An-Najah National University

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Knowledge and attitude toward genetic counseling and testing Among parents of children with genetic disorder in the West Bank /Palestine

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الإهداء

بسم الله الرحمن الرحيم

الحمد لله اولاً واخيراً

سنين مرت على دخولي كلية الدراسات العليا واخر المشوار حان بعد الكثير من الجهد المبذول للوصول الى اعتاب التخرج من هذا الصرح العلمي الشامخ بأقسامه وموظفيه كلا بمكانه، سنيني مرت مرور الكرام ولكن ايامي كانت زاخرة بالأصدقاء والمعارف والزملاء والمدرسين كلا له ذكرياته الخاصة منقوشة في وجداني وحياتي العملية والمهنية ، لا اسعني الا إن اتقدم بالشكر الجزيل لكل من ساهم في دعمي بحرف أو كلمة في مسيرتي التعليمية ، لكل من ساهم في وصولي للمعرفة العلمية والعملية . اجتهدت وقضيت اوقاتي في الوصول لهذه اللحظة .

اليكم احبتي عائلتي زوجي وولديّ

الذين ساندوني بكل مراحل حياتي وما زالوا

اليكم اهدي هذه الرسالة

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.

إقرار

أنا الموقع/ة أدناه، مقدم/ة الرسالة التي تحمل العنوان :

Knowledge and attitude toward genetic counseling and testing among parents of children with genetic disorder in the West Bank /Palestine

أقر بأن ما اشتملت عليه هذه الرسالة إنما هي نتاج جهدي الخاص ، باستثناء ما تمت الإشارة إليه حيثما ورد ، وأن هذه الرسالة ككل ، أو أي جزء منها لم يقدم لنيل أي درجة أو لقب علمي أو بحثي لدى أية مؤسسة تعليمة أو بحثية أخرى .

Declaration

The work provided in this thesis , unless otherwise referenced , is the researcher's own work, and has not been submitted elsewhere for any other degree or qualification .

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Abbreviations

Abbreviation	Full Name
DNA	Deoxyribonucleic acid
IVF	In Vitro Fertilization
PMC	Palestine Medical Complex
ANOVA	Analysis or variance
IRB	Institutional Review Board
MOH	Ministry of Health
SPSS	Statistical Package for the Social Science
ICU	Intensive Care Unit
PCBS	Palestinian Center Bureau of Statistics
CHD	Congenital Heart Defect

Knowledge and attitude toward genetic counseling and testing among parents of children with genetic disorder in the West Bank /Palestine

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Abstract

Introduction: Genetic disorder is a health problem that caused by a defect in theindividuals' DNA. In Palestine there is no specific statistics about mortality rate of children who suffer from genetic disorders.

Although, there is a big chance to catch a lot of genetic, because of consanguinity rate which exceed (44%) (Hussein, 2014). It is notacable that the newcase from the sane family have been increased without any genetic counseling or prevention. The insufficiency of public health services directed to the prevention of genetic disorders, with the lack of health care increase the problem. Therefor, the study aim is to describe parents knowledge and attitudes toward genetic counseling and testing and to determine if knowledge affect attitudes.

Methodology: A quantitative descriptive cross sectional study via a questionnaire, quiz test (to evaluate knowledge), and likert scale (to evaluate attitudes was used in this study, to discover the relationship between variables. The sample size was 121 participants who attended the two hospitals (Palestine Medical Complex and Al-Najah National Hospital) from (Feb\ 2016 to Sep\ 2016).

Results: The study showed that there is a significant relationship between parents educational level and their knowledge regards genetic disorders (P. 0.003). The most significant risk factors for genetic disorder were ignoring premarital genetic testing for (99.2%) ; consanguineous marriage (71,1%) and family history of genetic problem for (55.4%).

The study found that most of parents of children with genetic problems had good knowledge regards genetic disorders (63%), Whereas, the attitudes of these parents were positive for a majority of items that measure attitude level (81%for agreed answer). The relationship between knowledge and attitudes was positive and research hypothesis regards the effect of knowledge on attitude had been accepted. However, here was no association between number of children whose affected or lost by genetic problems and the parents knowledge and attitudes in this study.

This study recommended to increase awareness of parents about genetic importance of premarital testing which avoid consanguinity and these are the golden tool to decrease genetic problem in Palestine.

Key words: knowledge, attitudes, parents, genetic testing, genetic counseling, children, disorder.

Chapter 1
Introduction

1.1 Background:

In any pediatric hospital, there are children suffering from a variety of illnesses and diseases. This is particularly true for children with chronic diseases, which are mainly caused by genetic transmission. However, these genetic diseases can be prevented or limited using simple, low-cost methods and technologies. These methods are often cheaper and easier to implement than treatment, especially since the field of genetic sciences in Palestine has advanced greatly, and genetic labs have become more available. Additionally, individuals affected by genetic conditions are now more likely to seek information about inheritance and risk factors (Harvey et al., 2007).

Before the development of modern genetic technologies, genetic counseling was the only option, and health professinals attempted to characterize the genetic behavior of diseases based on family history (WHO, 2015).

1.1.1 Genetic disorders:

A genetic disorder is a health problem that is caused by an abnormal defect in the individual's DNA. Abnormalities can be as small as a single mutation in just one gene, or they may involve the addition or subtraction of entire chromosomes (University of UTAH Health Sciences, 2015).

1.1.2 Genetic counseling:

Genetic counseling is a service that provides information and advice about genetics conditions. These conditions are caused by changes (mutations) in known genes, which are usually passed down through a family. It is conducted by healthcare professionals who have been specially trained in the science of human genetics (a genetic counselor or a clinical geneticist) (WHO, 2015).

Genetic counseling provides the individual or family with information and support regarding health concerns that run in their family. Genetic counseling may involve the diagnosis of a genetic condition, as well as the provision of information and supportive counseling (advice and guidance) by a team of health professionals. This enables families and individuals to better adjust to the diagnosis. Follow-up counseling is available to ensure ongoing support, to review previous information, or to answer new questions as they arise (NHS Choices, 2014).

Individuals who come to see genetic counselors may be people who have a disorder themselves and are concerned about their family and vice versa, couples with an affected child who wish to plan another pregnancy, couples who are planning their first pregnancy and wish to understand the disease susceptibility of their future child, as well as couples who are planning a pregnancy late in life and want to assess any potential risks. Genetic counseling services may be useful at all stages of development. For instance, services can be available for infants undergoing screening,

teenagers being tested for Thalassemia genes, or adults assessing their predisposition for genetic disorders as they enter their mid-life stage, and attempt to make the appropriate lifestyle changes (WHO, 2013).

1.1.3 Genetic testing:

Genetic testing is a type of medical test which identifies changes in chromosomes, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition, or help determine a person's chance of developing or passing on a genetic disorder (WHO, 2015).

