know, except for the alcoholic case because it is against Islamic law.

Maha (24 year old Saudi female, highly educated with two healthy children and one child with thalassaemia)

...Abortion is not allowed in Islamic law, except if the pregnancy will affect the mother's life; that is what my father told me....

This mother had a different view from the religious opinion about the case where the child would affect his mother's life. Hence, she thought that the child might affect his mother's life psychologically but not biologically, therefore she wanted to terminate any condition that would disrupt family life.

Asma (34 year old Saudi female, highly educated with three healthy children and three with cystic fibrosis)

...I wanted to do prenatal diagnosis in order to abort, but I went to ask a religious authority if it is permitted in Islam, the answer given to me was no and that I have no right to take a life...

Before doing prenatal diagnosis, the mother consulted a religious authority on whether termination of pregnancy in the case of cystic fibrosis is allowed in Islamic Law or not. The answer she received was that abortion is considered as murdering the baby and that it is prohibited in Islamic Law. Being given different Fatwa from the religious authorities is one of the main factors that affect parents' attitudes towards prenatal diagnosis and termination of the pregnancy.

Leila (22 year old Saudi female, highly educated with one healthy child and one child with cystic fibrosis, she is currently pregnant)

...I wanted to do prenatal diagnosis in order to abort if the result came out positive, but the doctor told me that abortion is prohibited and I felt devastated and depressed. I don't want to have another child with the same disease...

Leila had a similar problem to Asma, except that Asma consulted a religious authority whereas Leila consulted her physician. In both cases the termination of pregnancy in the case of cystic fibrosis was not supported. The interview shows that in spite of the fact that the Fatwa is clear with respect to the time of termination of the pregnancy in case of a severe genetic condition, there are still some religious authorities and physicians who do not follow the Fatwa.

Iqbal (36 year old Saudi female, low education, who has 4 PKU children and two normal children)

...I have been told that, Islamic law does not allow terminating any kind of abnormality...

Despite the fact that the research assistant told the mother about the Fatwa, the mother still asserted one of the religious authorities had told her that Islamic law is against termination of the pregnancy in any kind of condition.

Fatma (35 year old Saudi female, of low education who lost two children to thyrosinemia and has 7 living children, 2 of whom they have the disease and she is currently pregnant)

I wish I could do test in the pregnancy that would save my life and my husband would not marry another woman, but we asked about termination before, but the religious authority said it is not allowed in Islam to terminate your pregnancy.

7.4 SUMMARY OF THE CHAPTER

According to the quantitative analysis, parents with and without an affected child had similar attitudes toward prenatal diagnosis. However, overall parents without an affected child were less willing to accept termination of the pregnancy than parents with an affected child and the differences were significant in some conditions.

Parents without an affected child did not live with an affected child; hence, their inclination towards termination of the pregnancy was less. In addition, the effect of the disabled child in the family could not be imagined by parents without an affected child. However, some parents without an affected child had seen parents with an affected child, and saw how the affected child in the family might cause shame to that family. This was especially true for mothers, and was probably one reason why mothers without an affected child held more favourable attitudes towards termination of the pregnancy than fathers without an affected child.

Parents with an affected child were able to express their feelings about the affected child in the family and how their quality of life changed as a result of having an affected child in the family. However, not all parents with an affected child wanted to terminate for reason of the genetic condition they have experienced. In addition, parents also cared about their healthy children and did not want to ignore them and pay more attention to the disabled children. Some parents' views depended on the gender of disabled children; they thought the situation of a female disabled child is worse than a male disabled child. Lack of health services and rehab centres in the villages was considered one of the important factors that increase parents' burden. Stigmatization may be less visible or more widespread, depending on where the parents of disabled children live. Social oppression is the main problem for disabled people, and one which it is important to discuss and deal with (Abberley, 1987; Oliver, 1990; Morris, 1991; Crow, 1996; Shakespeare, 1998; Gollust et al., 2003). In addition, parents with an affected child perceived the impairment or disability of their affected child differently according to their individual experience. New technology provides parents with more reproductive choices but also presents them with more dilemmas because of the choices they have to make. Furthermore, Islamic views toward termination of the pregnancy were not clear among the parents. In addition, not all the parents accepted the Fatwa. Further, religious authorities and physicians gave different interpretations of the Fatwa based on their understanding of the severity of the disease and the time of the termination of pregnancy. Parents with an affected child could, however, perceive the severity differently according to their individual experience. Therefore, conflicts between parents with an affected child and views expressed by religious authorities were clear from the interviews.

CHAPTER 8: DISCUSSION

8.1 INTRODUCTION

This chapter discusses the findings in real world terms and considers the extent to which the research has addressed its aims. The next chapter places the findings in a wider context and considers future implications for research and policy.

The five aims were:

1. To provide an understanding of parents' views about the acceptability of testing and termination of pregnancy for a range of different conditions.
2. To compare the views of fathers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions.
3. To compare the views of mothers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions.
4. To compare the views of fathers and mothers with and without an affected child towards prenatal diagnosis and termination of pregnancy for a range of different conditions.
5. To find the factors that affect parents' attitudes towards prenatal diagnosis and termination of the pregnancy.

The findings of the study will be discussed in relation to each of these aims, and followed by the limitations of the study.

8.2 DISCUSSION OF RESULTS

8.2.1 Attitudes to prenatal diagnosis and termination of pregnancy: Specific conditions

This section will discuss the first and the fifth aims of the study, which were to provide an understanding of Saudi parents' views about the acceptability of testing and termination of pregnancy for a range of different conditions. All the Saudi population is Muslim. Islamic law allows termination of pregnancy only in severe conditions and before the twelfth week of gestation. There is, however, no definition of a "severe" condition and Saudi parents' attitudes to different conditions have not previously been investigated. This study was successful in assessing Saudi parents' attitudes towards prenatal diagnosis and termination of pregnancy in a range of 30 different conditions, and a wide range of views was discovered. There was an unexpectedly high level of acceptance of prenatal diagnosis and termination of pregnancy for a range of different conditions in this Muslim sample, but there were also big differences between conditions.

The way the questionnaire was designed and the methods of data collection helped to explore Saudi parents' attitudes towards prenatal diagnosis and termination of pregnancy. Ordinary people might not understand the meaning of the genetic conditions by their scientific names. Therefore, scenarios of the conditions were used instead of the names of the conditions. In the scenario, four elements were mentioned that were likely to be important to parents' attitudes in decisions on prenatal diagnosis and termination of pregnancy: the medical characteristics of the condition, the life expectancy of the child, the level of care required and the gender that might be affected. Importantly, this approach left the parents free to make their own judgments about the relative severity of the different conditions. The importance of the factors outlined in the scenarios was corroborated by parent accounts, as the following sections show. The possibility of other important issues arising from the qualitative accounts is discussed in the limitations section at the end of the chapter.

In this summary chapter the results of the qualitative analysis (which addressed Aim 5) are not presented separately from the results of the quantitative comparisons of the different conditions (Aim 1). Instead, extracts from the qualitative data are used to illustrate and support quantitative findings. As will be recalled, the qualitative material was collected in response to four questions, about the kind of condition, the effects on the family, shame, and religious influences. The first two of these topics effectively acted as probes to cover material in the scenarios, but the possibility of shame and religious influences had not previously been mentioned. It was found that parents contributed material related to all scenario elements, in response to all of these interview questions. For example, when asked about religious influences, parents might mention specific conditions such as alcoholism. It was concluded that all four original scenario elements were highly relevant to Saudi parents, and that shame and religious influences were best understood in the context of specific conditions rather than in general terms.

The material below is presented according to the four scenario elements of the structured questionnaire. The quotations given in the sections to follow have been chosen to illustrate first, the kinds of reasons people gave for terminating conditions that were highly ranked overall (i.e. perceived as "severe"), and second, reasons given by people whose views differed from the overall pattern.

8.2.1.1 Medical characteristic of condition

The medical characteristic of the condition, e.g., whether the individual has a chronic debilitating disease, a learning difficulty, or only minor anomalies, may influence parental decisions about prenatal testing (Murph, 1968; Carter, 1969, Wertz, et al., 1991). Many studies (Kurdy, 2001; Tsianakas and Liamputtong, 2002) have looked at attitudes to prenatal diagnosis and termination of pregnancy without specifying the kind of condition that causes impairment or disability to the child. According to the findings in the present study, the characteristics of each condition have a large impact on how parents perceive that condition, as shown below in the parents' comments. Also, parents could have similar or different attitudes towards prenatal diagnosis and termination of each condition according to their individual experience. Therefore, the first influential factor in parents' attitudes towards prenatal diagnosis and termination of pregnancy is the kind of condition. Parents' comments from the interviews proved that kind of condition plays an import role to influence parents' attitudes towards prenatal diagnosis and termination of pregnancy. Overall, termination of the pregnancy was seen as appropriate for some conditions much more than others. When conditions were ranked, Anencephaly, Trisomy 13 or 18, severe learning disability, quadriplegia, Duchenne muscular dystrophy, and thalassaemia were regarded by at least 40% of the sample as justifying a termination of the pregnancy. By contrast, conditions at the opposite end of the ranking, Alzheimer's disease, mild learning disability, coronary at 50 y, and cleft lip and palate were regarded by at most 5% of the sample as justifying a termination of the pregnancy (See chapter 6 table 8).

In addition, it was found in the study that some parents might terminate one condition according to their individual experience and not terminate another, even if other parents considered the former condition more severe, judged by the overall rank order (See chapter 6 figure 5). For instance, thalassaemia is one of the most common genetic conditions in the Saudi population. It was noted that most of the parents in this study had heard about it and the data revealed (see chapter 6 figures 5) that they considered it one of the main conditions that should be terminated. Nevertheless, some parents did not even want to have a test for this condition and thought other conditions were more severe, according to their individual experience (See chapter 6 section 6.10).

It was found from the interviews that many reasons were given for intending to terminate different conditions, according to the parents' individual experience.

a) Thalassaemia was judged by many parents to justify termination of the pregnancy.

Faraj (30 year old Saudi male, low education with one healthy child and three thalassaemic children)

...A child with a blood transfusion in the society, is considered a problem to himself and to society. It is better for him not to come to this life. If he will not do anything and make other people tired with him all the time we should terminate this kind of genetic condition...

Collectively, parents classified thalassaemia as one of the conditions most justifying termination, partly because parents thought this kind of condition does not affect the disabled child only, but also parents and others.

b) Some parents felt that their condition was "severe" and should be terminated but less "severe" conditions according to their views, should not be terminated.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

.... I feel we should terminate only the mentally handicapped, because they will be hopeless, but those who will be late affected in his or her age should not be terminated at all because he or she should live their lives. Nobody knows when he or she will die, as that is unseen...

c) Some parents would not terminate any of the conditions that were presented in the scenarios.

Lamia (28 year old Saudi female, highly educated with two children)

... I would do the prenatal diagnosis so that I could be prepared psychologically and educate myself about the disease that the child might have, but I would never abort any kind of genetic condition unless it would affect my life...

Lamia's comment shows that not all the parents who agreed to do genetic testing would also agree to terminate the pregnancy, because they had their own reasons for doing the test only.

d) Some parents rejected termination of the pregnancy in all conditions except one.

Majed (35 year old Saudi male, highly educated with two normal children and one deaf child)

...We should not terminate any kind of abnormality because it's all from God and we can't do anything against God's creatures, but for the alcoholic condition we should terminate the pregnancy because it is against Islamic Law...

Despite the fact that alcoholism was not one of the most likely conditions that parents were willing to terminate, still some parents had their own justification for terminating this condition and not terminating any other conditions.

e) Some parents would terminate a less "severe" condition (as judged by the overall ranking)

Majedah (43 year old Saudi female, low education with three children)

...Ladies usually spend most of their time in front of the mirror for makeup purposes. I feel that if a lady is short, fat, deaf, blind, or missing a part of her body she will suffer a lot so termination of such an abnormality would be better...

Whenever the parents were willing to terminate a particular condition in the scenarios, they had their own justification, even if the condition was not "severe" according to other parents' opinion. Hence, parents had similar and different views toward termination of the pregnancy according to their individual experience.

8.2.1.2 Lifespan of the affected child

Very few studies have mentioned lifespan when they considered assessing parents' attitudes toward prenatal diagnosis and termination of the pregnancy. In one study, perceived burdens associated with abnormalities leading to prolonged illness or early deaths were found to be a serious factor affecting parents' attitudes toward prenatal diagnosis and termination of the pregnancy (Ekwo, et al. 1987). In the present study, parents in the interviews supported this factor by their comments, which indicate the importance of the lifespan of the affected child to the parents' life, as the following examples show:

a) The majority of the parents would agree to terminate conditions in which the child will die early in his life.

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)
...I would consider aborting in hopeless untreated cases such as a brainless foetus or a newly born whose lifespan won't exceed a couple of months...

According to Dina's opinion, a deaf child should not be terminated, because he has a normal lifespan and his condition is not "severe", whereas the child who will die early in his life should be terminated. Most of the parents thought there was no point in carrying the child nine months in the woman's body if at the end of day, he would die; this kind of condition should be terminated early rather than waiting for nothing, according to most parents' views.

b) Most of the parents thought that the late onset conditions should not be terminated.

Fahdah (35 year old Saudi female, low education with three healthy children and two with a metabolic disease)
...I would abort in cases in which the child suffers anyway. But in cases in which the disease shows after 40, I wouldn't abort because the patient would have had a normal childhood...

As long as the child spends most of his life without facing any genetic abnormality that makes him and others suffer, this condition should not be terminated, according to most parents' views. However, some parents had different opinions towards termination of the pregnancy in early onset and late onset conditions, according to their individual experience.

c) Some parents would not terminate early onset conditions.

Assad (30 year old Saudi male, highly educated with three children)
"The condition that makes a child die early should not be terminated; because the child will die early anyway, and not leave his parents to suffer life long"

Some parents thought that when an affected child would die early in his life, the pregnancy should not be terminated because he would die early anyway, and the parents would not expose themselves to punishment from God as a result of the termination of the pregnancy. Some parents thought that when an affected child dies early, it can be considered a mercy from God, according to their belief. Thus, parents had their own justification to agree or disagree with termination of the pregnancy as a result of the lifespan of the condition.

d) Some parents were willing to terminate late onset conditions.

Mamdoh (34 year old Saudi male, highly educated with two children)
...Regarding the late onset, dying in adulthood or having problems, I have not seen that yet. But if I was sure then I would terminate the pregnancy because I do not want to inform him or wait for his sickness and death, and I would blame myself if that happened. I would be cheating his or her partner if I hid the secret from them and this is not allowed in Islamic Law...

Thus, parents considered lifespan one of the important factors that influenced their attitudes. However, parents had similar and different attitudes toward prenatal diagnosis and termination of the pregnancy of the lifespan to the affected children according to their individual experience.

8.2.1.3 Level of care required

It was found in other studies that the most stressful burden would be having to take care of a chronically ill child (Carter, 1969; Beresford, 1994; Menahem and Grimwade, 2003). It was also apparent from the present study, that the level of care required influenced parents' attitudes toward prenatal diagnosis and termination of the pregnancy, as the following examples from the interviews show:

a) Conditions that require life long care were collectively ranked very highly.

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU)

...I have to hide my healthy children at meal time in a locked room as a jail like criminal people, because I do not want the affected daughters to be upset by looking at their brothers and sisters eating what they want to eat. I am sleeping in a different room because my two daughters wake up every hour. I cannot sleep with my wife because she takes care of our daughters...