Genetic testing is voluntary. Testing has benefits as well as limitations and risks; therefore, the decision to be tested is a personal and complex one. A geneticist or genetic counselor can help by providing information about the pros and cons of the test, and by discussing the social and emotional aspects of testing (WHO, 2015).

Genetic testing is often used for other reasons as well. For example, carrier testing can be used to help couples learn if they carry a gene mutation for a disorder they might pass on to a child, such as cystic fibrosis, sickle-cell anemia, or Tay-Sachs disease. Meanwhile, prenatal screening can be used to diagnose some conditions in babies before they are even born, such as Down syndrome (WHO, 2013).

Newborn screening is the most widespread form of genetic testing. Newborns are screened for a number of inherited conditions, such as phenylketonuria (PKU), cystic fibrosis, sickle cell disease, and others. The tests required vary from state to state (WHO, 2013).

1.1.4: Consanguinity:

Consanguinity, or intermarriage, is defined as the marriage of two relatives, second cousins or two who are more closely related (NCHPEG, 2013). Consanguineous marriages have been practiced since the early existence of modern humans (Tadmori et al., 2009). It is a rooted social trend among one-fifth of the world's population. This tradition is mostly practiced in the Middle East, West Asia and North Africa, as well as among emigrants from these communities now residing in North America, Europe and Australia (Hamamy, 2012).

Until recently, consanguinity was widely practiced in several global communities, with a variety in rates depending on religion, culture, and geography (Tadmori et al., 2009). Arab populations have a long-held tradition of consanguinity due to socio-cultural factors. Many Arab countries display some of the highest rates of consanguineous marriages in the world, especially first cousin marriages which may reach 25-30% of all marriages. In some countries like Qatar, Yemen, and UAE, consanguinity rates are increasing in the current generation. Research among Arabs and worldwide has indicated that consanguinity could influence some reproductive health parameters such as postnatal mortality rates, and rates of congenital malformations (Tadmori et al., 2009)

1.2 Thalassemia as a successful example:

Thalassemia or Mediterranean anemia is endemic in almost all Arab countries. This is probably due to the historical presence of malaria in the region, and the high levels of consanguinity (WHO, 2014).

In the year 2012, there were 815 Palestinian patients suffering from anemia, and 16,000 carrying the genetic trait. The number of Thalassemia patients in Palestine before the year 2000 was 45. This number decreased to five in 2000, and to zero after 2013 (PCBS, 2014).

This excellent achievement is related to the application of premarital genetic counseling to avoid new cases of Thalassemia. The experience of Thalassemia offers strong evidence in support of the effectiveness of genetic counseling to prevent or reduce future cases of genetic disorders.

1.3 Significance of the problem:

In the West Bank, pediatric wards in governmental and private hospitals have little to no statistics about the mortality rate of children suffering from genetic disorders. In some occasions, many members from the same family have been diagnosed with the same disorder. From the researcher's own experience as a nurse in the pediatrics suit in the Palestinian Medical Council, new children are often born with the same genetic diseases as previous siblings and family members, without the families being offered any genetic counseling or any prevention tools.

Unfortunately, only few epidemiological population studies were conducted to investigate the prevalence of genetic disorders among Palestinians (Abu Lebdeh and Teebe, 2010), especially for thalassemic and hemophiliac patients (PHIC, 2013).

On the level of the Arab world, a study was conducted by Ghazi Tadmori summarizing data from industrialized countries, which indicated that significant genetic diseases or birth defects may affect approximately 3% of all pregnancies, account for up to 30% of pediatric hospital admissions, and cause about 50% of childhood deaths (Tadmori, 2010).

1.3.1 Genetic disorders in Palestine:

As an eastern society where consanguintity marriage is very common, the Palestinian society is particulalry prone to genetic disorders (Abu-Libdeh and Teebe, 2010). The Palestinian population is characterized by high consanguinity rates (about 44%), large family size (5.5 children per family), and pregnancies in women over the age of 45. These factors result in the high prevalence of genetic disorders among Palestinians (Hussein, 2014).

Additionally, insufficient public health services directed to the prevention of congenital and genetic disorders, as well as inadequate health care before, during, and after pregnancy, especially in low income countries, are all factors that increase the chances of genetic disorders among newborn children (Al-Gazali, 2006).

Services aiming to limit and control genetic disorders are constrained by certain cultural, legal, and religious limitations. Examples include the cultural fear of families with genetic diseases being stigmatized within their community, and the legal restrictions on selective termination of pregnancy of an affected fetus (Al-Gazali, 2006).

There is a need for easy public access to health resources, including the knowledge of the types of human diseases and methods to decrease and manage them. Misinformation or insufficient information can affect the public's impression about the fundamental concepts genomics, while an informed public can influence policy makers in the development of guidelines, and address the ethical, social and legal issues raised by expanding genomic technologies (WHO, 2015).

Sometimes, health professionals are unable to accurately diagnose a genetic condition. When this happens, physicians will say that a patient has an undiagnosed or rare genetic condition (NIH, 2011).

There is an advanced genetic lab in Al-maqased Hospital, where very rare genetic disorders are discovered. The genetic disease specialists summerized genetic disorders among Palestinians in the book "Genetic Disorders Among Arab Population" (2010). These diseases and disorders briefly are:

"Hemoglobinobathy, Familial Meditranian Fever, Cystic Fibrosis, Phenylketonuria, Bardet-Biedle Syndrom, Meckel Syndrom, Lysosomal Disorder, Familial Hydrocephalus, Genetic Disorders Causing Blindness,

Glansmann's Tthrompocytopenia, Nesidioblastosis (pancriatic disorder), Inborn Errors of Metabolism (46 defferent metabolic diseases), Cancer, Osteogenesis imperfecta" (Abu-Libdeh and Teebe, 2010).

1.3.2 New diseases reported among Palestinians:

Interestingly, there has been a number of new genetic diseases and disorders reported among Palestinians. These include:

"Limb/Pelvis Hypoplasia/aplasia Syndrom, Microcephaly with Normal Intelligence, Microfhthalmia, Disordered Pigmentation, Spastic Paraplagia, Hypogonadotropic Hypogonadism with Mental Retardation and Skeletal Abnormalities. Majeed Syndrom (congenetal deserthropiotic anemia type (1)) with chronic recurrent ostiomyelitis and sweet's syndrom" (Abu-Libdeh and Teebe, 2010).

From the resaercher's point of view, these diseases deserve to be studied from several aspects. It is especillay important to become familiar with the knowledge and attitudes of parents and caretakers of the sick children with genetic problem.

In fact, genetic disorders are a big social, health, and economic problem. It is continuously increasing, and patients' families are often in the center of the problem, as well as the center of the solution. It is therefore important to become familiar with their knowledge and attitudes toward genetic disorders**.**

Chapter 2

Literature Review

2.1. Search strategy and key words:

Science Direct, PUBMED, Google Scholar, and HINARI are all databases that were used to research the body of literature on the topic, and to write the literature review.

The keywords used in the research were: knowledge, attitude toward genetic counseling, testing, awareness about genetic counseling and testing, perception toward genetic counseling, testing, family, parents, relatives, children, genetic diseases, genetic counseling, and genetic problems. Table (1) shows how these keywords were combined in the research.

Table (2.1): Key words:

No	Term	Combined with
1	Knowledge OR attitude OR awareness OR perception.	And
2	Genetic counseling OR genetic testing OR genetic screening.	
3	Family OR mothers OR parents OR relatives.	
4	Genetic disorders OR genetic disease OR genetic problems.	

2.2. Inclusion and exclusion criteria of articles:

A systematic review was conducted in order to capture the most relative articles to this research. Both qualitative and quantitative studies were included; some articles were excluded after reviewing the abstract, while

others were excluded after reviewing the entire article. The systematic review targeted articles published between 2005 and 2017. However, some articles were included in the literature review despite being published before 2005, as they were valuable and closely related to the topic.

2.3. Systematic review:

The following diagram (figure 1) showcases how this systematic review of the literature was conducted. After applying the inclusion and exclusion criteria, a total of 23 articles were selected for the review.

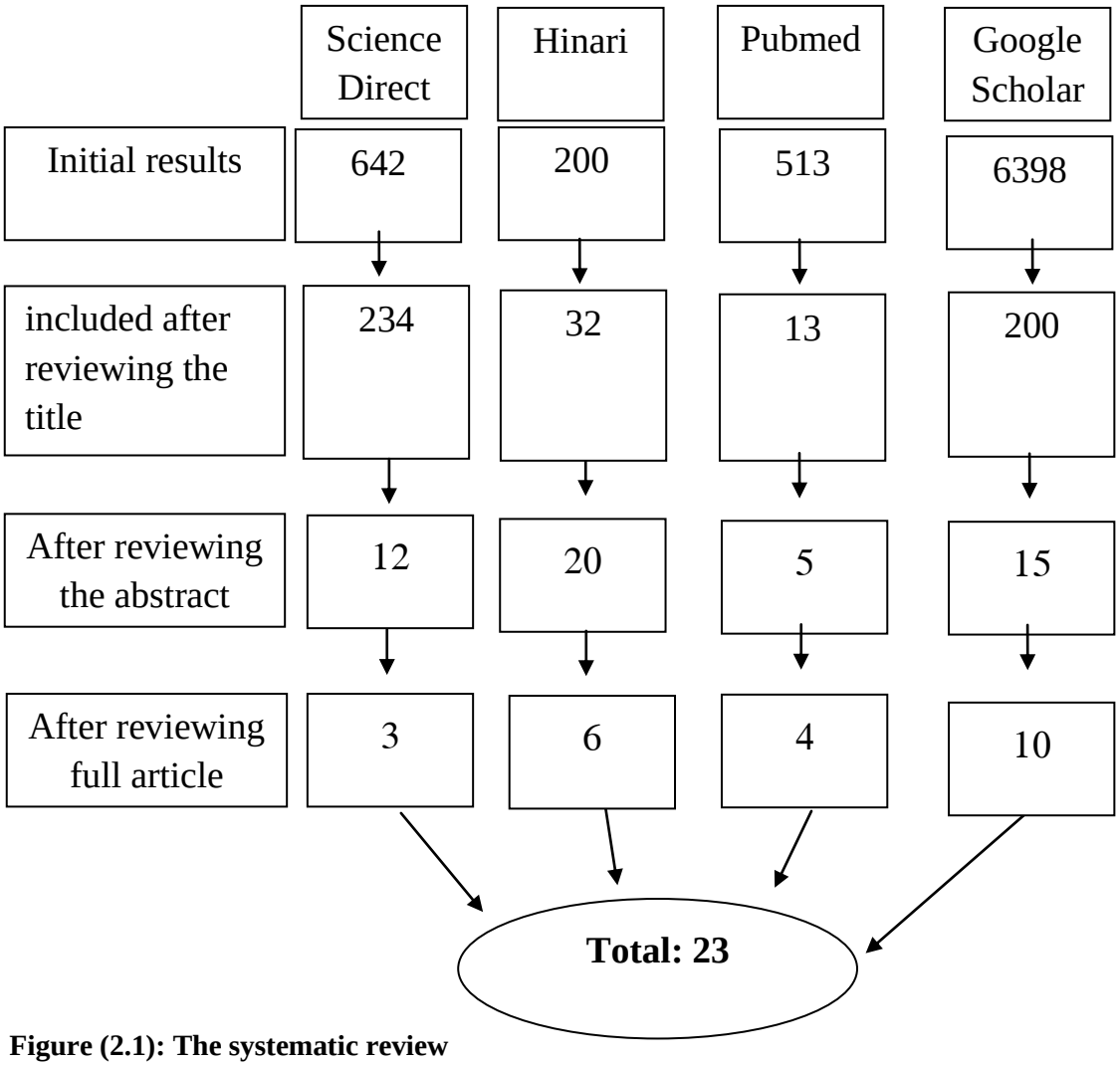

Figure (2.1): The systematic review

2.4. Literature Review Discussion:

2.4.1. Knowledge and attitudes about genetic testing and genetic counseling:

A knowledge, attitudes, and practice (KAP) study was conducted in the Kingdom of Saudi Arabia (KSA) in 2006 to assess knowledge of and attitudes toward premarital counseling. The study revealed that most subjects supported the application of premarital screening in KSA (Alam, 2006). Two years later, an interventional study (educational program) assessed the knowledge on the topic before and after the implementation of the educational campaign. The study found that knowledge about genetic counseling and testing was lower before the campaign, and significantly increased after the educational program (Ibrahim, et al. 2011).

Another cross-sectional study in the Netherlands used a questionnaire and a DNA test to conclude that older and lower-educated patients had less knowledge about genetic issues. Meanwhile, attitudes toward genetic testing and counseling were rather positive, and higher levels of genetic knowledge were associated with a more positive attitude toward genetic counseling (Morren and Rijken, 2006).

Another knowledge and attitude follow up study was conducted in the Netherlands over the span of two years, from 2002 to 2004. The study was done among patients of asthma, diabetes mellitus, and cardiovascular disease. Perceived knowledge on DNA-testing did not increase over the

span of the study, and attitudes toward genetic testing also were rather consistent. Little medical genetic knowledge as opposed to social genetic knowledge seems to be a predictor for a more reserved attitude toward genetic testing (Calsbeek et al., 2007).

Another knowledge and attitude study conducted in Ohio (US) in 2014 among parents of children with congenital heart defect showed that 73.8% of parents had accurate knowledge about the disease. There was a significant positive association between the accuracy of parents' knowledge, and their educational level and household income. Attitudes toward the health concerns of genetic testing were favorable, with about 57% of parents agreeing that genetic testing should be used for managing health care and finding cures for diseases (Fitzgerald-Butt et al., 2014).