Some parents would think the condition itself not severe, but the level of care that the disabled child required from his parents made many parents complain, and willing to terminate conditions that required lifelong care.

b) Some parents had a heavy burden from life long care, but were still not willing to terminate such conditions.

Iqbal (36 year old Saudi female low education, who has 4 PKU children and two normal children)

I have 4 children with PKU but thank God it's not that bad a disease; I mean they can clean and feed themselves and that is important to me. My main problem is giving them the medication. I have a very hard time doing that because of timing and because each one has his own dose.

Despite the fact that this mother had four children with PKU, and their condition required a massive amount of time and care from their mother, she still did not think this kind of condition was severe enough to justify termination of a future pregnancy, according to her experience.

c) Some conditions might not require a lot of care in most parents' view, but other parents might have different opinions.

Mohib (29 year old Saudi male, highly educated with five healthy children and two deaf children)

...I am not from Riyadh. I am traveling and spending lots of time and money on hearing aids and high tuition fees for speech therapy. A disabled child demands a lot of care from the parents...

The 'severity' of the condition can be assessed only in light of parents' experience, because there are many factors that generate a heavy burden on parents, causing them to rank a condition as "severe", as in this father's experience, which influenced his attitude to justify termination of a future pregnancy.

8.2.1.4 Gender

The final important element in the scenario was the gender. In four conditions in the questionnaire (Duchenne muscular dystrophy, Klinefelter's syndrome, Turner's syndrome, and not preferred gender) gender was mentioned. Parents showed a slight tendency to be more favourable towards termination of the pregnancy in Klinefelter's syndrome than Turner's syndrome (27.2% vs. 22.2%), and this was probably because Klinefelter's syndrome affects only boys and Turner's syndrome affects only girls. A fertile boy is important to his family, because his children will carry the family name in the future, whereas for a fertile girl, her children will belong to her husband's family. However, from the qualitative interviews it emerged that for conditions such as deafness, parents with an affected boy thought they would have a better chance of finding a marriage partner for their child than did parents of girls, because a girl's parents would have to wait for someone to marry her.

None of the parents were willing to terminate the pregnancy in the condition, not preferred gender, which suggests that parents were concerned only about a healthy child, regardless of gender.

From the qualitative interviews, parents commented on the importance of the gender for other conditions, as the following examples show:

a) Gender is considered important in the Saudi society

Mazen (34 year old Saudi male, highly educated with three healthy children and two deaf children)
In my view boys and girls are equal; but I think most of the Saudi society is concerned about the gender. Therefore, kind of gender is important to the parents towards termination of the pregnancy in these conditions.

Because of this father's position as a student counsellor in a big school, he had been exposed to many situations were the parents showed that they valued boys more than girls, and he related many stories illustrating parents' preference towards termination of the future pregnancy if their affected child was a female.

b) Gender of an affected child was important to some parents.

Rasha (26 year old Saudi female, highly educated with one healthy child and one deaf child)
...In milder cases such as deafness or blindness, a girl would suffer more than a boy because a boy, in my opinion, can depend on himself unlike a girl; girls are weaker and more sensitive by nature. Another point in the gender issue is marriage; I believe the chance of a disabled male getting married is greater than the chance of a disabled female getting married...

This mother clearly mentioned the factors that she thought would justify termination of a future pregnancy, if the child would be a female, based on her experience, because of the implications of what her deaf daughter would face in her future.

c) Some parents only wanted a healthy child regardless of gender.

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

I am counting on benefiting from my sons and daughters who are expected to cooperate with me in social affairs so any kind of genetic condition should be terminated if it is hopeless...

Having a healthy child was important to this mother, regardless of gender, according to her experience. Hence, the gender of an affected child was not considered important to some parents, which indicated that parents have different views toward the relevance of gender when making decisions about termination of the pregnancy.

Overall, it was apparent that there was also some pulling together of factors that led to the majority favouring particular views for a particular condition, although there were similarities and differences in attitudes toward prenatal diagnosis and termination of the pregnancy according to parents' individual experience, and this finding supports those of other studies (Ekwo and Gosselink, 1987; Wertz, et al., 1991, Evers-Kiebooms, et al., 1993; Michie, et al., 1995; Hietala, et al., 1995; Anionwu and Atkin, 2001; Zahad and Nabulsi, 2002; Hewison et al, 2004). It was proposed in chapter two that culture plays an important role to influence parents' attitudes toward prenatal diagnosis and termination of the pregnancy, but in addition, how parents perceive the condition depends on their individual experience. This is consistent with the view of Koch (2001) that the severity of the condition which leads to impairment or disability is defined by social prejudice, not by physical or medical facts. Because humans see themselves in the framework of the reactions of others (Lashely, 1998), parents' concerns are often related to perceptions of self-image rather than physical disability or impairment. However, it is disability and impairment which are reported by physicians, in terms of biological features and the kind of treatment that the disabled child needs. In addition, the informed choice of the parents is very important, because there is a gap between description of disabilities and potential disabilities and consequence for family life as a child develops (Rapp, 2000). The relationship between parental views and the legal position regarding termination of the pregnancy is discussed further in chapter nine, section 9.2.2.

8.3 ATTITUDES TOWARD PRENATAL DIAGNOSIS: COMPARING GROUPS

This section of the discussion will cover the second, third, and fourth aims of the study, in respect of prenatal diagnosis, while the next section will address the same aims in respect of termination of pregnancy.

8.3.1 Attitudes of Fathers with and without an affected child towards PND

According to the findings, fathers with and without an affected child had very favourable attitudes towards prenatal diagnosis in total score, and the medians were almost the same in the two groups of fathers (see figure 21) (maximum score is 60, medians are 53 and 54).

Exploratory analyses showed that fathers with an affected child were significantly more favourable toward prenatal diagnosis than fathers without an affected child in four conditions: quadriplegia (96% vs. 87%; P=0.04), Duchenne muscular dystrophy (94% vs. 84%; P=0.04), cystic fibrosis (92% vs. 80%; P=0.024), and phenylketonuria (92% vs. 77%; P=0.006). There were no conditions in which fathers of an affected child had significantly less favourable attitudes to prenatal diagnosis than fathers without affected children. This suggests there may be an underlying trend for fathers of affected children to have more favourable attitudes toward prenatal diagnosis, which would be in keeping with other findings of the study. However, it must be stressed that the specific conditions showing a significant difference were not predicted in advance. These differences might have arisen by chance and future research would be needed to confirm the findings reported.

8.3.2 Attitudes of Mothers with and without an affected child towards PND

It was found that mothers with and without an affected child had very favourable attitudes towards prenatal diagnosis in total score, and the medians were the same in the two groups of mothers (see figure 21) (maximum score is 60 median is 56 in both cases). Mothers with and without an affected child had some similar and some different attitudes towards prenatal diagnosis for each condition, but differences were not significant, except that mothers without an affected child were significantly more favourable towards prenatal diagnosis in the not preferred gender condition (59% vs. 42%; P=0.023). This may have been a chance finding.

8.3.3 Attitudes of Fathers and Mothers with an affected child towards PND

It was found that fathers and mothers with an affected child had very favourable attitudes towards prenatal diagnosis in total scores, and the medians were almost the same between fathers and mothers with an affected child (see figure 21) (maximum score is 60 medians are 54 and 56).

Exploratory analyses showed that fathers with an affected child were significantly more favourable towards prenatal diagnosis than mothers with an affected child for six conditions: thalassaemia (96% vs. 81%; P=0.001), quadriplegia (96% vs. 79%; P<0.001), Duchenne muscular dystrophy (94% vs. 77%; P=0.001), cystic fibrosis (92% vs. 70%; P<0.001), trisomy 13 or 18 (93% vs. 81%; P=0.019), and phenylketonuria (92% vs. 80%; P=0.024) respectively. There were no conditions in which fathers of an affected child had significantly less favourable attitudes to prenatal diagnosis than mothers with affected children, which may suggest an underlying trend. Again however, the specific conditions showing a difference were not predicted in advance and further research is needed into both the trend, which is in the opposite direction from that for termination of the pregnancy, and the specific conditions involved.

8.3.4 Attitudes of Fathers and Mothers without an affected child towards PND

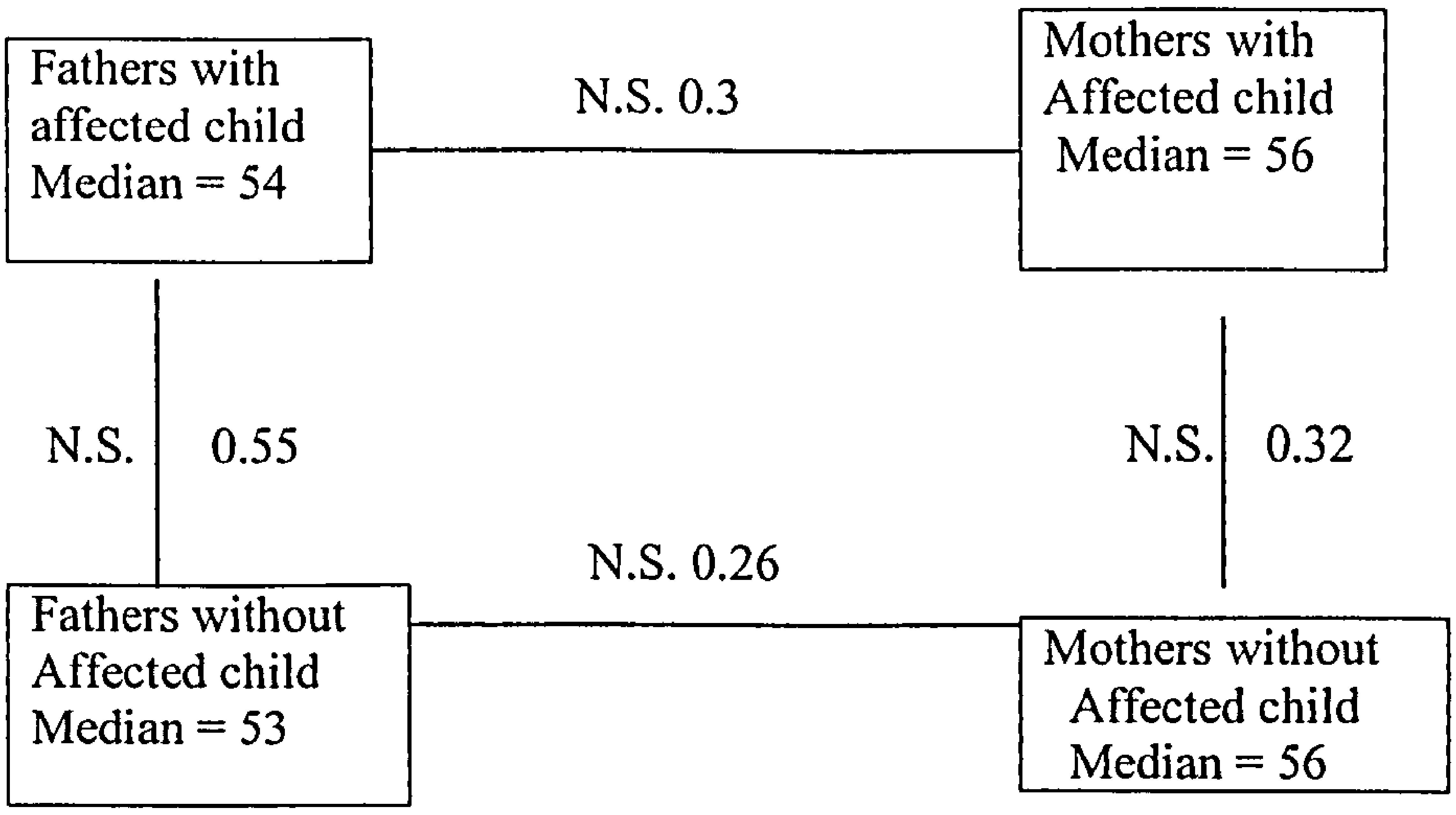
It was found that fathers and mothers without an affected child had very favourable attitudes toward prenatal diagnosis in total scores, and the medians were similar (see figure 21) (maximum score is 60 medians are 56 and 53).

Exploratory analyses revealed no significant differences for any of the 30 conditions.

8.3.5 Demographic comparisons of PND

It was found that parents with and without an affected child had different demographic characteristics, in terms of age, number of children, and monthly income. However, these differences in demographic characteristics did not explain group differences in attitudes towards prenatal diagnosis for the conditions studied, i.e. demographic differences were not introducing bias into the comparisons of attitudes between sample groups. All the groups of parents in the study had favourable attitudes toward prenatal diagnosis.

8.4 SUMMARY OF ATTITUDES TOWARDS PND



N.S = Not significant

Figure 21: Summary of parents' attitudes towards PND (Max score = 60)

The diagram shows the median total scores were high in all groups and comparison between all groups in total scores shows similar attitudes of Saudi parents in this study in relation to prenatal diagnosis. Thus, fathers and mothers with and without affected children all had generally favourable attitudes towards prenatal diagnosis.

8.5 ATTITUDES TOWARDS TERMINATION OF THE PREGNANCY: COMPARING GROUPS

This section addresses the second, third and fourth aims of the study, with respect to termination of pregnancy.

8.5.1 Attitudes of Fathers with and without an affected child towards TOP

It was apparent from the total scores, that fathers with an affected child were significantly more inclined than fathers without an affected child to accept termination of the pregnancy (P= 0.027) (maximum score is 60, medians are 19 and 12) see figure 22.

Exploratory analyses showed that fathers with an affected child were significantly more inclined than fathers without an affected child to terminate nine conditions: Duchenne muscular dystrophy (50% vs. 31%; P=0.009), schizophrenia (39% vs. 19%; P=0.003), high risk of alcoholism (34% vs. 15%; P=0.003), Klinefelter's syndrome (36% vs. 14%; P=0.001), epilepsy (29% vs. 13%; P=0.009), Huntingdon's disease (27% vs. 11%; P=0.006), quadriplegia (53% vs. 38%; P=0.047), diabetes (35% vs. 20%; P=0.026), and cystic fibrosis (31% vs. 17%; P=0.03) respectively. There were no conditions in which fathers of affected children had significantly less favourable attitudes to termination of the pregnancy than fathers without affected children. This suggests there may be an underlying trend for fathers of affected children to have more favourable attitudes towards termination of the pregnancy, which would be in keeping with other findings of the study. However, it must be stressed that the specific conditions showing a significant difference were not predicted in advance. These differences might have arisen by chance and future research would be needed to confirm the findings reported.

These results suggest that fathers without an affected child do not really appreciate how difficult is the burden that fathers with an affected child suffer. Hence, an affected child in the family influences fathers' attitude toward termination of the pregnancy.

8.5.2 Attitudes of Mothers with and without an affected child toward TOP

It was apparent from the total scores, that the difference in attitudes towards termination of the pregnancy of mothers with an affected child and mothers without an affected child were not significant in total score (maximum score is 60, medians are 22.5 and 18.5) see figure 22.

Exploratory analyses showed that mothers with an affected child were significantly more favourable towards termination of the pregnancy than mothers without an affected child in two conditions: diabetes (48% vs. 33%; P= 0.04), and cystic fibrosis (32% vs. 19%; P=0.05) respectively. There were no conditions in which mothers of affected children had significantly less favourable attitudes to termination of the pregnancy than mothers without affected children. This suggests there may be an underlying trend for mothers of affected children to have more favourable attitudes toward termination of the pregnancy, which would be in keeping with other findings of the study. However, it must be stressed that the specific conditions showing a significant difference were not predicted in advance. These differences might have arisen by chance and future research would be needed to confirm the findings reported.