Finally, a study was done in Australia in 2013 among Parkinson's disease patients to evaluate their knowledge and attitudes toward genetic testing. The level of knowledge was relatively low (37% accurate responses), but attitudes were positive. The vast majority of patients (97%) supported diagnostic testing, while 90% would undertake a genetic test themselves. Support for predictive tests was lower (78%), and prenatal genetic testing had the least support (58%) (Scuffham et al., 2013).

2.4.2 Attitudes of families which have experienced genetic problems:

A study in Finland by Boardman (2014) revealed that the Finnish population in general, and family members of patients with genetic disorders in particular, have a favorable attitude toward genetic testing

(Hietala et al., 2000). In addition, a communication study done in America in 2007 showed that subjects who have a known history of genetic mutations communicated positively about genetic issues during counseling and testing (Ellington and Maxwel, 2006).

A study about cystic fibrosis (CF) found that the majority of affected families reject selective abortion for CF, and that many will curtail childbearing rather than use prenatal diagnosis (Wertz and Janes, 1992). The University of Central Lancashire in 1997 in UK studied the attitudes of deaf adults toward genetic testing for hereditary deafness. Participants had negative attitudes toward genetic testing, and said that they would rather have deaf children (Middleton and Hewison, 1998). This seems to contradict the findings of a study done in the USA in 2000, which showed that there was strong interest by families in genetic testing for deafness (Brunger et al., 2000). It also contradicts the results from the study in the Netherlands which examined the genetic knowledge and attitudes of patients with chronic diseases, and showed that attitudes toward genetic testing were rather positive, especially among younger and higher educated patients (Morren and Rijken, 2006).

2.4.3 Parents' attitudes toward prenatal testing and abortion:

All previous studies were conducted among families, however, in 2015, a comparative study was conducted among university students in Israel. Using Likert scale, the study compared students' attitudes towards genetic testing based on three aspects: their gender, their field of study, and their

religious affiliation. The most influential factor was found to be the religious affiliation of the student. Religious students, especially those who do not study life sciences (LS), place less trust in genetic tests than secular students and students studying LS. Students of LS show more critical thinking towards genetic testing than others. Gender was the least influential factor, showing a mixed trend of influence (Siani and Assaraf, 2015)

A study about prenatal testing used qualitative interviews and found that for families living with a case of spinal muscular atrophy, decisions against selective termination of pregnancy after prenatal testing were made by family members themselves (Boardman, 2014). However, there was high acceptability for prenatal diagnosis in b-Thalassemia afflicted families, and all couples with affected fetuses opted for abortion (Thawabteh et al., 2005).

2.4.4 In Vitro Fertilization (IVF) and genetic testing:

A study was conducted in the United Kingdom about pre-implantation diagnosis and other reproductive options in IVF to study attitudes of male and female carriers of recessive disorders. The majority of participants did not feel that pre-implementation genetic testing and diagnosis was the most useful option in their situation, especially for those who would not consider a termination (Snowdon and Green, 2000).

A German study analyzed the results of chromosome analysis and genetic counseling of infertile couples referred to genetic testing before undergoing

intracytoplasmic sperm injection. The study found a high rate of chromosomal abnormalities in female patients (Kaiser and Kiesel, 1997).

2.4.5 Genetic disorders: prevalence and statistics.

Ghazi Tadmori mentioned that there are around 752 genetic diseases in the Arab world. He further explained the data from industrialized countries, which showed that significant genetic diseases or birth defects may affect approximately 3% of all pregnancies, account for up to 30% of pediatric hospital admissions, and cause about 50% of childhood deaths (Tadmori, 2010).

Among the Palestinian population, Dr. Bassam Abu. Lebdeh and Dr. Ahmad Teebe highlighted about 98 types of genetic disorders, some of which are newly discovered mutations. They recommended increasing research and public education programs around issues of genetic diseases and genetic testing (Abu-Libdeh and Teebe, 2010).

2.4.6 Psychology and genetic counseling:

Elina Rantanen researched the literature to understand the expectations and concerns around genetic testing and counseling. The ideal genetic counseling seems to consist of information about the test, the condition, and the risks and their management. It also offers support in adjusting to this information, and in decision-making process concerning the test and its result (Rantanen, 2014).

To support these conclusions, another literature review study explored the psychological impact of genetic testing. The study found that highly

specific information provided by genetic testing can empower both clinicians and patients to develop behavioral strategies with the greatest impact on reducing disease morbidity and mortality (Tercyak et al., 2002). A meta-analytic review to discover the impact of genetic counseling found that genetic counseling significantly decreased anxiety (Meiser and Halliday, 2002).

2.4.7 The situation of genetic counseling and genetic testing:

Kocha and Svendsenb wrote about genetic counseling as imperative in disease prevention. They suggested that “solutions provide the framework within which certain problems can be stated (Kocha and Svendsenb, 2005). To evaluate genetic testing and counseling, a study conducted in the USA in 2004 found that traditional practice philosophies that have been longstanding in genetic counseling are being re-conceptualized to accommodate the shifts in genetics research brought about by the Human Genome Project. For future directions they recommended the implementation of more sophisticated research methods to overcome some of the existing limitations in the literature (Wanga et al., 2004).

2.5 Framework:

The framework was conceptualized according to the literature review, and helped the researcher develop the questionnaire. Figure 2 shows a flow chart of the development of the framework.

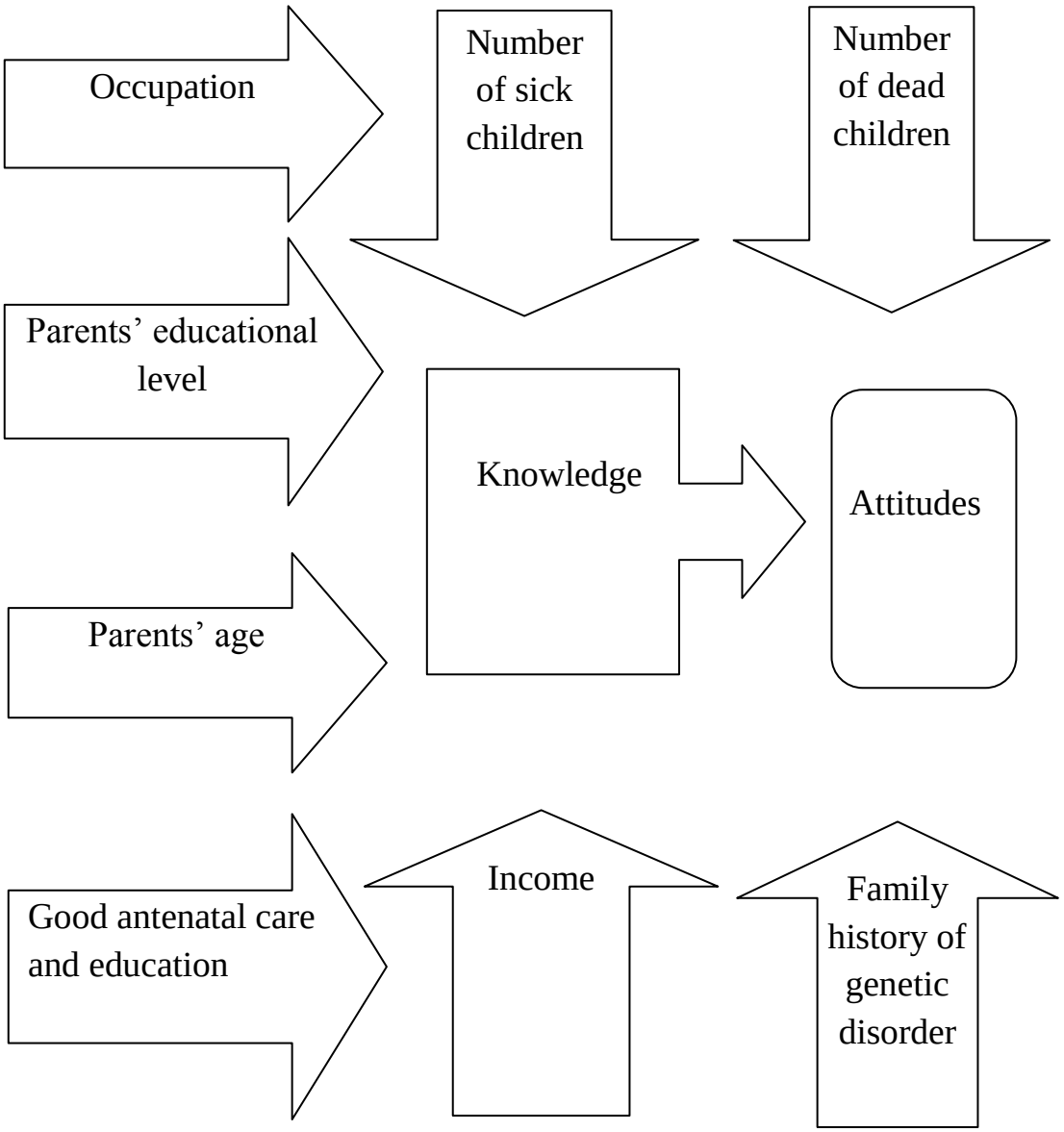

Figure (2.2): Framework

Chapter 3

Methodology

3.1 Introduction

This chapter describes the research and the aspects of the methodology, it identifies population, design, setting, data collection and analysis, validity and ethical considerations.

3.2 Study Design

A quantitative descriptive cross-sectional survey was used in this study in the form of a questionnaire. This design is the most appropriate to study knowledge and attitudes, and to investigate the relationships between different variables. The questionnaire covered all variables of the research, as shown in annex (1).

3.3 Hypothesis

1.Parents with high knowledge about genetic testing and counseling are expected to have positive attitudes toward it, and be more likely to use it.

2. Parents with sick children have more knowledge, and a more positive attitude toward genetic counseling.

3. Parents who have lost one or more children due to a genetic problem are more knowledgeable, and have more positive attitudes toward genetic counseling.

3.4 Aim and objectives:

3.4.1 Aim:

To determine parents' knowledge and attitudes toward genetic counseling and testing, and to determine if knowledge affects their attitudes.

3.4.2Specific objectives:

1.To assess parents' knowledge about genetic counseling and genetic testing.

2.To survey the associated risk factors for the emergence of genetic diseases.

3.To evaluate the effect of demographic data on parents' level of knowledge.

4.To explore parents' attitudes toward genetic counseling.

5.To investigate the relationship between the level of parents' level of knowledge about genetic testing and counseling, with their attitudes towards genetic counseling**.**

6.To compare the levels of knowledge of parents who have lost children due to genetic conditions or who have children diagnosed with genetic conditions, and parents who do not have these experiences.

3.5 Setting:

The study was conducted in two hospitals in the West Bank. The first hospital is Al-Najah National Hospital in Nablus (private hospital),

particularly in the pediatric ward and pediatric genetic clinic. The second is the Palestine Medical Complex (PMC) in Ramallah (governmental hospital), in the pediatric suite (Neonate ICU, Pediatric ICU and Pediatric ward) and pediatric clinic. Both hospitals are assumed to cover cases from all cities of the West Bank because they receive referrals from all of governmental and private hospitals.

3.6 Sampling and Population

3.6.1 Population

The population is all families of children who were admitted to pediatric suites in Al-Najah Hospital and PMC as cases of genetic disorders from the 15th of February to the 15th of September 2016.

3.6.2. Sampling and Sample size

Sampling Method

This study used a convenience sampling method. All cases present in both hospitals during the research period **(15\2\2016 – 15\9\ 2016)** were included. The researcher visited both hospitals to collect data. If the same family happened to have more than one file, the researcher considered it as a single case.

Sample Size

Subjects from the consecutive sample were a total of (121) from both hospitals. There was (140) subjects from the convenient sample, (19) of them were excluded, (10) subjects were excluded because they were

recurrent admission cases, and (9) subjects were brothers of the same family.

3.7 Data Collection

The data collection period was from 15\2\2016 to 15\9\2016 using a questionnaire with four sections:

1.Demographic data.

2.Potential risk factors: this section explains the risk factors for having genetic disease.

3.The knowledge section: this section is essentially a quiz that aims to evaluate the awareness of parents. There is no literature discussing a cut-off point to determine parents' knowledge levels. Therefore, results were summed into three groups (high, moderate and low). Details are given in page 36.

4. The attitudes section: this section is used to evaluate parents' attitudes toward genetic consulting and genetic testing. It also aims to understand what future plans parents have in order to avoid having more children with genetic conditions. A Likert scale questionnaire was used with five scales: (strongly agree, agree, I don't know, disagree, strongly disagree).

The researcher and supervisor built the questionnaire based on the literature review, with help from many experts in research and the field of genetics.
To fill the questionnaire, the researcher met the families, asked the mother or father the different questions, and documented their answers.

3.8 Data analysis

The statistical analysis software, SPSS version 19, was used to analyze the data.

The questionnaire included the following sections:

1.Independent variables: education, address, age, number of lost children, number of sick children, income and knowledge.

2.Dependent variables: parents' attitudes toward genetic testing and counseling.

Parents' knowledge had been evaluated by a quiz, the quiz had ten multiple choice questions, and a total of ten marks, each correct answer equals one mark, with a scoring scale ranging from 0 to 10. Scores were classified into three categories: good, moderate, and weak knowledge.

Parents attitudes were studied using a Likert scale questionnaire, which used five responses to answer questions. These were: strongly agree, agree, undecided, disagree, and strongly disagree. Positive attitudes were indicated by the answers: agree and strongly agree, while negative attitudes were indicated by disagree and strongly disagree.

Knowledge and attitudes relationship studied by (chi square) and the significant results studied by correlation to determine the type of relationship.

Associated factors had evaluated just by frequency.