These results suggest that mothers without an affected child have much more understanding of the implications of an affected child in the family than do fathers without an affected child. Hence, mothers without an affected child have attitudes toward termination of the pregnancy that are similar to those of mothers with an affected child, whereas fathers without an affected child were significantly less inclined than fathers with an affected child to accept termination.

8.5.3 Attitudes of Fathers and Mothers with an affected child towards TOP

The difference between fathers and mothers with an affected child in attitude towards termination of pregnancy was not significant in total scores (maximum score is 60, medians are 19 and 22.5) see figure 22.

Exploratory analyses showed that mothers with an affected child were significantly more inclined than fathers with an affected child to favour termination of the pregnancy in four conditions: Proteus syndrome (44% vs. 28%; P=0.027), Alzheimer's disease (16% vs. 5%; P=0.019), mild learning difficulty and mental retardation (16% vs. 4%; P=0.008), and cleft lip and palate (11% vs. 1%; P=0.005) respectively. There were no conditions in which mothers of an affected child had significantly less favourable attitudes to termination of the pregnancy than fathers with an affected child. This suggests there may be an underlying trend for mothers of affected children to have more favourable attitudes toward termination of the pregnancy, which would be in keeping with other findings of the study. However, it must be stressed that the specific conditions showing a significant difference were not predicted in advance. These differences might have arisen by chance and future research would be needed to confirm the findings reported.

8.5.4 Attitudes of Fathers and Mothers without an affected child towards TOP

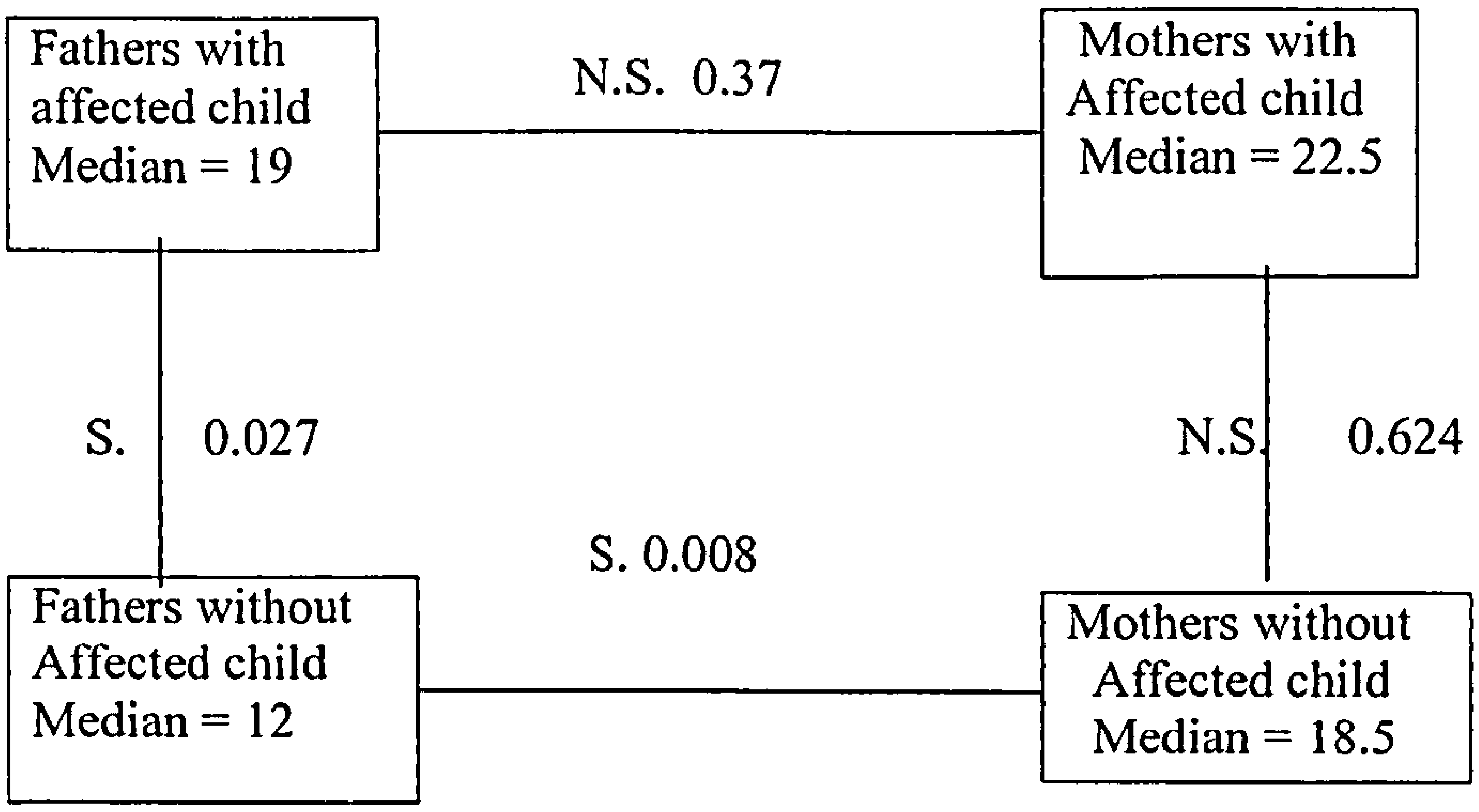
Mothers without an affected child were significantly more likely than fathers without an affected child to favour termination of the pregnancy (P=0.008) in total score (maximum score is 60, medians are 18.5 and 12) see figure 22.

Exploratory analyses showed that mothers without an affected child were more favourable towards termination of the pregnancy than fathers without an affected child in ten conditions: Proteus syndrome (39% vs. 24%; P=0.033), schizophrenia (33% vs. 19%; P=0.036), phenylketonuria (33% vs. 16%; P=0.008), Klinefelter's syndrome (31% vs. 14%; P=0.006), epilepsy (32% vs. 13%; P=0.002), Turner's syndrome (25% vs. 13%; P=0.046), Huntingdon's disease (23% vs. 11%; P=0.037), cancer (24% vs. 10%; P=0.014), moderate learning difficulty (18% vs. 6%; P=0.015), and deafness (14% vs. 4%; P=0.024). Fathers without an affected child were significantly more favourable than mothers without an affected child towards termination of the pregnancy in severe learning difficulty (55% vs. 38%; P= 0.023). This suggests there may be an underlying trend for mothers without an affected child to have more favourable attitudes towards termination of the pregnancy, which would be in keeping with other findings of the study. However, it must be stressed that the specific conditions showing a significant difference were not predicted in advance. These differences (especially the one going against the overall trend) might have arisen by chance and future research would be needed to confirm the findings reported.

8.5.5 Demographic comparisons of TOP

As noted earlier (see 8.3.5), the four groups of parents in this study differed in some demographic characteristics. To ensure that these differences were not introducing bias into the attitude comparisons, the comparisons were repeated within demographic bands. The differences in attitudes identified previously were still seen when demographic factors were taken into account.

8.6 SUMMARY OF ATTITUDES TOWARDS TOP



S = Significant

N.S = Not significant

Figure 22: Summary of the parents' attitudes towards TOP (Max score = 60)

The diagram above shows the median scores and comparisons between all groups of Saudi parents. The differences in attitudes toward termination of the pregnancy were not significant between the two groups of mothers, or between mothers and fathers with an affected child, but they were significant between mothers and fathers without an affected child at P=0.008, and between the two groups of fathers P=0.027. These findings show that fathers without an affected child held the least favourable attitudes toward termination of the pregnancy among all of the parents groups.

The overall trend (significant for fathers) that parents with affected children were more willing to accept termination of the pregnancy than parents without affected children was supported by some other studies (Meryash and Abuelo, 1988; Beeson and Golbus, 1985). They found that parents with X-linked conditions were more favourable towards termination of the pregnancy than the general population.

In contrast, other studies report that the majority of parents do not consider abortion acceptable for Down syndrome, and Huntington disease (Elkins, et al., 1986; Markel et al., 1987; Bryant, 2003). In Finnish, studies Hietala, et al (1995), and Aro, et al (1997) found that the Finnish population in general, and those with a child or other family member with aspartylglucosaminuria (AGU) had similar attitudes towards genetic testing and risk determination for a variety of genetically determined disorders.

As the above studies show, the literature in this area contains apparently conflicting findings. The studies differed in many respects and circumstances in which attitudes change in a more or a less favourable direction are unclear, and deserving of future study.

Since this study is the first of its kind to apply current research to the field of prenatal diagnosis and termination of pregnancy for a range of different conditions in Saudi Arabia, it explores important new areas of research and methodology. Although the results of the present study are important as an exploratory step for understanding parents' attitudes toward prenatal diagnosis and termination of pregnancy, it has some limitations which will be explored in the next section.

8.7 LIMITATIONS OF THE STUDY

There are several limitations in this study, for example, the location of the present study limits the generalizablity of the results, and thus, the study should be replicated in other settings to see if the results are confirmed. The findings obtained by the present research should be tested in other larger samples.

There are many other conditions which were not covered by the questionnaire in the present study, which parents might have different views about. Furthermore, the researcher could only interview four groups of parents with children affected by different conditions (metabolic disorder, thalassaemia and sickle cell anemia, cystic fibrosis, and deafness) presented in the questionnaire, because these conditions are common in Saudi Arabia. However, due to the difficulty and lack of time to interview other parents with experience of the rest of the conditions presented in the questionnaire, further investigation of their attitudes towards prenatal diagnosis and termination of pregnancy in their situation and other conditions, according to individuals' experience and how they view themselves, is important. In particular, no parents of children with chromosome abnormality were included in the present study.

In a Tunisan study of Muslim parents whose unborn children had an abnormal karyotype, with poor prognosis (chromosomal imbalance, physical and mental effects), 90 out of 95 parents opted to terminate the pregnancy (Chaabouni et al., 2001). Further, the sample of this study is not representative of the general population in Saudi Arabia; all participants were married with children. A study in Belgium (Ever-Kiebooms, et al., 1993) found that respondents who had not yet had children were more concerned about the risk of Down's syndrome at the age of 40 than those who already had children. In a Lebanese study, Zahed et al. (2002) found married individuals were significantly less favourable towards abortion than non married, and argued that this was because of acquired family values and responsibilities. Despite the fact that in the present study the researcher selected only parents of reproductive age to ensure that they were still able to have more children in the future, he did not ask whether or not the parents had plans to have more children in the future. Hence, those parents who did not plan to have more children in the future might have different attitudes towards prenatal diagnosis and termination of the pregnancy. Future research in Saudi Arabia should include people who are not yet parents and those who are not yet married.

8.7.1 Genetic risk and other factors

The present study indicates four important aspects of genetic disorder which parents may be concerned about, namely, characteristic of the condition, lifespan, level of care required and gender. However, genetic risk and strong chance of occurrence were not mentioned in the scenarios of the conditions. Hence, some parents might think the conditions mentioned in the questionnaire might happen only once and not realize they run in the family. Therefore, mentioning the risk of the condition might increase the burden and cause inclinations towards prenatal diagnosis and termination of pregnancy to increase. Such a trend was found in the study by Ever-Kiebooms, et al., (1993), in which varying proportions of respondents said they would solve the hypothetical genetic risk situation by giving up reproductive plans (38% in case of a 25% risk of physical handicap, 46% in case of a 25% risk of mental handicap and 20% in case of a 3-5% risk of early death) or by taking the risk and having children without prenatal diagnosis (8% in case of physical handicap, 6% in case of mental handicap and 17% in case of early death). Snowdon et al., (1997), questioned 1757 women booking for antenatal care in Britain, and found that 66% might consider abortion if there was a strong chance that the baby would be handicapped.

8.7.2 Tape recorder

Using a tape recorder is very important for a qualitative study, to increase the reliability by enabling analysis of the outcome by a different person. Also, recording parents' views in response to open questions would give more in-depth information about parents' feelings. Therefore, the researcher tried to use a tape recorder, but he was concerned about the validity, because parents refused to record their voice (See methodology chapter pilot study). Therefore, the researcher had some difficulty to write in detail what the parents said, which might have resulted in some important comments being missed. In addition, parents might have given more explanations in response to open-ended questions about the factors which might influence their attitudes toward prenatal diagnosis and termination of pregnancy. It is acknowledged that the method of data collection adopted imposed limits on the kind of analysis which could be conducted.

8.7.3 Translation of the interview from Arabic to English language

In translating parents' views from Arabic to the English language, the value of the parents' explanation might be missed, which is very important to understand the factors that affected parents' attitudes. Taking into consideration that there was no direct translation for many words or phrases and that there are differences in grammatical structure between English and Arabic, the researcher opted for free translation. This was to ensure that the meaning of participant's words was clearly presented. Literal translation (translating word-by-word) would have reduced the readability of the transcripts and the readers' ability to understand the participants' perspective (Birbili, 2000).

8.7.4 Setting and Data collection

Data was collected in Riyadh at King Faisal Specialist Hospital and Research Centre, where the researcher lives and works. Hence, the researcher could only interview those parents able to come and use the health services in King Faisal Specialist Hospital and Research Center, while those parents who lived in the villages, or could not use the health services, or attended another hospital because other factors prevented them coming, whose views are very important, were missing in this study. It may be speculated that their burden will be heavier than that of parents who are able to use health services. In addition, there may be differences related to factors such as accessibility of health services and resources, existence of and membership of support groups, and availability of leaflets in the clinics regarding the Fatwa. Questions on such, which were not included in this study, might have helped parents to recognize some other important factors, which they considered important in their daily life.

CHAPTER 9: FINAL DISCUSSION AND IMPLICATIONS

9.1 INTRODUCTION

This chapter aims to provide an overview of the findings that emerged from the research and compare them to similar studies reported in the literature to illustrate different attitudes towards prenatal diagnosis and termination of the pregnancy for a range of different conditions. This is very important research, in view of the fact that it is the first study of its kind concerning genetic testing for a range of different conditions in Saudi Arabia. Quantitative methods were used to build an overall picture of attitudes toward prenatal diagnosis and termination of pregnancy for a range of different conditions; then qualitative methods were employed to clarify the factors that affect parents' attitudes in more detail than could be obtained from the quantitative analysis. In addition, this chapter aims to consider the significant implications of these findings and draw recommendations from them with regard to the future study of parents' attitudes to prenatal diagnosis and termination of the pregnancy.

9.2 ATTITUDES TO PRENATAL DIAGNOSIS AND TERMINATION OF PREGNANCY: INTERNATIONAL COMPARISON.

In the present study, conditions were ranked according to the parents' attitudes towards termination of the pregnancy. In the cases of mild disorder or in the cases of severe clinical conditions, rank orders were similar to those reported from other populations (Wertz, et al., 1991; Hietala, et al., 1995, Hewison, et al., 2004). For instance, data from participants in the present study and in the above three studies showed that the situation in which they would be least inclined to favour termination of the pregnancy was sex preference (0.4%, 2%, 1.9% respectively), and one of their highest ranked choices was severe learning difficulty (58%, 55%, 35.7% respectively). For prenatal diagnosis (Hietala, et al., 1995, Hewison, et al., 2004) a similar trend was found in rank order for sex preference (18%, 34.4% respectively) and one of the highest conditions in the ranking order was severe learning difficulty (68%, 78% respectively). Furthermore, correlation tests showed a strong relationship between attitudes toward prenatal diagnosis and termination of the pregnancy across all conditions in this study (Spearman's. rho= +0.896). In the Leeds study (Hewison, et al., 2004), the correlation between prenatal diagnosis and termination of pregnancy across a range of different conditions was strong as well (Spearman's. rho= +0.821). As expected for any one condition, attitudes towards prenatal diagnosis were more favourable than towards termination of pregnancy, but across all conditions, attitudes towards termination of pregnancy became more favourable when attitudes towards prenatal diagnosis changed in that direction.