3.8.1 Variable types and definitions:

Table (3.1) variable types and definitions:

Variable	Type of variable	Conceptual definition	Operational definition
Genetic disorder	Categorical Nominal	Is an illness caused by one or more abnormalities in the genome, especially a condition that is present from birth (congenital) (Oxford, 2015).	A disease or deformity caused by genetic issue (Ellington et al., 2006).

Knowledge	Categorical Nominal	Facts, information and skills acquired through experience, or education, the theoretical or practical understanding of a subject (Oxford, 2015).	A score of answers of parents on many questions about genetic counseling and testing (Ibrahim et al., 2011).
Attitude	Categorical Nominal	A settled thinking or feeling about something (Oxford, 2015).	If you accept or refuse genetic testing and counseling and your conviction toward it (Ibrahim et al., 2011).
Counseling	Categorical Nominal	The provision or professional assistance or guidance in resolving personal or psychological problems (Oxford, 2015).	Asking a consult or advice from a specialist (Ellington et al., 2006).

Genetic testing	Categorical Nominal	The condition of being of the same blood; relationship by descent from a common ancestor; blood-relationship (Oxford, 2015).	DNA exam to avoid genetic disorder (Ellington et al., 2006).
Parents	Categorical Nominal	A person's mother or father (Oxford, 2015).	Mothers and fathers of children with genetic disorders (Ellington et al., 2006).
Consanguinity	Categorical Ordinal	Relationship by blood or by a common ancestor (Oxford, 2015).	Consanguinity, or intermarriage, is defined as the marriage of two relatives, second cousins or more closely related individuals (NCHPE,G2013).

3.9 Validity

3.9.1 Piloting:

The questionnaire was given to seven experts in the genetic research field to critique it and provide their suggestions. All feedback and comments were incorporated into the final questionnaire design. A pilot study was then conducted with ten families who have one or more children with a genetic disorder. The goal of the pilot study was to evaluate the questionnaire and to seek the families' feedback. These ten families were chosen randomly, five from PMC and the other five from Al-Najah National Hospital. No changes were made to the questionnaire's design as a result of the pilot study. The pilot sample was included in the main sample, and both were analyzed together.

3.9.2 Translation

The questionnaire was translated from Arabic to English by a specialist in the English language. Another specialist then translated it to Arabic without any significant differences. Lastly, a doctor specialized in genetics reviewed the final questionnaire, and gave positive comments.

3.10 Reliability

Cronbach's alpha is a measure of internal consistency, that is, how closely related a set of items are as a group. It is not a statistical test, but a coefficient of reliability (or consistency). It can be written as a function of

the number of test items and the average inter-correlation among the items (IDRE, 2016)

Stability of the scale, or the internal consistency, was calculated using Cronbach's alpha coefficient (Cronbach Alpha). The stability coefficient was 0.72, which means the tool of the study has good stability.

Case Processing Summary			
		No.	%
Cases	Valid	119	98.3
	Excluded	2	1.7
	Total	121	100.0

Table (3.2): Stability

3.11 Ethical considerations

The researcher obtained the permission of Al-Najah University's Institutional Review Board (IRB) before starting this study. Additionally, the thesis supervisor oversaw the development and implementation of all other steps throughout the research. Permission to conduct this study was also obtained from the directors of both the Palestine Medical Complex, and Al-Najah University Hospital.

The subjects were each given a consent form to sign prior to starting the questionnaire. All subjects had the option to withdraw from the study at

any point they wanted. In addition, no subject was obliged to provide their name or any piece of private information. Protecting the privacy of the subjects was taken into consideration in all steps of the data collection and analysis process.

The completed questionnaires and any information on the subjects are carefully kept in the researcher's office. The only people with access to this data are the researcher and the supervisor; however, they do not have the right to publish any of the subjects' private information.

3.12 strengths and limitation

3.12.1 Strengths of the study

1.Palestinian researchers rarely explore this topic, so it is still a relatively young research field.

2.This study is unique because it deals with parents of sick children.

3.This study will highlight the most important factors that help improve parents' knowledge about genetic counseling and testing.

3.12.1Limitations of the study

1.Patients of children with physical deformities due to genetic conditions could not be included, as they usually visit physiotherapy centers not hospitals.

2.Geographic limitations: the study was conducted in two hospitals only.

3.Small sample size.

3.13 Summary

The main method of this research was a quantitative, descriptive, cross-sectional survey. This method was the most suitable to achieve the aim of this study, which was to determine parents' knowledge and attitudes toward genetic counseling and testing, and if knowledge affects attitudes.

The study was conducted in two hospitals: the first is governmental (PMC), and the other is private (AL- Najah National Hospital). A questionnaire was used to collect data from 15\2\2016 to 15\9\2016, the data was then analyzed using SPSS version 19. Ethical research standards were followed and taken into consideration.

Knowledge was measured by a quiz and attitudes by Likert scale. The relationship between knowledge and attitudes was measured using chi squire

Chapter 4

Results

4.1. Introduction:

Data from the descriptive cross-sectional study was analyzed using one-way ANOVA to assess the relationships and correlations between dependent and independent variables.

The first section of the questionnaire collected demographic data, which was then analyzed as descriptive data, and the variables treated as independent variables. Variables from the second section were also considered independent. These included causes and main risk factors of genetic problems. The third section was essentially a quiz to evaluate parents' knowledge, while the fourth section was a Likert scale used to discover parent' attitudes toward genetic testing and counseling. SPSS version 19 was used to analyze the data. The filter question "How many children with genetic disorders do you have?" helped in analyzing the data.

ANOVA as a parametric test.

4.2 Sample distribution:

As figure 3 shows, the sample is normally distributed so it is suitable to use

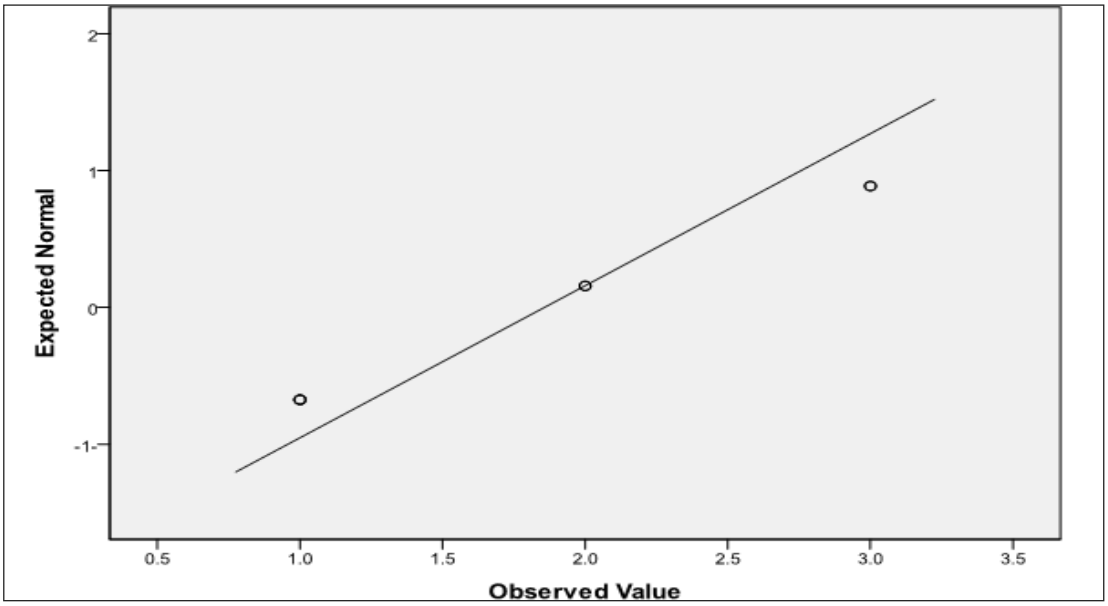

Figure (3.1): Sample distribution

4.3 Descriptive statistics

4.3.1 Demographic data:

Table (4.1): Demographic data:

Demographic Data			
Variables		No.	%
1.Hospital	P MC	42	35
	A l-Najah	79	65
2.Occupation	City	37	30.6
	Village	59	48.8

	Camp	18	14.9
	Bedouin	7	5.8
3.Gender	Male	30	25
	female	91	75
4.Age	≤ 20 years old	2	1.7
	21-30 years	54	44.6
	40-31years	52	43.0
	≥ 40 years old	13	10.7
5.Educational level	Primary school	8	6.6
	Middle school	30	24.8
	Tawjihi (Secondary)	34	28.1
	Diploma	17	14.0
	Higher academia	32	26.4
6.Work	Employed	54	44.6
	Unemployed	67	55.4
7.Income	≤ 1500	19	15.7
	1500- 2500	22	18.2
	2500- 3500	38	31.4
	3500- 4000	33	27.3
	> 4000	9	7.4
8.Number of children with genetic problem	One child	96	79.3
	Two children	23	19.0

	Three children	2	1.7
9.Genetic problem	Heart defect	10	8.3
	Diabetic	14	11.6
	Neurology	18	14.9
	Metabolic disorder	34	28.1
	Hemophilia	8	6.6
	Digestive	19	15.7
	Dermal	7	5.8
	Immunity	8	6.6
	Skeletal	3	2.5
10.Lost a child or children or child	Yes	35	28.9
	No	86	71.1
11.Number of children lost	One	27	77.1
	Two	4	11.4
	Three	2	5.7
	Four	0	0
	Five	0	0
	Six	2	5.7

Demographic data was collected using ten questions in the survey. The purpose of collecting this data is to discover if different demographic factors enhances parents' knowledge and attitudes (table 4).

The first question was used to indicate the distribution of subjects between the two hospitals. 35% of subjects (n=42) were in PMC, and 65% (n=79) were in Al-Najah National Hospital. Additionally, 75% (n=91) of subjects were females (mothers) and 25% (n=30) were males (fathers). This is because individuals accompanying patients in pediatric wards tend to be women, particularly the mothers of the patients.

Near the half of subjects (48.8%, n=59) lived in villages, while 30% (n=37) lived in cities, 14.9% (n=18) in camps, and 5.8% (n=7) were Bedouins nomads. The age of these parents ranged from 16 to 45 years old. Out of the total sample, 1.7% of parents (n=2) were 20 years old or younger, most of them (44.6%, n=54) were in the 21-30 age group, around 43% (n=52) were in the 31-40 age group, and only 10.7% (n=13) were older than 40 years old.

This study paid particular attention on the impact of the educational level of parents on their knowledge and attitudes toward genetic counseling and testing. About one third of subjects had low levels of educational, not exceeding the 12^{th} grade (secondary education or Tawjihi). Out of these parents, 6.6% (n= 8) have only finished primary education, 24.8% (n=30) have only finished middle school, while 28.1% (n=34) completed secondary school (Tawjihi). As for the subjects with education beyond the secondary school level, 14% (n=17) completed a diploma program, while 26.4% (n=32) had higher academic education.

It was also important to investigate the influence income has on knowledge and attitudes, therefore income data was collected. In this sample, 15.7% (n=19) of families lived on very low income (less than 1500 shekels a month). These families are considered to be living below the Palestinian poverty line. About 18.2% (n=22) were in better conditions, and had an income between 1500-2500 shekel a month. 31.4% of participants (n=38) had an income of 2500-3500 shekel a month, and 27.3% (n=33) had an income of 3500-4000 shekels, which is considered a middle income level. However, only 7.4% of subjects (n=9) made what's considered a good income level, with more than 4000 shekel a month. Over half of the participants (55.4%, n=67) had a job, while 44.6% (n=54) did not. This is because the majority of subjects were mothers 75% (n=91), who are often unemployed.

Families were also asked about the number of children suffering from genetic disorder. This was done to study if a complex problem affects the knowledge and attitude of parents. Most parents (79.3% n=96) had one affected child, 19% (n=23) had two children, and only 1.7% (n=2) had the maximum number of three children. The genetic diseases the patients suffered from were classified according to body systems as: congenital cardiac problems (8.3%, n=10), diabetes (11.6%, n=14), neurology (14.9%, n=18), metabolic disorders (28.1%, n=34) which are considered the most common in Palestine, hemophilia (6.6%, n=8), gastrointestinal (15.7%, (n=19), dermal problems (5.8%, n=7), immune system problems (6.6%,

n=8), and skeletal problems (2.5%, n=3). Skeletal problems were the least common genetic problems.

Among these families, 28.9% (n=35) have lost children due to the same genetic problem while 71.1% (n=86) did not. Most families who lost children lost one child (77.1%, n=27), 11.4% (n=4) lost two, 5.7% (n=2) lost three children, and 5.7% (n=2) lost six children.

4.3.2 Associated risk factors for genetic disorder:

Table (4.2): associated risk factors for genetic disorders

Associated risk factors			
Variables		N	%
1.Mother age on marriage	20 years or less	78	64.5
	21-30 years	41	33.9
	40-31years	2	1.7
	40 years or more	0	0
2. Mother age when have The first baby	20 years or less	43	35.5
	21-30 years	76	62.8
	40-31years	2	1.7
	40 years or more	0	0
3.Consanguineous marriage	Yes	86	71.1
	No	35	28.9
4.Level of consanguinity	First degree	34	39.5
	Second degree	40	46.5
	Third	12	14.0

5.Genetic test before marriage	Yes	1	0.8
	No	120	99.2
6.a The result	Positive	1	100
	Negative	0	0
7.Genetic problem with Relatives	Yes	67	55.4
	No	54	44.6
	Heart defect	6	9.0
	Diabetic	7	10.4
	Neurology	11	16.4
	Metabolic	16	23.9
	Hemophilia	7	10.4
	Digestive	9	13.4
	Dermal	7	10.4
	Immunity	4	6.0
	Skeletal	0	0
8.Do you live in an industrial Country?	Yes	8	6.6
	No	113	93.4
9.Did the mother do a detailed ultrasound?	Yes	65	53.7
	No	56	46.3
10.A Gestational age on detailed ultrasound	Less than 4 months	5	7.7
	4months or more	60	92.3

11.Did you receive information about genetic counseling and genetic problems?	Yes	66	54.5
	No	55	45.5
12.A The source of information	A health center	29	43.9
	Social media	22	33.3
	school	7	10.6
	The family	1	1.5
	A clerk	0	0
	Health lecture	5	7.6
	The people around	2	3.0

This study wanted to investigate the main associated risk factors leading to genetic problems in Palestine, especially under the common culture of consanguineous marriage. A variety of associated factors were explored using ten questions in the survey (annex 1) and analyzed as shown in table (4.2).

Despite the well-known high levels of consanguineous marriages in Palestine, only one of the subjects (0.8%) underwent a genetic test before marriage, while 99.2% (n=120) did not. This is the most important association for genetic problems. Additionally, 55.4% (n=67) of the subjects had a family history of genetic disorders.

Genetic disorders of subjects relatives were classified into the same categories as those of the children. However, the percentages differ as follows: congenital cardiac problems (9%, n=6), diabetes (10.4%, n=7), neurology (16.4%, n=11), metabolic disorders (23.9%, n=16) which are considered the most common in Palestine, hemophilia (10.4%, n=7), gastrointestinal (13.4%, n=9), dermal problems (10.4%, n=7) and immune system problems (6%, n=4). None of the relatives had skeletal problems. It is important to note that the distribution of genetic problems among relatives is similar proportionally to the distribution of problems among the sick children

Consanguinity was a common cause of genetic disorders, this was clear in this study, where more than two thirds of couples (71%, n=86) were relatives, and only 29% (n=35) were not. In addition, 39.5% (n=34) of couples had first degree marriages, 46% (n=40) of consanguineous marriages were second degree, and 14% (n=12) were third degree consanguinity.

Another associated factor investigates is the mother’s age at marriage. Most mothers (64.5%, n=78) got married at 20 years younger, 33.9% (n=41) got married at ages between 21-30 years , and just 1.7% (n=2) got married between 31-40 years of age. The first child was born at the age of 20 or younger for 35.5% (n=43) of mothers, while most of them (62.8%, n=76) gave birth to the first child between 21-30 years of age.

Industrial areas may affect human genes and lead to creating genetic mutation, therefore subjects were asked about whether they lived in industrial areas or not. The answer of 6.6% (n=8) of them was yes, and 93.4% (n=113) answered no. However, it cannot be ignored that Palestine is not an industrialized country, and that the presence of heavily industrialized areas is scarce.

Another important associated factor in protecting children from advanced genetic problems is lack of antenatal care. Early diagnoses of genetic conditions can increase the opportunity of effective therapy. A detailed ultrasound is an advanced eco test done to examine the fetus's organs. Half of the mothers in this study (53.7% n=65) had this test done, while 46.3% (n=56) did not. Mothers did the test in different gestational ages, 7.7% (n=5) did it before the gestational age of 4 months, and 92.3% (n=60) did it after the gestational age of 4 months.

Health education is also very important for reproductive health, and when the subjects were asked whether they received any health education, 54.5% (n=66) answered with yes, and 45.5% (n=55) said that they did not receive any health education. Sources of education were various, and often not valid or professional. Only 43% (n=29) of families received education from health centers, 33.3% (n=22) from social media, and 10.6% (n=7) remembered information from school. Family was a source of information for 1.5% (n=1) of subjects, health lectures were a source for 7.5% (n=5), and 3% (n=2) of subjects used other people around them as sources.

4.3.3 Knowledge evaluation:

4.3.3.1 Parents' knowledge:

This section covers the process and results of the evaluation of parents' knowledge about genetic counseling. It is essentially a quiz from which the knowledge was assessed. The quiz had ten multiple choice questions, and a total of ten marks (table 4.3).

Table (4.3): knowledge Evaluation

Knowledge evaluation			
Question	Answers	N	%
1. The meaning of genetic testing:	Analyze the genes of the Mother and Father	31	25.6
	2. Analyze DNA to determine a genetic problem	21	17.4
	3.Discover the chromosome of defected Genes	13	10.7
	4. All of the above	56	46.3
2.the method of transmission of genetic disease is	1.genes	105	86.8
	2.infection by touch	1	.8
	3.contaminated air and water	1	.8
	4.couldnt be transmitted	14	11.6

3. The main purpose of genetic counseling is:	1. decrease the cases of genetic problems in the Society	68	56.2
	2. terminate the pregnancy of defected fetus	13	10.7
	3. treat children of genetic Problem	40	33.1
4. Most suitable time for genetic counseling	1. when planning for pregnancy	69	57.0
	2.the first trimester of pregnancy	39	32.2
	3. the last trimester of pregnancy	0	0
	4. directly after delivery	13	10.7
5. Genetic problem could be Decreased	1.Yes	99	81.8
	2. No	22	18.2
6. Consanguineous marriage may increase genetic problem	1. Yes	120	99.2
	2.No	1	0.8
7. The responsibility of transmission	1.Both mother's and father's genes	103	85.1

of genetic problem is due to:	2.Just mother's genes	10	8.3
	3.Just father's genes	8	6.6
8.Genetic counseling is important :	1. In the first pregnancy	51	42.1
	2.In every pregnancy	68	56.2
	3. Not important at all	2	1.7
9.The most prior Relatives to analyze DNA to determine the problem of the baby are	1.Child,s mother and father	109	90.1
	2.His grand parents	10	8.3
	3.Cousins	2	1.7
	4.No body	0	0
10.Genetic counseling before marriage is important for:	1.treat the genetic problems	59	48.8
	2.control the expansion of genetic disorders in Palestinian society	54	44.6
	3. to determine the gender of the baby.	4	3.3
	4.to avoid infectious diseases.	4	3.3

Question (1) was about the "meaning of genetic testing." The breakdown for the first question was as follows: analyzing the genes of the mother and father (25.6%, n=31), analyzing DNA to determine a genetic problem (17.4%, n=21), discovering the chromosome of defected genes (10.7%, n=13), or all of the above, which is the correct answer (46.3%, n=56).

Question (2) got the highest number of correct answers. The question was about "the method of transmission of genetic disease." The answer breakdown was: genes, which was the correct answer, (86% n=105), infection by touch (0.8%, n=1), by contaminated water and air (0.8% n=1), while (11.6% n=14) seemed to believe that genetic disorders could not be transmitted.

Question (3) asked about "the purpose of genetic counseling." Most subjects (56.2%, n=68) chose the right answer which was "to decrease the cases of genetic problems in society." Meanwhile, 10.7% (n=13) thought the purpose is to terminate the pregnancy of fetuses with genetic problems, and 33.1% (n=40) assumed that the purpose is for treatment.

Question (