9.2.1 Attitudes to specific conditions in different cultures

It was found that parents with and without an affected child had favourable attitudes towards prenatal diagnosis, because Islam permits testing and parents wanted to reassure themselves about the pregnancy and prepare themselves for the coming baby. In this section, we will concentrate on parents' attitudes towards termination of the pregnancy looking at specific conditions, and compare the findings of this study to the Leeds sample, because the scenarios in the questionnaire in both studies were the same. However, the Saudi sample was divided into two groups: fathers with and without affected children and mothers with and without affected children, whereas in the Leeds study, the sample included only mothers and their previous conception history was not taken. In addition, half of the Leeds sample was white indigenous UK women and other half was UK Muslim Pakistani women. It was therefore decided to look more closely at the attitudes of the different subgroups by comparing only Saudi women without affected children to white indigenous UK women and UK Pakistani women, to avoid any kind of bias between the two studies

There was found a wide spectrum of attitudes to abortion. The highest proportions of respondents in this study and among UK white indigenous women and UK Pakistani women would terminate where the child would die early, such as a child born without brain (56% vs. 85.1%, 43%, respectively), and a child with trisomy 13 or 18 (56% vs. 66.8%, 29.6% respectively). For both conditions, attitudes were significantly more favourable in white indigenous UK women than Saudi women, but Saudi women were significantly more favourable towards termination than UK Pakistani women.

A substantial number of respondents in this study, and white indigenous UK women and UK Pakistani women would terminate where the child required lifelong care, such as in the case of severe learning difficulty (38% vs. 51.4%, 18.5% respectively). In this condition, attitudes were significantly more favourable in white indigenous UK women than Saudi women, but Saudi women were significantly more favourable than UK Pakistani women. The same was true in other conditions that required life long care such as quadriplegia (38% vs. 48.6%, 26.3% respectively). In this condition Saudi women were significantly more favourable than UK Pakistani women, but less favourable than UK white indigenous women

There was found a significantly more favourable inclination among the respondents in this study than in the white indigenous UK women and UK Pakistani women towards termination of the pregnancy, for the chromosomal abnormalities, such as Klinefelter's (31% vs. 10%, 15.3%), and Turner's (25% vs. 4.6%, 1.5%), but not muscular dystrophy (41% vs. 42.2%, 28.1%). Saudi women were significantly more favourable than UK Pakistani women, but not significantly different from white UK women in case of fragile X syndrome (20% vs.17.4%, 12.8%).

In the cases of autosomal recessive conditions, such as thalassaemia, diabetes, phenylketonuria, and cystic fibrosis which are common in Saudi society because of the high rate of consanguinity in marriage, it was found that the Saudi women were significantly more favourably disposed than the white indigenous UK women and UK Pakistani women towards termination in each of these conditions (thalassaemia, 40% vs. 13.7%, 14.6%. diabetes, 33% vs. 16%, 21.4%. Phenylketonuria, 33% vs. 2.3%, 4.6%) but not cystic fibrosis, (19% vs. 17.3%, 11.2%) for which although the Saudi women were more favourably inclined, the difference was not statistically significant.

It was found that the Saudi women were significantly more favourable than the white indigenous UK women and UK Pakistani women towards termination in the cases of late onset such as schizophrenia (33% vs. 19.8%, 15.4%), high risk of alcoholism (26% vs. 0.9%, 6.6%), cancer at 30 years old (24% vs. 11%, 16.4%), and coronary at 50 years old (9% vs. 1.8%, 3%), but not Huntingdon's disease (23% vs. 23%, 15.9%), or Alzheimer's disease (12% vs. 6%, 10%) for which the Saudi sample were more favourable but the difference was not significant.

It was found that the Saudi sample were significantly more favourably disposed than white indigenous UK women and UK Pakistani women towards termination of the pregnancy in cases which make other people stare, such as Proteus syndrome (39% vs. 9.7%, 7.6%), epilepsy (32% vs. 3.2%, 9.2%), absence of a limb (25% vs. 7.8%, 14.9%), dwarfism (17% vs. 4.1%, 7.1%), and deafness (14% vs. 2.3%, 4.6%). For blindness (13% vs. 4.1%, 12.8%), or being grossly overweight (12% vs.3.7%, 6.7%), Saudi women were significantly more favourable than white indigenous UK women and somewhat more favourable than UK Pakistani women but not significantly so. In addition, in the cases of mild learning disability (8% vs. 3.7%, 4%), autism (12% vs. 12.4%, 5%), and cleft lip and palate (5% vs. 2.3%, 4%) the Saudi women were more favourable than white indigenous UK women and UK Pakistani women, but not autism, where white indigenous UK women were more favourable, but not significantly so.

The last comparison of these groups was for the case where the foetus was not the preferred gender, none of the Saudi women were willing toward termination in this condition, whereas a small number of the white indigenous UK women and UK Pakistani women were favourable towards termination in this condition, but the differences were not significant (0%vs. 0.9%, 3%).

9.2.2 Factors that affect parents' attitude between the countries

Culture plays an important role to influence parents' attitudes towards termination of the pregnancy. This study and the study in Leeds have begun to identify some of the contributory factors that influence attitudes to prenatal diagnosis and termination of the pregnancy.

a) Health services, resources for a disabled child and support groups in UK are different than in Saudi Arabia,

b) Saudi traditions of marriage arrangement make the mother enquire after and prefer a wife for her son who is free from any kind of impairment or disability, although the prophet Mohamed encouraged Muslim men to look for piety in a bride above other qualities. Hence, Saudi parents are more worried about their daughter's future when she has any kind of impairment or disability, whereas in the western tradition, men and women can meet freely and may be won over by personality, irrespective of physical appearance.

c) Cultural importance is placed on sexual identity, and fertility (Christian et al., 2000), which are often associated with physical or behavioural manifestations (Petrueelli et al., 1998) in Saudi parents.

d) In Saudi tradition, children stay with or close to their parents even after they become adults, in contrast to the western tradition, as in the Leeds sample, where children leave their parents when they become more independent, which may make their parents less concerned about late onset conditions.

e) Despite the fact that the Saudi women and UK Pakistani women were Muslims, they were still significantly different in their attitudes towards termination of the pregnancy, which might indicate that religious beliefs are not the only factor that influences parents' attitudes towards termination of the pregnancy.

9.2.3 Factors that affect parents' attitudes

There are several possible explanations for parents' attitudes towards prenatal diagnosis and termination of the pregnancy for a range of different conditions within the same culture or different cultures, as found in this study. Saxton (1984 pp.307-308. cited in Weil 2000. pp. 268) writes:

> There is no doubt that there are disabled people who 'suffer' from their physical conditions. There are even those who may choose to end their lives rather than continue in pain or with severe limitations, but is this not obviously as true for non-disabled people who suffer from emotional pain and limitation of resource? [sic] As a group, people with disabilities do not 'suffer' any more than any other group or category of humans. Our limitations may be more outwardly visible, our need for help more apparent, but, like anybody else, the 'suffering' we may experience is a result of not enough human caring, acceptance, and respect.

That might be because the symptoms appear to result in reduced life satisfaction beyond the impairment or disability that they cause. Disability and quality of life do not describe the same phenomenon and should be differentiated from one another when they are being used to describe parents' experience. Therefore, illness may best be understood as partially bridging the gap between symptom expression and a person's self perceived quality of life. While there is likely to be some correlation between symptoms of illness and quality of life, not all therapeutic outcomes translate into meaningful benefit to an individual or family; given their own appraisal of their conditions and circumstances, and taking into account the adverse side effects that may be associated with treatment (Atkin, Waqar, and Anionwu. 2000. pp103-122). Some parents perceived conditions lower in the ranking order as major problems to them, according to their experience. Therefore, parents have different perceptions of the severity of various conditions, which cannot be determined on a clinical basis or from other parents' experiences. Tom Shakespeare (1998) has argued about the meaning of the International Classification of Impairment, Disability, and Handicap (ICIDH) which is different from what has been defined by Wood (1980). Tom Shakespeare argued that in distinguishing between impairment as a "medical condition of the body" and disability as "discrimination and prejudice in society", the disability movement reflects the medical model's focus on impairment as the defining characteristic of life as a disabled person.

Shakespeare has further argued that it is social barriers which create disability, and prejudice, rather than impairment. Therefore, the impact of disorders can be expressed in relation to three domains: symptoms, functional impairment or disability, and quality of life. Symptoms are the cognitive, behavioural, and affective characteristics associated with the disorder. Functional impairment, or disability, describes the impact of the disorder on one's ability to fulfil responsibilities as employee, family member, or friend. By contrast, quality of life is the person's subjective sense of well being, based on factors related to overall life satisfaction. These constructs have all been put forward as indicators of both the impact of disorder and parents' attitudes toward prenatal diagnoses and termination of pregnancy, and the adequacy of treatment interventions (Safren et al., 1997; Hager, 2002). Although these three constructs are distinct, they are closely related.

Impairment or disability is certainly related to the presence and characteristics of symptoms and changes in relation to symptom remission, which in turn could influence parents' attitudes (Oliver. 1996; Olfson et al., 1997). Furthermore, impairment or disability may be more severe at home, influencing marital relationships and homemaking, as compared to social and out of home occupational impairment or vice versa. Symptoms, impairment or disability, and quality of life were all moderately related in the experience of social anxiety disorder (Shakespeare, 1998; Mogotsi et al., 2000 Hambrick et al., 2003). However, a significant amount of the variance in quality of life is not accounted for by impairment or disability.

Impairment or disability and quality of life appear to be somewhat overlapping constructs that tap different aspects of parents' experiences, which is why the parents in this study and other similar studies had some similar and some different attitudes toward prenatal diagnosis and termination of the pregnancy.

Put another way, two people with the same disability can have very different levels of quality of life. It was shown in the qualitative data how different parents with the same condition had different views towards prenatal diagnosis and termination of the pregnancy. Hence, parents' views are specific to them, and specific to that condition

9.3 IMPLICATIONS OF THE STUDY

In this section, the findings summarized and discussed previously are translated into implications for policy and practice, for theory, and for research methods.

9.3.1 Implications for policy and practice

The implications are discussed for health care staff, for religious authorities, for health service planners and for societies at large.

9.3.1.1 Implications for health care staff

This study has described some aspects of parents' attitudes towards prenatal diagnosis and termination of pregnancy in an attempt to get as deep an understanding of the nature of parents' views as possible. It was found that different individuals have different experience. Hence, the individual's and parent's perception of their position in life needs to be assessed by health care staff in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Kersnik, 2003).

Individuals or parents who perceive their quality of life to be low might attribute this to having a disorder, and individuals might have a more serious perception of the condition due to its impact on their life (Capelli et al., 1989). Richards (1998), Rees et al., (2001), and Frank (2002) offer explanations of the factors relating to illness perception and note that an adolescent's perception of his/her physical health and the reaction of family members are important sources of discord in the family, which might influence individuals to perceive their conditions differently. Parents who perceive their affected children as having more serious problems may have a more negative perception of their own quality of life as a result. Therefore, individual disability is defined by social prejudice, not by physical or medical facts (Koch, 2001). It has been argued that if the general public was more familiar with the condition in an accurate way, discrimination and negative stereotyping might be reduced, potentially leading to improvements in affected individuals' life experiences (Shakespeare, 1998). It must also be acknowledged, however, that increased knowledge might in some circumstances have the opposite effect.

However, it must also be remembered that even if the attitudes reported are valid, attitudes should not be confused with behaviour; what people say does not always indicate what they will do. For instance, other studies showed that a majority of those at risk of Huntington's disease said they would have a genetic test when it became available, yet only a small proportion underwent the test when it did become available (Bundey 1997). Similar findings have been obtained for predictive testing for cancers in the both Europe and United States (Lerman et al., 1996; Doudok de Wit et al., 1997). Other studies have shown that after finding out that their child is affected with Downs syndrome, a much higher proportion of parents are willing to terminate the pregnancy than attitude studies would suggest (Mutton et al., 1998). This might indicate that when the parents face the real implications in their life, they might change their minds and go for termination. Hence, genetic counsellors should explore the implications that parents might face with their affected child according to their culture. However, in a country like Saudi Arabia, where termination is not allowed in all genetic conditions, there is no point in the genetic counsellor exploring the implications with the family, in the case of conditions for which termination is not allowed.

Health professionals may vary both in their knowledge of the conditions and in their perception of the quality of life in those affected by the conditions (Anionwu and Atkin 2001; Abramsky et al., 2001). There is evidence from other studies to show that parents counselled by a clinical geneticist or a specialist pediatrician are more likely to continue a pregnancy affected with a sex chromosome anomaly than those counselled by other health professionals such as obstetricians (Homes-Siedle et al., 1987; Robinson et al., 1989). It is widely acknowledged that following the diagnosis of a fetal abnormality, decisions concerning whether to terminate the pregnancy or not should be made by a woman and her partner, based on good information, supported, but not influenced, by health professionals (Gessner, 2003). Therefore, in line with the notions of informed choice and freedom but within the boundaries permitted by law, it is important to explore the broader social and cultural context in which decisions are taken, and allow parents to explain their concerns according to their individuals' experience, which might influence their attitudes toward prenatal diagnosis and termination of pregnancy.

9.3.1.2 Implications for religious authorities

Prenatal diagnosis and termination of the pregnancy in Saudi Arabia should be offered according to the Saudi culture. Culture can be defined as the ideation, symbols, behaviours, values, and beliefs that are shared by a human group (Banks, 1997, p.8). A person's culture, therefore, can be shaped by many factors including but not limited to religion, race, economic status, level of education, and environmental factors. Although it is wise to avoid underestimating the role of various other factors, Islam is undoubtedly the main factor responsible for shaping the Saudi culture. Alkuraya and Kilani (2001) showed the importance of the Fatwa to Muslim parents and how their attitudes to termination of pregnancy changed after they were told the correct Fatwa.

In the past, Islamic authorities have allowed termination of the pregnancy only if the woman's life was at risk. After awareness of genetic conditions increased, and prenatal diagnosis become possible, the Islamic authorities had to give a Fatwa based on the severity of the condition, the criterion being whether or not it is treatable, in the physicians' view, in order to safeguard family life by preventing the birth of children with such conditions. Therefore, Islamic authorities agreed that two physicians should decide whether the condition is severe or not. They will decide what they think and tell the Islamic authority. However, physicians sometimes have different opinions about the severity of a condition, as found in Zahad's and Nabulsi study (2002). As a result, the Islamic authorities face a dilemma. It was found from the present study that different parents did not have the same perception about the characteristics of genetic conditions.

As argued above, physicians should understand how parents perceive their child's condition and the kinds of difficulty that parents face from their individual experience. This would give physicians a clearer view about parents' concerns, so they can convey them to the religious authority. How parents perceive their condition based on their individual experience may influence whether or not it is classed as severe and, hence, whether or not termination is acceptable. One of the implications from the findings in this study seems to be that promoting cultural awareness among health care professionals would improve their confidence and skills in treating the whole quality of life of the person, rather than just particular isolated symptoms (Murphy and Clark, 1993).

9.3.1.3 Implications for health service planners

The positive attitude towards prenatal diagnosis found in this study reflects the overall positive attitudes of the population towards health care. Hence, it should be borne in mind that it makes sense for health service planners to understand the implications that the parents with an affected child might face when there is a lack of health services around them.

This study showed that lack of health services and rehabilitation centres in the villages increased parents' suffering and made it difficult to cope with their affected child. Atkin (1998, 2000) mentioned the importance of the health services in society and how it influences parents' attitudes. Therefore, understanding the impact of care on patients' overall quality of life is important in establishing the social value of health care interventions. Indeed, in some instances reduction in symptoms may not result in measurably higher quality of life (Swanson, 2003). Therefore, patients' views about their condition play an important role in health care policy decisions and their evaluation of care can be use as a tool for quality improvement (Donabedian, 1992; Baker, 1996; Kersnik, 2003).

9.3.1.4 Responsibility of society

In this study, some sources of concern about genetic testing were revealed. The possibility of discrimination on the basis of test results and the concept of disturbing the order of nature made some respondents hesitant or negative towards gene tests. Hence, lack of knowledge about the nature of the genetic diseases in society increased parents' burden and isolated them from society. Therefore, awareness of genetic diseases in society is very important to support the families with an affected child so they are not isolated from society. Also, increasing the level of trust in health care, including medical genetics, informing the public and educating health care personnel must be made high priorities when launching testing programmes in Saudi Arabia.

Social support has been identified as a major factor relevant to parents of children with disabilities, women who have experienced reproductive loss, and parents during the terminal illness of their child (Rando, 1983; Harper, 1998; Weil, 2000). Conversely, social barriers play an important role in creating disability. The difficulties of living as a disabled person are often due to discrimination and prejudice, rather than impairment; social oppression is the main problem for disabled people (Oliver, 1990; Shakespeare, 1998; Gollust et al., 2003). Despite the prevalence of genetic disorders, and the availability of treatment and media exposure, many lay people and professionals are still unaware of their impact on the individual, his/her family and environment.

According to the findings of this study, Saudi parents are surrounded by many barriers in their society, which make it difficult for them to cope with their affected child. They are reluctant to disclose their secret to others, and so carry the burden alone to safeguard their reputation. The way of getting married in Saudi society, as mentioned earlier (See chapter three section 3.2) influences parents with an affected child to hide the truth about their affected child, in order to safeguarded their reputation and their healthy children's future marriage prospects, which could be changed by the stigma of genetic disorder. In addition, parents had considered the implications of having an affected child for other family members. This was one of the main issues that parents with an affected child were concerned about; because of the way that a mother shops for a normal wife for her son to marry, she will prefer to choose a family free from any kind of genetic disorder. For these kinds of reasons, Saudi parents were just as, or even more concerned, about the quality of their life and their child's life in society, than the impairment or the disability of the condition itself. Creating an ideal world is difficult, as Shakespeare (1998) has pointed out.

9.3.2 Methodological implications for future research

It was found that in order to examine Saudi parents' attitudes towards prenatal diagnosis and termination of pregnancy from different perspectives, employing different research methods and designs was very helpful. Indeed, in this study an attempt has been made to go beyond the binary distinction between quantitative and qualitative research. That is, there has been an attempt to employ both approaches in combination and to draw on both perspectives in appropriate contexts in order to capitalise on the strengths of the different techniques and combine them in this research project. However, it should be made clear that each method has its own strengths and weaknesses, especially when considered in relation to a particular problem. In the case of this study, the aim was to assess parents' attitudes towards prenatal diagnosis and termination of the pregnancy for a range of different conditions, and also the factors that affect these attitudes. It is apparent that the methodology that was used for addressing the research questions was useful because the combination of quantitative and qualitative techniques elicited different kinds of information needed to fulfil the research objectives. The questionnaire in the quantitative method was used to probe for any differences in the attitudes toward prenatal diagnosis and termination of pregnancy for a range of different conditions among parents with and without an affected child, resulting from their different experiences. It was useful in identifying patterns, especially in terms of the variation and strength of parents' attitudes.

On the other hand, the questions in the qualitative interview were useful because parents with and without an affected child could address their individual experience, and describe the factors that influenced their attitudes. From the literature consulted, the qualitative method has not been used before to assess Saudi parents attitudes toward prenatal diagnosis and termination of the pregnancy. Thus, use of a variety of methods of data collection facilitates validation of the findings (Seliger and Shohamy, 1989:122; Pope and Mays, 1995) by demonstrating the same findings through different sources.

Researchers use a variety of methods of investigation that are related to each other. For example, Saudi parents have their own traditions. In interviewing the parents, the researcher's gender is important; it should match parents' gender, in order to break the barrier between the researchers and parents. Woollett and Dosanjh-Matwala (1990a) showed that Asian women are willing to talk openly if the researcher's characteristics such as gender, ethnicity and spoken language are matched with the participant's. Bowes and Domokos (1996) also comment that matching the researcher to the participants on such characteristics empowers the participants to express their views. Evidence of this was also noted during the present studies. In contrast, the same researcher conducted a study in the same country (Alsulaiman 2000) about *attitudes toward prenatal and preimplantation* genetic diagnosis where both partners were together in the interview and he noticed that the father dominated the interview, and the researcher could not go in depth. By contrast, in the present study, interviews were conducted separately, and parents felt free to talk about their views. Furthermore, collecting data by means of face to face interviews is important in Saudi Arabia. Self completion questionnaires might not be useful there, because Saudi parents are not familiar with the idea of filling in a questionnaire and sending it back. Other members of the family might fill in the questionnaire, and the Saudi mail system is different from the UK one, as explained before (See chapter five methodology section 5.4.1). The present study met a need for getting information from parents.

9.4 CONCLUSION

The major conclusion from the above findings is that Saudi parents are favourably inclined towards prenatal diagnosis and there is a strong correlation between parents' attitudes toward prenatal diagnosis and termination of the pregnancy in a range of diseases. However, parents have different attitudes towards prenatal diagnosis and termination of the pregnancy between conditions; this finding suggests that parents' perceive the genetic condition differently according to their individual experience. Hence, a great deal of knowledge about parents' culture and experience and a large range of powerful strategies for attacking parents' problems through proper counselling, would encourage development of more effective ways of addressing problems such as the effect of the disabled child on other family members' marriage prospects. Also, it was apparent that the kind of participants (e.g. with or without an affected child) and parents' individual experience both play a critical part within and between countries in influencing attitudes toward prenatal diagnosis and termination of pregnancy. New technologies provide parents with more reproductive choices but also present them with more dilemmas because of the choices they have to make and religious opinion about their choices.

9.5 RECOMMENDATIONS

It is hoped that what has been learned from this research will contribute to future research. Thus, in this section, several recommendations are made for the benefit of the authorities of health services and religious authorities. I would recommend that when a solution is proposed to the ongoing problems of using prenatal tests in different conditions, we should not implement it without prior investigation and careful study of the consequences. While the following recommendations are open for debate, they are least to be offered at this point:

1. The custom of consanguineous marriage and the way of getting married are deeply rooted in Arab culture and may not be widely discouraged; however, given the value placed on healthy children, parents may be encouraged to participate in a screening programme and genetic counselling service aimed at couples who are heterozygous

carriers. Progress in medical genetics and medically assisted procreation allow some at risk parents to have healthy children. However, both doctors and parents can achieve this goal only after a long process of which each step has to be carefully considered. Therefore, learning about how parents' cultural values and religious beliefs affect their perceptions of heath and illness, will allow health professionals to improve the quality of assessment and intervention and provide culturally appropriate care. Studies should also be conducted of the beliefs and attitudes of married couples who have not yet had children, of people not yet married, and of people with children of marriageable age.

2. The attitudes and beliefs of health care providers and religious authorities in Saudi Arabia toward prenatal diagnosis and termination of pregnancy in a range of different conditions such as those presented in the questionnaire need to be explored and compared with the parents' attitudes reported in this study. This is necessary in order to understand the similarities and differences in views between them, since investigators from other countries (Faden et al., 1987; Ever-Kiebooms et al., 1992; Darke et al., 1996) have shown that health professionals usually have more positive attitudes towards termination of pregnancy for foetal abnormality than do lay groups.

3. Having an ideal world is difficult. Therefore, finding ways of increasing social awareness of genetic disorders and the implications of new genetic technologies is important to make people aware of genetic disorders and reduce the stigma and social isolation experienced by parents with an affected child.

4. Parents' views and understanding of the nature of the test they going to have are very important. Therefore, research is needed to examine how informed choice may be maximised.

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Appendix 1: The frequency tables

Fathers attitudes toward PND (Score out of 60)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	4	2.0	2.0	2.0
	2.00	1	.5	.5	2.5
	6.00	1	.5	.5	3.0
	8.00	1	.5	.5	3.5
	10.00	2	1.0	1.0	4.5
	12.00	2	1.0	1.0	5.5
	14.00	1	.5	.5	6.0
	16.00	2	1.0	1.0	7.0
	18.00	3	1.5	1.5	8.5
	19.00	1	.5	.5	9.0
	20.00	2	1.0	1.0	10.0
	22.00	2	1.0	1.0	11.0
	24.00	1	.5	.5	11.5
	28.00	2	1.0	1.0	12.5
	29.00	1	.5	.5	13.0
	30.00	2	1.0	1.0	14.0
	31.00	2	1.0	1.0	15.0
	32.00	4	2.0	2.0	17.0
	33.00	3	1.5	1.5	18.5
	34.00	1	.5	.5	19.0
	36.00	5	2.5	2.5	21.5
	38.00	2	1.0	1.0	22.5
	39.00	3	1.5	1.5	24.0
	40.00	4	2.0	2.0	26.0
	41.00	1	.5	.5	26.5
	42.00	4	2.0	2.0	28.5
	43.00	2	1.0	1.0	29.5
	44.00	4	2.0	2.0	31.5
	45.00	1	.5	.5	32.0
	46.00	5	2.5	2.5	34.5
	47.00	2	1.0	1.0	35.5
	48.00	6	3.0	3.0	38.5
	49.00	2	1.0	1.0	39.5
	50.00	5	2.5	2.5	42.0
	51.00	3	1.5	1.5	43.5
	52.00	9	4.5	4.5	48.0
	53.00	3	1.5	1.5	49.5
	54.00	12	6.0	6.0	55.5
	55.00	2	1.0	1.0	56.5
	56.00	16	8.0	8.0	64.5
	57.00	9	4.5	4.5	69.0
	58.00	32	16.0	16.0	85.0
	59.00	2	1.0	1.0	86.0
	60.00	28	14.0	14.0	100.0
	Total	200	100.0	100.0	

a.

Mothers attitudes towrd PND (Score out of 60)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	9	4.5	4.5	4.5
	2.00	2	1.0	1.0	5.5
	4.00	3	1.5	1.5	7.0
	5.00	1	.5	.5	7.5
	6.00	3	1.5	1.5	9.0
	8.00	1	.5	.5	9.5
	10.00	3	1.5	1.5	11.0
	13.00	1	.5	.5	11.5
	14.00	1	.5	.5	12.0
	18.00	2	1.0	1.0	13.0
	20.00	3	1.5	1.5	14.5
	21.00	1	.5	.5	15.0
	22.00	2	1.0	1.0	16.0
	24.00	1	.5	.5	16.5
	27.00	1	.5	.5	17.0
	28.00	2	1.0	1.0	18.0
	30.00	2	1.0	1.0	19.0
	31.00	1	.5	.5	19.5
	32.00	4	2.0	2.0	21.5
	33.00	2	1.0	1.0	22.5
	34.00	1	.5	.5	23.0
	35.00	2	1.0	1.0	24.0
	36.00	2	1.0	1.0	25.0
	37.00	2	1.0	1.0	26.0
	38.00	2	1.0	1.0	27.0
	40.00	5	2.5	2.5	29.5
	41.00	3	1.5	1.5	31.0
	42.00	1	.5	.5	31.5
	43.00	3	1.5	1.5	33.0
	44.00	3	1.5	1.5	34.5
	45.00	2	1.0	1.0	35.5
	46.00	2	1.0	1.0	36.5
	47.00	3	1.5	1.5	38.0
	48.00	3	1.5	1.5	39.5
	49.00	2	1.0	1.0	40.5
	50.00	2	1.0	1.0	41.5
	51.00	2	1.0	1.0	42.5
	52.00	3	1.5	1.5	44.0
	53.00	1	.5	.5	44.5
	54.00	4	2.0	2.0	46.5
	55.00	4	2.0	2.0	48.5
	56.00	7	3.5	3.5	52.0
	57.00	2	1.0	1.0	53.0
	58.00	32	16.0	16.0	69.0
	59.00	6	3.0	3.0	72.0
	60.00	56	28.0	28.0	100.0
	Total	200	100.0	100.0	

a.

Attitudes to fathers and mothers with an affected child towrd PND (Scour out of 60)[a]

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	7	3.5	3.5	3.5
	2.00	1	.5	.5	4.0
	4.00	2	1.0	1.0	5.0
	5.00	1	.5	.5	5.5
	6.00	1	.5	.5	6.0
	8.00	1	.5	.5	6.5
	10.00	4	2.0	2.0	8.5
	12.00	1	.5	.5	9.0
	14.00	1	.5	.5	9.5
	16.00	2	1.0	1.0	10.5
	18.00	3	1.5	1.5	12.0
	20.00	2	1.0	1.0	13.0
	22.00	1	.5	.5	13.5
	24.00	1	.5	.5	14.0
	28.00	2	1.0	1.0	15.0
	30.00	2	1.0	1.0	16.0
	31.00	3	1.5	1.5	17.5
	32.00	6	3.0	3.0	20.5
	33.00	3	1.5	1.5	22.0
	34.00	1	.5	.5	22.5
	35.00	1	.5	.5	23.0
	36.00	4	2.0	2.0	25.0
	38.00	2	1.0	1.0	26.0
	40.00	7	3.5	3.5	29.5
	41.00	1	.5	.5	30.0
	42.00	2	1.0	1.0	31.0
	43.00	1	.5	.5	31.5
	44.00	3	1.5	1.5	33.0
	45.00	2	1.0	1.0	34.0
	46.00	4	2.0	2.0	36.0
	47.00	1	.5	.5	36.5
	48.00	4	2.0	2.0	38.5
	49.00	1	.5	.5	39.0
	50.00	4	2.0	2.0	41.0
	51.00	4	2.0	2.0	43.0
	52.00	6	3.0	3.0	46.0
	54.00	10	5.0	5.0	51.0
	55.00	3	1.5	1.5	52.5
	56.00	15	7.5	7.5	60.0
	57.00	9	4.5	4.5	64.5
	58.00	35	17.5	17.5	82.0
	59.00	3	1.5	1.5	83.5
	60.00	33	16.5	16.5	100.0
	Total	200	100.0	100.0	

a.

Attitudes to fathers and mothers without an affected child toward PND (Score out of 60)[a]

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	6	3.0	3.0	3.0
	2.00	2	1.0	1.0	4.0
	4.00	1	.5	.5	4.5
	6.00	3	1.5	1.5	6.0
	8.00	1	.5	.5	6.5
	10.00	1	.5	.5	7.0
	12.00	1	.5	.5	7.5
	13.00	1	.5	.5	8.0
	14.00	1	.5	.5	8.5
	18.00	2	1.0	1.0	9.5
	19.00	1	.5	.5	10.0
	20.00	3	1.5	1.5	11.5
	21.00	1	.5	.5	12.0
	22.00	3	1.5	1.5	13.5
	24.00	1	.5	.5	14.0
	27.00	1	.5	.5	14.5
	28.00	2	1.0	1.0	15.5
	29.00	1	.5	.5	16.0
	30.00	2	1.0	1.0	17.0
	32.00	2	1.0	1.0	18.0
	33.00	2	1.0	1.0	19.0
	34.00	1	.5	.5	19.5
	35.00	1	.5	.5	20.0
	36.00	3	1.5	1.5	21.5
	37.00	2	1.0	1.0	22.5
	38.00	2	1.0	1.0	23.5
	39.00	3	1.5	1.5	25.0
	40.00	2	1.0	1.0	26.0
	41.00	3	1.5	1.5	27.5
	42.00	3	1.5	1.5	29.0
	43.00	4	2.0	2.0	31.0
	44.00	4	2.0	2.0	33.0
	45.00	1	.5	.5	33.5
	46.00	3	1.5	1.5	35.0
	47.00	4	2.0	2.0	37.0
	48.00	5	2.5	2.5	39.5
	49.00	3	1.5	1.5	41.0
	50.00	3	1.5	1.5	42.5
	51.00	1	.5	.5	43.0
	52.00	6	3.0	3.0	46.0
	53.00	4	2.0	2.0	48.0
	54.00	6	3.0	3.0	51.0
	55.00	3	1.5	1.5	52.5
	56.00	8	4.0	4.0	56.5
	57.00	2	1.0	1.0	57.5
	58.00	29	14.5	14.5	72.0
	59.00	5	2.5	2.5	74.5
	60.00	51	25.5	25.5	100.0
	Total	200	100.0	100.0	

a.

Fathers attitudes toward TOP (Scoure out of 60)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	20	10.0	10.0	10.0
	1.00	3	1.5	1.5	11.5
	2.00	8	4.0	4.0	15.5
	3.00	3	1.5	1.5	17.0
	4.00	14	7.0	7.0	24.0
	5.00	3	1.5	1.5	25.5
	6.00	5	2.5	2.5	28.0
	7.00	4	2.0	2.0	30.0
	8.00	7	3.5	3.5	33.5
	9.00	6	3.0	3.0	36.5
	10.00	6	3.0	3.0	39.5
	11.00	2	1.0	1.0	40.5
	12.00	13	6.5	6.5	47.0
	13.00	2	1.0	1.0	48.0
	14.00	6	3.0	3.0	51.0
	15.00	2	1.0	1.0	52.0
	16.00	11	5.5	5.5	57.5
	17.00	2	1.0	1.0	58.5
	18.00	4	2.0	2.0	60.5
	19.00	5	2.5	2.5	63.0
	20.00	2	1.0	1.0	64.0
	21.00	3	1.5	1.5	65.5
	22.00	4	2.0	2.0	67.5
	23.00	3	1.5	1.5	69.0
	24.00	5	2.5	2.5	71.5
	25.00	2	1.0	1.0	72.5
	26.00	3	1.5	1.5	74.0
	27.00	5	2.5	2.5	76.5
	28.00	3	1.5	1.5	78.0
	29.00	3	1.5	1.5	79.5
	30.00	3	1.5	1.5	81.0
	31.00	4	2.0	2.0	83.0
	32.00	5	2.5	2.5	85.5
	33.00	3	1.5	1.5	87.0
	35.00	3	1.5	1.5	88.5
	36.00	5	2.5	2.5	91.0
	37.00	2	1.0	1.0	92.0
	38.00	1	.5	.5	92.5
	40.00	4	2.0	2.0	94.5
	41.00	1	.5	.5	95.0
	42.00	2	1.0	1.0	96.0
	43.00	2	1.0	1.0	97.0
	45.00	2	1.0	1.0	98.0
	47.00	1	.5	.5	98.5
	48.00	1	.5	.5	99.0
	52.00	1	.5	.5	99.5
	58.00	1	.5	.5	100.0
	Total	200	100.0	100.0	

a.

Attitudes fathers and mothers with an affected child toward TOP (Score out of 60)[a]

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	29	14.5	14.5	14.5
	1.00	4	2.0	2.0	16.5
	2.00	8	4.0	4.0	20.5
	3.00	2	1.0	1.0	21.5
	4.00	6	3.0	3.0	24.5
	5.00	5	2.5	2.5	27.0
	6.00	6	3.0	3.0	30.0
	7.00	3	1.5	1.5	31.5
	8.00	3	1.5	1.5	33.0
	9.00	4	2.0	2.0	35.0
	10.00	1	.5	.5	35.5
	11.00	2	1.0	1.0	36.5
	12.00	2	1.0	1.0	37.5
	13.00	1	.5	.5	38.0
	14.00	1	.5	.5	38.5
	15.00	1	.5	.5	39.0
	16.00	8	4.0	4.0	43.0
	17.00	4	2.0	2.0	45.0
	18.00	4	2.0	2.0	47.0
	19.00	3	1.5	1.5	48.5
	20.00	6	3.0	3.0	51.5
	21.00	2	1.0	1.0	52.5
	22.00	4	2.0	2.0	54.5
	23.00	3	1.5	1.5	56.0
	24.00	5	2.5	2.5	58.5
	25.00	3	1.5	1.5	60.0
	26.00	5	2.5	2.5	62.5
	27.00	5	2.5	2.5	65.0
	28.00	2	1.0	1.0	66.0
	29.00	4	2.0	2.0	68.0
	30.00	4	2.0	2.0	70.0
	31.00	3	1.5	1.5	71.5
	32.00	5	2.5	2.5	74.0
	33.00	5	2.5	2.5	76.5
	34.00	3	1.5	1.5	78.0
	35.00	3	1.5	1.5	79.5
	36.00	5	2.5	2.5	82.0
	37.00	5	2.5	2.5	84.5
	38.00	2	1.0	1.0	85.5
	40.00	2	1.0	1.0	86.5
	41.00	1	.5	.5	87.0
	42.00	4	2.0	2.0	89.0
	43.00	3	1.5	1.5	90.5
	44.00	1	.5	.5	91.0
	45.00	2	1.0	1.0	92.0
	46.00	1	.5	.5	92.5
	47.00	2	1.0	1.0	93.5
	48.00	3	1.5	1.5	95.0
	52.00	2	1.0	1.0	96.0
	54.00	1	.5	.5	96.5
	55.00	1	.5	.5	97.0
	56.00	2	1.0	1.0	98.0
	58.00	4	2.0	2.0	100.0
	Total	200	100.0	100.0	

a.

Attitudes of fathers and mothers without an affected child toward TOP (Score out of 60)[a]

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	20	10.0	10.0	10.0
	1.00	4	2.0	2.0	12.0
	2.00	6	3.0	3.0	15.0
	3.00	3	1.5	1.5	16.5
	4.00	15	7.5	7.5	24.0
	5.00	2	1.0	1.0	25.0
	6.00	2	1.0	1.0	26.0
	7.00	4	2.0	2.0	28.0
	8.00	8	4.0	4.0	32.0
	9.00	5	2.5	2.5	34.5
	10.00	6	3.0	3.0	37.5
	11.00	2	1.0	1.0	38.5
	12.00	14	7.0	7.0	45.5
	13.00	4	2.0	2.0	47.5
	14.00	8	4.0	4.0	51.5
	15.00	5	2.5	2.5	54.0
	16.00	6	3.0	3.0	57.0
	17.00	3	1.5	1.5	58.5
	18.00	5	2.5	2.5	61.0
	19.00	3	1.5	1.5	62.5
	20.00	5	2.5	2.5	65.0
	21.00	1	.5	.5	65.5
	22.00	2	1.0	1.0	66.5
	23.00	2	1.0	1.0	67.5
	24.00	4	2.0	2.0	69.5
	25.00	6	3.0	3.0	72.5
	26.00	3	1.5	1.5	74.0
	27.00	2	1.0	1.0	75.0
	28.00	5	2.5	2.5	77.5
	29.00	3	1.5	1.5	79.0
	30.00	2	1.0	1.0	80.0
	31.00	3	1.5	1.5	81.5
	32.00	2	1.0	1.0	82.5
	33.00	3	1.5	1.5	84.0
	34.00	3	1.5	1.5	85.5
	35.00	2	1.0	1.0	86.5
	36.00	4	2.0	2.0	88.5
	37.00	1	.5	.5	89.0
	38.00	2	1.0	1.0	90.0
	39.00	4	2.0	2.0	92.0
	40.00	2	1.0	1.0	93.0
	41.00	3	1.5	1.5	94.5
	42.00	2	1.0	1.0	95.5
	45.00	2	1.0	1.0	96.5
	50.00	2	1.0	1.0	97.5
	52.00	1	.5	.5	98.0
	54.00	1	.5	.5	98.5
	55.00	1	.5	.5	99.0
	56.00	1	.5	.5	99.5
	58.00	1	.5	.5	100.0
	Total	200	100.0	100.0	

a. CLINIC = 5

Mothes attitudes toward TOP (Score out of 60[a])

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	29	14.5	14.5	14.5
	1.00	5	2.5	2.5	17.0
	2.00	6	3.0	3.0	20.0
	3.00	2	1.0	1.0	21.0
	4.00	7	3.5	3.5	24.5
	5.00	4	2.0	2.0	26.5
	6.00	3	1.5	1.5	28.0
	7.00	3	1.5	1.5	29.5
	8.00	4	2.0	2.0	31.5
	9.00	3	1.5	1.5	33.0
	10.00	1	.5	.5	33.5
	11.00	2	1.0	1.0	34.5
	12.00	3	1.5	1.5	36.0
	13.00	3	1.5	1.5	37.5
	14.00	3	1.5	1.5	39.0
	15.00	4	2.0	2.0	41.0
	16.00	3	1.5	1.5	42.5
	17.00	5	2.5	2.5	45.0
	18.00	5	2.5	2.5	47.5
	19.00	1	.5	.5	48.0
	20.00	9	4.5	4.5	52.5
	22.00	2	1.0	1.0	53.5
	23.00	2	1.0	1.0	54.5
	24.00	4	2.0	2.0	56.5
	25.00	7	3.5	3.5	60.0
	26.00	5	2.5	2.5	62.5
	27.00	2	1.0	1.0	63.5
	28.00	4	2.0	2.0	65.5
	29.00	4	2.0	2.0	67.5
	30.00	3	1.5	1.5	69.0
	31.00	2	1.0	1.0	70.0
	32.00	2	1.0	1.0	71.0
	33.00	5	2.5	2.5	73.5
	34.00	6	3.0	3.0	76.5
	35.00	2	1.0	1.0	77.5
	36.00	4	2.0	2.0	79.5
	37.00	4	2.0	2.0	81.5
	38.00	3	1.5	1.5	83.0
	39.00	4	2.0	2.0	85.0
	41.00	3	1.5	1.5	86.5
	42.00	4	2.0	2.0	88.5
	43.00	1	.5	.5	89.0
	44.00	1	.5	.5	89.5
	45.00	2	1.0	1.0	90.5
	46.00	1	.5	.5	91.0
	47.00	1	.5	.5	91.5
	48.00	2	1.0	1.0	92.5
	50.00	2	1.0	1.0	93.5
	52.00	2	1.0	1.0	94.5
	54.00	2	1.0	1.0	95.5
	55.00	2	1.0	1.0	96.5
	56.00	3	1.5	1.5	98.0
	58.00	4	2.0	2.0	100.0
	Total	200	100.0	100.0	

a.

بسم الله الرحمن الرحيم

Appendix 2: Scholar notes about the Islamic views towards PS,PND, and TOP

صاحب السعادة الأخ العزيز الأستاذ أيمن بن عبدالعزيز السليمان سلمه الله

سلام عليكم ورحمة الله وبركاته وبعد التحية

وصلتني رسالتكم المتعلقة بمعاناة بعض الأسر بسبب إصابة أحد أبنائها بمرض وراثي وتسأل عن الحكم الشرعي في بعض الوسائل التي تمنع من حصول ذلك من أجل تضمين ذلك في أطروحتكم العلمية ، وأحب أن أتقدم لكم بالشكر على اختيار هذا الموضوع الجدير بالبحث فإن الحاجة شديدة لدراسة هذا العنوان ولازلت أتلقى العديد من الأسئلة حوله سواء كان من أطباء يريدون التعرف على حكم الشريعة الإسلامية أو من الآباء والأمهات الذين تعرض أبناؤهم لمثل ذلك أو من المحتمل أن يتعرضوا له ، ولاشك أن معرفة الحكم الشرعي في مثل هذه المسألة ينتج عنها فوائد عديدة منها حصول رضا رب العالمين على العبد باتباعه لشريعته ومنها حصول المصلحة فإن الشريعة الإسلامية مبنية على جلب المصالح ودرء المفاسد كما قال تعالى: (وما أرسلناك إلا رحمة للعالمين) فانظر كيف استعمل مصطلح (العالمين) الذي يشمل أهل الإسلام وغيرهم والمتأمل في تعاليل الأحكام يجد أن النصوص الشرعية كثيراً ما تجعل السبب في تشريع الحكم هو حصول المصلحة للخلق وإبعاد المفسدة عنهم ، وبذلك نعرف كمال هذه الشريعة وشمولها لجميع الحوادث فما من أمر صغير أو كبير إلا وقد شملته الشريعة الإسلامية بأحكامها كما قال تعالى: (ونزلنا عليك الكتاب تبياناً لكل شيء) ومن هنا فيجب على الفقهاء أن يعودوا لنصوص القرآن والسنة من أجل استخراج حكم ما يرد عليهم من مسائل جديدة.

و من أول الوسائل المذكورة إجراء الفحوصات الطبية
على الراغبين في الزواج من بعضهما قبل حصول الزواج. بحيث
يتم الفحص على الدم في المرحلة الأولى للنظر في مدى توافق
فصائل الدم و التحقق من خلو الزوجين من الأمراض
المعدية و التأكد من عدم حملها لأمراض معينة يمكن أن
تنتقل إلى أبنائهما بحسب ما توصل له الباحثون في علم الوراثة
من اكتشاف قوانين ذلك .

و الشريعة الإسلامية فيما يظهر لي تدل إجراء هذه
الفحوصات مستحباً و مندوباً إليه و مرغباً فيه ويدل على
ذلك العديد من الأدلة الشرعية و منها ما يأتي :-

١- الأدلة الشرعية التي تبين أن الزواج ~~مشروع~~ مقرر شرعاً
من أجل فوائد يحصل عليها المتزوجان من حصول السكن بينهما
والاستقرار والمودة والرحمة قال تعالى: (ومن آياته أن
خلق لكم من أنفسكم أزواجاً لتسكنوا إليها وجعل بينكم
مودة ورحمة إن في ذلك لآيات لقوم يتفكرون) وعند حصول
الأمراض المتكررة تنتفي بعض هذه الحكم والمقاصد من
الزواج ، لكن عند إجراء الفحص قبل الزواج تزداد لدينا
نسبة حصول الزوجين على هذه الفوائد .

٢- الأدلة الشرعية الدالة على الترغيب في الزواج من الكفؤ
رجلاً كان أو امرأة ، كما قال النبي صلى الله عليه وسلم : (إذا
جاءكم من ترضون دينه وخلقه فزوجوه إلا تفعلوا تكن فتنة
في الأرض وفساد عريض) رواه أهل السنن وروى ابن ماجه أن
النبي صلى الله عليه وسلم قال : (تخيروا لنطفكم وانكحوا الأكفاء)

في بعض الألفاظ: (تخيروا لنطفكم فإن النساء يلدن أشباه إخوانهن وأخواتهن) وفي رواية: (اطلبوا الأكفاء لنطفكم فإن الرجل ربما يشبه أخواله) والأسانيد المفردة لهذه الأحاديث فيها ضعفها، لكن عند ملاحظة تعدد الأسانيد تحكم عليه بأنه حديث حسن، ومن طرق اختيار الكفء في الزواج إجراء الفحوصات الطبية اللازمة قبل الزواج، ولذلك تتابعت أقوال الفقهاء المسلمين في ملاحظة اختيار الكفء من حق الولد على والده: (لانتقاء الأم وتحسين الاسم وتعليم الأدب) وقد ورد عن عثمان بن أبي العاص رضي الله عنه أنه قال لأبنائه: (يا بني الناكح مغترس، فلينظر امرؤ حيث يضع غرسه والعرق السوء قلما ينجب فتخيروا ولو بعد حين)، وقد ورد في بعض الأسانيد اختيار الزوجة غير القريبة رغبة في نجابة الولد وسلامة جسمه من الأمراض الوراثية.

- ترغيب الشرع في اختيار الزوجة الولود التي تنجب كما قال النبي صلى الله عليه وسلم: (تزوجوا الودود الولود)، ومن طرق معرفة كونها ولوداً إجراء الفحص قبل الزواج، وكما يرغب الشرع في كون الزوجة ولوداً يرغب في ~~كون~~ نجابة أبنائها وسلامتهم في أبدانهم ومما يحصل به ذلك إجراء الفحص قبل الزواج. ~~ومن القواعد المقررة عند فقهاء الشريعة أن الوسائل~~

٤- أن هذه الفحوصات تتحقق بها المصلحة للمولود والشريعة جاءت بجلب المصالح ودرء المفاسد.

٥- أن هذه الفحوصات وسائل لتحصيل مقاصد شرعية ومن القواعد المقررة عند الفقهاء أن الوسائل لها أحكام المقاصد.

٥- الأدلة الدالة على مشروعية التداوي كقول النبي صلى الله عليه وسلم: (تداووا عباد الله ولا تتداووا بحرم فإنه ما من داء إلا وله دواء) ومشروعية التداوي من أجل دفع الأمراض وإزالتها، وهذه الحكمة موجودة في إجراء الفحوصات قبل الزواج فيكون هذا الفحص مشروعاً.

٦- قرر الفقهاء قاعدة (الدفع أولى من الرفع) والمراد بالدفع منع حصول الضرر قبل وقوعه، والمراد بالرفع إزالة الضرر بعد حصوله، وإجراء الفحص الطبي قبل الزواج يتم به منع الأضرار المتوقعة قبل حصولها فيكون أولى من ~~[illegible]~~ ترك الناس يصابون بهذه الأمراض ثم نقوم ~~[illegible]~~ بإزالة تلك الأمراض أو التخفيف من أضرارها.

٧- من قواعد الشريعة أن (الضرر يزال) فنقول: (لا ضرر ولا ضرار) وقد دل على هذه القواعد العديد من الأدلة الشرعية وبواسطة هذه الفحوص نتمكن من منع الضرر قبل وقوعه.

٨- أن الشريعة نهت عن كل أمر يؤثر على نفسيات الخلق ويجعلهم يتضايقون ويتبرمون ولا تستقر نفوسهم ومن هنا نهت الشريعة عن السخرية بالآخرين وعن الكلام في معائبهم و ~~[illegible]~~ أمرت بحسن التعامل وانتقاء الألفاظ الطيبة فالكلمة الطيبة صدقة، وتبسمك في وجه أخيك صدقة كما ورد عن النبي صلى الله عليه وسلم، ولا شك أن مما يؤثر على نفسيات الأفراد إصابة أبنائهم بالأمراض أو إصابتهم هم، ومن وسائل دفع ذلك إجراء الفحوصات الطبية قبل الزواج فيكون ذلك مشروعاً.

تواترت نصوص الشريعة في النهي عن الإسراف والأمر بترك التبذير قال تعالى: (ولا تبذر تبذيراً إن المبذرين كانوا إخوان الشياطين وكان الشيطان لربه كفوراً) وقال سبحانه: (وكلوا واشربوا ولا تسرفوا إنه لا يحب المسرفين) وقال سبحانه: (والذين إذا أنفقوا لم يسرفوا ولم يقتروا وكان بين ذلك قواماً) ولا شك أن معالجة الأمراض الوراثية تتطلب الكثير من النفقات التي يقوم بها الأفراد لمعالجة أنفسهم أو أبنائهم أو تقوم بها الحكومات، فإذا تخلصنا من درء تلك النفقات الباهظة من خلال إجراء الفحوصات الطبية اللازمة قبل الزواج كان ذلك أمراً مشروعاً.

لكن يجب قبل إجراء مثل هذه الفحوصات أن نراعي الضوابط الشرعية والقيود والشروط التي يأمرنا الشرع المطهر بالتزامها ومن تلك الشروط ما يأتي:-

١- الاقتصار على ما يؤدي الغرض وعدم إجراء فحوصات أخرى ليس لإجرائها فائدة في تحقيق الغرض من الفحص وهو ما يتعلق بالتأكد من سلامة الزوجين وخلوهما من الأمراض المعدية والوراثية.

٢- سرية المعلومات وعدم إخبار أي أحد مهما كان بنتائج هذه الفحوص ويقتصر في ذلك على إخبار المريض نفسه فقط بنتائج الفحص كاملة، أما الزوج الآخر فيخبر بملائمة الزوجين لبعضهما أو عدم ملائمتهما، فإن الشريعة تأمر بكتم الأسرار.

٣- ملاحظة إتقان عمل الفحوص والقيام بها على خير وجه وأحسن طريقة لأن الشريعة تأمر بإتقان العمل الذي يوكل للإنسا

٤- عدم استغلال هذه الفحوص في اختبارات أو بحوث أو غير ذلك أو إجراء فحوصات أخرى على عينة الدم بدون أخذ إذن صاحب الدم، فإن هذا الدم من اختصاص صاحبه فلا يجوز لأحد أن يتصرف فيه بدون إذن صاحبه المختص به.

٥- أن لا يكون في طرق إجراء هذه الفحوص ما ينافي كرامة الإنسان المقررة شرعاً قال تعالى: (ولقد كرمنا بني آدم) الآية.

فإذا تقرر أن الأصل في إجراء الفحوصات قبل الزواج أنه مندوب إليه فإن إجراء الفحص قد يجب في حالات معينة، فقد يجب الفحص في الحالات الآتية:

أولاً: إذا ألزم ولي الأمر بإجراء هذه الفحوصات، فإن الشريعة تأمر بطاعة ولاة الأمر قال تعالى: (يا أيها الذين آمنوا أطيعوا الله وأطيعوا الرسول وأولي الأمر منكم) وقال النبي صلى الله عليه وسلم: (اسمعوا وأطيعوا ولو ولي عليكم عبد أسود).

ثانياً: إذا كانت إصابة الأبناء بالأمراض متحققة أو غالبة على الظن، فإن الشريعة توجب على الإنسان ~~[illegible]~~ عدم إلحاق الضرر بغيره وتحرم عليه أذية الآخرين قال تعالى: (والذين يؤذون المؤمنين والمؤمنات بغير ما اكتسبوا فقد احتملوا بهتاناً وإثماً مبيناً) ومن وسائل عدم إلحاق الأذى بالأبناء إجراء الفحوصات على الراغبين في الإقدام على الزواج، ومتى كانت نسبة إصابة الأبناء بمرض عالية في بلد من البلدان وجب اتباع الطرق المؤدية لتجنب إصابتهم بذلك المرض، ومن وسائل ذلك إجراء الفحوصات اللازمة قبل الزواج.

أما عن حكم إجراء الفحوص اللازمة على الجنين في بطن أمه من أجل التحقق من سلامته ومعالجته في وقت مبكر فلا شك أن هذا الأمر من القربات التي يتقرب بها العباد إلى ربهم فإنه من التداوي المقرر شرعاً وهو أيضاً مندرج في التعاون على الخير المأمور به شرعاً في قول الله تعالى: (وتعاونوا على البر والتقوى ولا تعاونوا على الإثم والعدوان) ولا بد من مراعاة الضوابط الشرعية في ذلك ومنها عدم إلحاق الضرر بالجنين أو بوالدته ومنها كتمان نتائج الفحوص ومنها عدم التداوي بالأمور المحرمة شرعاً وغير ذلك مما هو معروف عند الفقهاء من ضوابط المعالجات الطبية.

أما عن أخذ خلية من خلايا الجنين في بطن أمه للتأكد من سلامته أو معرفة مدى إصابته بالمرض فالأصل في هذا الجواز وقد صدرت عدد من الفتاوى في المجامع الفقهية بجواز أخذ العينات من جسد المريض من أجل إجراء الكشف عليه، وأخذ العينة من الجنين في بطن أمه مماثل لذلك إذ من القواعد المقررة درء أعلى المفسدتين بارتكاب أدناهما وجلب أعلى المصلحتين بترك أقلهما.

أما إذا كان يترتب على أخذ العينة ضرر محقق بالجنين فإن الشريعة تنهى عن إلحاق الضرر بالآخرين والجنين في بطن أمه له حرمة يحرم على الطبيب انتهاكها والاعتداء عليه وإذا اعتدى عليه أحد وجب على المعتدي دفع عشرة في المائة (١٠٪) من دية الإنسان الكبير.

ما إذا كان أخذ هذه العينة المحتوية على خلية من الخلايا من أجل الكشف عليها ووضع طريقة مناسبة للتعامل مع الجنين فيها نسبة ضئيلة لاحتمال وقوع الضرر به كاحتمال سقوط الجنين من بطن أمه، فإنه حينئذ يرجع للأطباء فما جعلوا فيه النسبة نادرة وغير معتبرة طبياً فإنه لا حرج في إجراء هذه الفحوص وأخذ هذه العينات، وما اعتبره ~~[illegible]~~ الأطباء نسبة عالية أو متوسطة فإنه حينئذ يحرم إجراء تلك الفحوص، لأن الأطباء هم أهل الاختصاص، والشريعة تحكم على الأمور الغالبة ومن هنا قرر الفقهاء أن (العبرة بالغالب الشائع) وقرروا أنه (لا عبرة بالنادر).

أما عن مسألة إجهاض الجنين إذا تبين لنا أنه مصاب بمرض من الأمراض التي لها تأثير في حياته وتمنع من مساهمته في بناء مجتمعه وتسبب حالته العناء لوالديه وينتج منها زيادة التكاليف وتتطلب حالته النفقات الباهظة فإنه حينئذ لابد من ملاحظة أن هذا التقرير لا يعتبر إلا إذا وجدت فيه الشروط التالية :-

١- أن يصدر هذا التقرير من أهل الاختصاص .

٢- أن يتوفر في هذا التقرير العدد المعتبر شرعاً بما لا يقل من طبيبين يكون كل واحد منهما مستقلاً له في الحكم بذلك .

٣- أن يكون هذا التقرير مبنياً على الأسس العلمية المعتمدة، ولا يكتفى في ذلك بالنظريات المجردة أو غير المعترف بها رسمياً .

٤- أن يكون التقرير جازماً بحصول ذلك المرض، فلا يعتمد على الظن المجرد في ذلك .

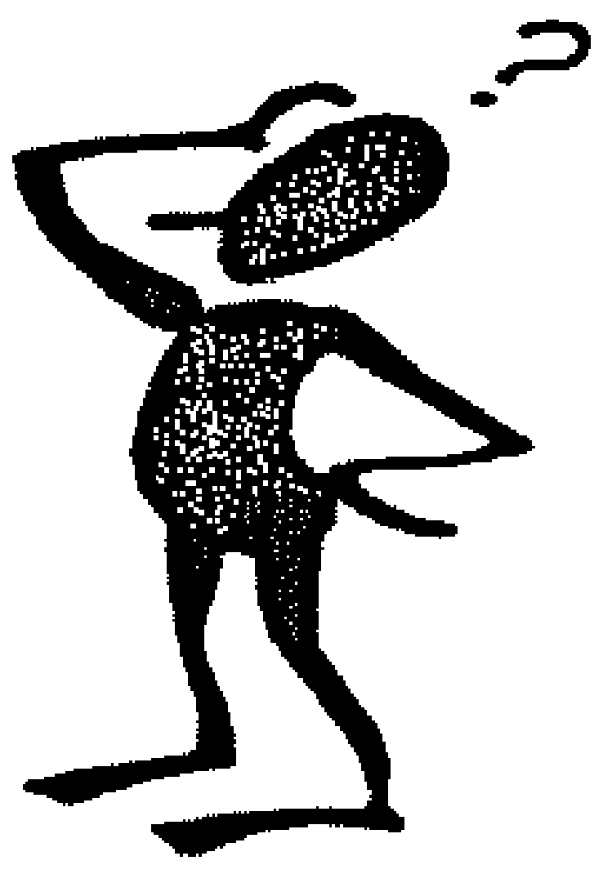
٥- مراعاة الضوابط الأخرى التي تتطلبها الجهات الرسمية والطبية .

فإذا صدر التقرير بذلك فلا يجوز إجراء الإجهاض إذا امتنع
الوالدان أو أحدهما عن إجرائه فلا بد من أخذ إذنهما بذلك.

فإذا حصل الإذن منهما فلا بد أن يكون ذلك في الوقت المعتبر
عند الفقهاء، وقد قال أكثر الفقهاء بعدم جواز الإجهاض بعد
أربعين يوماً كما هو مذهب الشافعية والحنابلة لقول النبي صلى الله عليه
وسلم: (إذا مر بالنطفة اثنتان وأربعون ليلة بعث الله ملكاً فصورها
وخلق سمعها وبصرها وجلدها ~~[illegible]~~ ولحمها وعظامها ثم يقول: يا رب
أذكر أم أنثى فيقضي ربك ما شاء ويكتب الملك) الحديث وفي لفظ: (يدخل
الملك على النطفة بعد ما تستقر في الرحم بأربعين) الحديث وفي لفظ: (إن ملكاً
موكلاً بالرحم إذا أراد الله أن يخلق شيئاً بإذن الله لبضع وأربعين ليلة) روى
ذلك كله مسلم، وذهب بعض الحنفية إلى تحديده بمائة وعشرين يوماً لحديث:
(إن أحدكم يجمع خلقه في بطن أمه أربعين يوماً ثم يكون في ذلك علقة مثل ذلك
ثم يكون مضغة مثل ذلك ثم يرسل الله الملك فينفخ فيه الروح) وذهب المالكية
إلى منع الإجهاض مطلقاً منذ تستقر النطفة في الرحم ولعموم النصوص
الدالة على تحريم الاعتداء على الجنين وهذا هو أقرب الأقوال في المسألة لأن
النصوص السابقة دالة على وقت تعلق الروح بالجنين ولا تدل على عدم تحريم
الاعتداء على الجنين قبل ذلك وكما لا يجوز للمرء التصرف بعضوه المصاب بلا مسوغ
شرعي لا يجوز للمرأة التصرف في جنينها بلا مسوغ شرعي، وكما لا يجوز إنهاء حياة
المريض الذي تحقق من إصابته بالمرض فكذلك الجنين والمسألة موطن خلاف ولكل بحث
ولكل منهم أدلته، أما إذا قرر الأطباء بأن الجنين سيموت بعد ولادته مباشرة فهذه
المسألة تحتاج إلى مزيد بحث. هذا وأسأل الله لك التوفيق والإعانة ورفعة
الدرجة في الدنيا والآخرة وصلى الله على نبينا محمد كتبه محمد بن سعد بن ناصر بن عبد العزيز
الشثري الأستاذ المشارك في كلية الشريعة بالرياض في

Appendix 3: Questionnaire (English version)

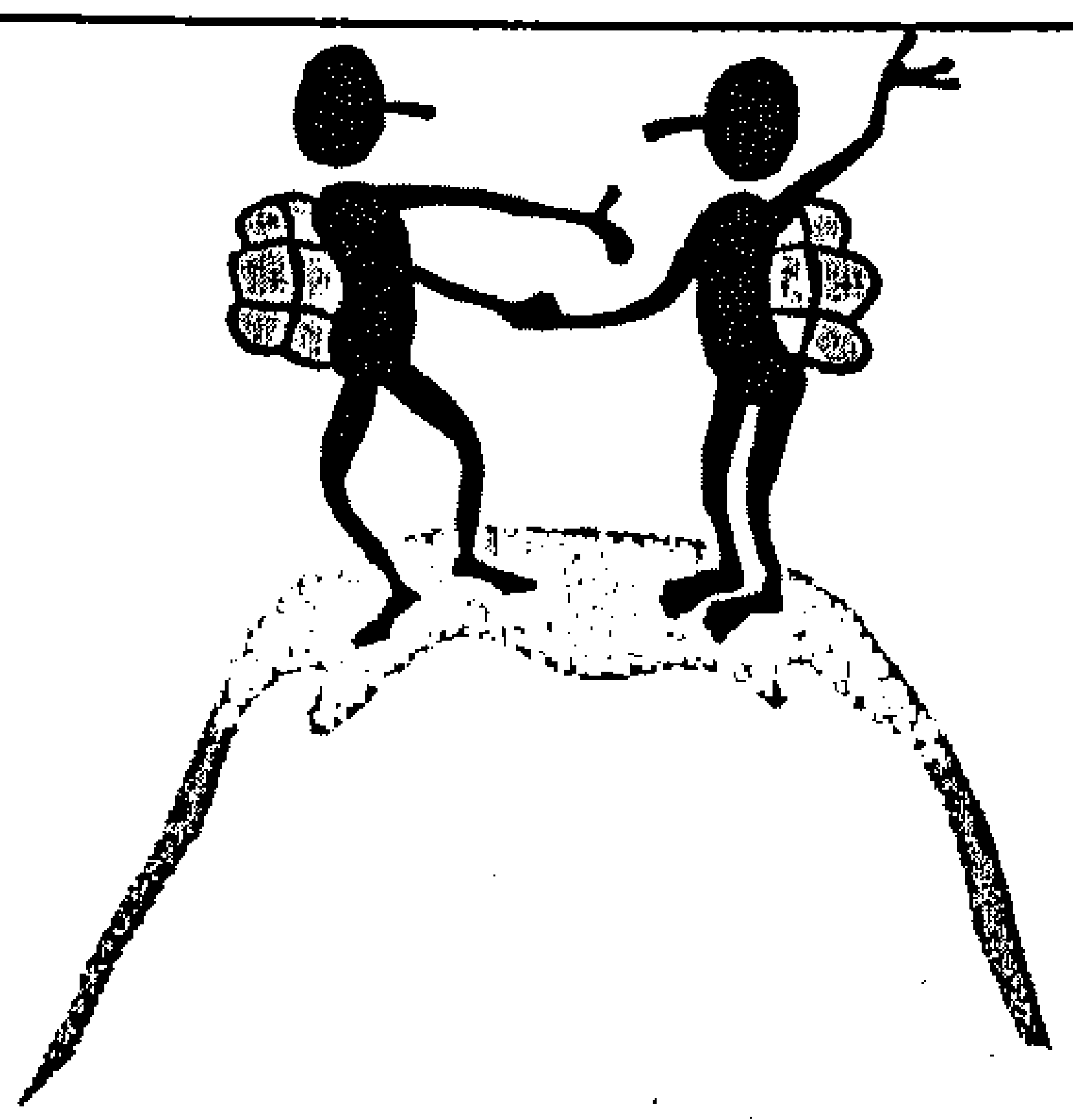
Please tick either 'Yes', 'No', or 'Not sure'.

 Main features of the condition	Would you want a prenatal test?	Would you consider termination if the test showed the baby had this condition?
1 Child would have severe learning disabilities/mental handicap, unable to speak or understand, require a lot of looking after and have a nearly normal lifespan. (Severe LD/MH)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
2 Child would be unable to move from the neck down, require a lot of looking after and have a normal lifespan. (Quadriplegia)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
3 Child would have a normal lifespan and be extremely short. (Dwarfism)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
4 Child would have a treatable cleft lip or palate, require medical interventions throughout childhood and have a normal lifespan. (Cleft lip and palate)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
5 Child would develop a degenerative mental condition by age 60, require a lot of looking after and possibly have a shortened lifespan. (Alzheimer's early death)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ 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. (Turner's syndrome)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ 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. (Trisomy 13 or 18)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐

8 Child would have mild learning disabilities/mental handicap, able to work and live independently and have a normal lifespan. (Mild LD/MH)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
9 Child would be born without a brain and die before or soon after birth. (Anencephaly)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
10 Child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan. (Thalassaemia)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
11 Child would be at high risk of heart attack (before age 50). (Coronary at 50 yrs)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
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)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
13 Child would be at high risk of becoming alcoholic and have a potentially shortened lifespan. (High risk of alcoholism)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
14 Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after. (Moderate LD/MH)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ 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. (Klinefelter's syndrome)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ 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. (Proteus syndrome)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
17 Child would be grossly overweight and have a potentially shortened lifespan. (Grossly overweight)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐

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. (Phenylketonuria)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
19 Child would be deaf from birth and have a normal lifespan. (Deafness)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
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)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
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. (Huntingdon's disease)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
22 Child would have severe behavioural and communication problems, have a normal lifespan and require looking after. (Autism)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
23 A male child would have a progressive muscle-wasting disease, be wheelchair-bound by 11 or 12 years and have a much-shortened lifespan (death probably before 20 years of age). (Duchenne muscular dystrophy)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
24 Child would have a normal lifespan, behavioural and communication problems, have moderate learning disabilities / mental handicap and require looking after. (Fragile X)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
25 Child would be blind from birth and have a normal lifespan. (Blindness)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
26 Child would develop bowel cancer in early adulthood, require surgery and medication and have a potentially shortened lifespan. (Cancer bowel)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐

27 Child would have a neurological condition that causes fits/convulsions from early life, have a normal lifespan and require long-term medication. (Epilepsy)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
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)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
29 Child would have a normal lifespan and be born without a limb, or have a limb that does not function. (Absent/ dysfunctional limb)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐
30 Child is not the sex desired by the parents. (Not the preferred gender)	No ☐ Yes ☐ Not sure ☐	No ☐ Yes ☐ Not sure ☐



Appendix 4: Questionnaire (Arabic version)

ID ☐☐☐

CLINIC

C	M	D	H	F
1	2	3	4	5

SEX

M	F
1	2

صحة العائلة

الزوج

في هذا القسم سوف أسألك أسئلة عامة عنك ... الرجاء التكرم بالإجابة عليها .

إسم الطفل : ________________

رقم الملف الطبي للطفل : ________________ ☐☐☐☐☐☐

١- عمر الزوج : ________________ ☐☐

٢- المستوى التعليمي للزوج :
(١) أمي (٢) إبتدائي (٣) متوسط (٤) ثانوي (٥) جامعي (٦) دراسات عليا ________________ ☐

٣- الدخل الشهري إن وجد : ________________ ☐☐☐☐☐

٤- هل حضرت زوجتك معك للعيادة (١) نعم (٢) لا ________________ ☐

إ:

٥- المستوى التعليمي للزوجة :
(١) أمي (٢) إبتدائي (٣) متوسط (٤) ثانوي (٥) جامعي (٦) دراسات عليا
________________ ☐

٦- دخل الزوجة الشهري إن وجد :
________________ ☐☐☐☐☐

٧- هل أنت متزوج بامرأة أخرى (١) نعم (٢) لا
________________ ☐

٨- كم عدد اطفالك
________________ ☐☐

٩- هل جميعهم أصحاء (١) نعم (٢) لا
إذا كانت الإجابة بلا بقية الأسئلة لا تتطابق ________________ ☐
إذا كانت الإجابة بنعم :
ماهو عمر آخر طفل
________________ ☐☐ ☐

في هذا القسم سوف أقوم بقراءة ٣٠ حالة مختلفة ، والتي من الممكن فحصها أثناء الحمل.
الرجاء بعد الإستماع لكل حالة إختار أحد الإجابات التاليه : لا أو نعم أو غير متأكد وذلك كإجابة للسؤالين التاليين :

١- هل ترغب عمل فحص قبل الولاد ؟

٢- هل تفكر بالإجهاض لو تبين من الفحص أن الطفل لديه هذه الحالة ؟ .

	هل ترغب عمل فحص قبل الولادة ؟	هـل تفكـر بالإجهـاض لـو تبيـن من الفحص أن الطفل لديه هذه الحالة ؟
1- طفل سيجد صعوبة شديدة في التعلم ، تخلف عقلي شديد ، غير قادر على الكلام والفهم ، يتطلب عناية كثيرة ويعيش قريبا من عمرة الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
2- طفل غير قادر على الحركة من الرقبة فما دون يتطلب عناية كثيرة ويعيش عمرة الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
3 - طفل سيعيش عمرة الزمني الطبيعي، ولكن قصير جدا .	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
4- طفل سيكون لديه شرم في الشفه أو اللهاة ممكن معالجته يتطلب تدخل طبي خلال طفولته ويعيش العمر الزمني الطبيعي .	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
5- طفل تصبح لديه حالة تدهور في العقل عندما يبلغ الستين من العمر يتطلب عناية كثيرة واحتمال أن يعيش أقصر من العمرالزمني الطبيعي	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
6- طفل (أنثى) قصيرة جدا من الممكن أن تكون لديها مشاكل طبيه ، تعيش العمر الزمني الطبيعي ولكن غير قادرة على الا نجاب.	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
7- طفل يجد صعوبة شديدة في التعلم ، تخلف عقلي شديد يتطلب عناية كثيرة ويموت خلال الأشهر الأولى .	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
٨- طفل يوجد عنده عجز بسيط في التعلم وتخلف عقلي بسيط ، قادر على العمل وأن يعيش حياه غير معتمد على الآخرين ويعيش العمر الزمني الطبيعي .	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
9 - طفل يولد بدون مخ ويموت قبل أو بعد الولادة مباشرة .	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐
١٠- طفل سيكون عنده مرض في الدم ، يتطلب نقل دم وعلاج طبي طيلة حياته يعيش اقصر من العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متأكد ☐	(1) لا (٢) نعم (٣) غير متأكد ☐

	هل ترغب بعمل فحص قبل الولادة ؟	هل تفكر بالإجهاض لو تبين من الفحص ان الطفل لديه هذه الحالة ؟
11- طفل سيكون معرض إلى حد كبير لحدوث سكتة قلبية قبل سن الخمسين من العمر.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
12- طفل سيكون عنده مشاكل في الرئتين والجهاز الهضمي يتطلب عناية طبيه كبيره خلال حياته ويعيش أقصر من العمر الزمني الطبيعي (احتمال أن يموت قبل الأربعين من عمره).	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
13- طفل سيكون معرض إلى حد كبير أن يصبح مدمن كحول واحتمال أن يعيش اقصر من العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
14- طفل يوجد عنده عجز متوسط في التعلم ، وتخلف عقلي متوسط ويستطيع التخاطب ، يعيش العمر الزمني الطبيعي يتطلب عناية كثيره.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
15- طفل (ذكر) يوجد عنده عجز بسيط في التعلم و تخلف عقلي بسيط أو مشاكل في سلوكه، عادة طويل القامة ومظهره غير رجولي يحتاج إلى عناية خاصة لا يستطيع الإنجاب (عقيم) يعيش العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
16- طفل يكون مشوه بكتله على الرأس والوجه واضحه من مسافة و يعيش العمر الزمني الطبيعي قد يحتاج إلى عناية طبيه في مرحلة الطفولة.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
17- طفل يكون سمين جداً بشكل مزعج من الممكن أن يعيش اقصر من العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
18- طفل يكون عنده مرض في الدم ، قد تسبب له مشاكل عقليه إذا لم يعالج يعيش العمر الزمني الطبيعي ، يتطلب حمية صارمة ومقيدة طيلة حياته.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
19- طفل لا يسمع من الولادة يعيش العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
20- طفل يعيش العمر الزمني الطبيعي مع احتمال كبير لحدوث مرض عقلي في سن الشباب يحتاج بعض الرعاية وعلاج لمدة طويلة ، غير قادر على العمل أوتفهم و الاحساس بالأخرين.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐

	هل ترغب عمل فحص قبل الولادة ؟	هل تفكر بالإجهاض لو تبين من الفحص أن الطفل لديه هذه الحالة ؟
21- طفل يصبح لديه حالة عند سن الأربعين لايمكن علاجها يصاحب ذلك تدهور شديد في العقل ولحركة ، يتطلب عناية كثيرة ومستمرة ومساعده طبيه ويعيش اقصر من العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
22- طفل عنده مشاكل حادة في السلوك والتخاطب يعيش العمر الزمني الطبيعي ويتطلب عناية.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
23- طفل (ذكر) قد يعاني من حالة مرضية تتسبب في ضمور العضلات، يكون مقعد على العربة عند سن الحادي عشر أو الثاني عشر من عمره يعيش اقصر بكثير من العمر الزمني الطبيعي (يموت على الأرجح قبل العشرين سنه من عمره) .	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
24- طفل يعيش العمر الزمني الطبيعي مع مشاكل في السلوك والتخاطب ولديه عجز متوسط في التعليم ، تخلف عقلي متوسط يتطلب عناية .	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
25- طفل يولد أعمى يعيش العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
26- طفل يمكن أن يحدث له سرطان في الأمعاء عند بداية سن الشباب يحتاج عمليه وعلاج ، احتمال أن يعيش اقصرمن العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
27- طفل عنده مرض عصبي يسبب له نوبات في الصرع من بداية حياته، يعيش العمر الزمني الطبيعي ويتطلب علاج لفترة طويلة .	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
28- طفل يكون عنده مرض عضوي يتطلب حقن يومياً ، إحتمال أن تظهر عليه مضاعفات مثل مرض القلب والكلى أو العمى يعيش طوال عمره على وجبات طعام محددة ومن المحتمل أن يعيش اقصر من العمر الزمني الطبيعي.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
29- طفل يعيش العمر الزمني الطبيعي يولد بدون أحد الأطراف أو أحد الأطراف لا تعمل.	(1) لا (٢) نعم (٣) غير متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐
30- إذا كان جنس المولود غير مرغوب فيه من الأم أو الأب	(1) لا (٢) نعم (٣) غيز متاكد ☐	(1) لا (٢) نعم (٣) غير متاكد ☐

عزيزي:

نرجو منك المشاركة في هذه الدراسة وهى عبارة عن رسالة تحضيرالدكتوراة "و التي سوف تستغرق ٢٥ دقيقه" هذه الدراسة تهتم لمعرفة اتجاهات أفراد المجتمع السعودي من فحص مختلف الأمراض الوراثية أثناء فترة الحمل.

إن اختيارك للمشاركة في هذه الدراسة قد تم بشكل لاإنتقائي.

إن جميع المعلومات سرية ولا يمكن الكشف عنها للأخرين، ومن حقك التوقف عن الاجابه في أي وقت خلال المقابلة.

التوقيع: ______________

التاريخ: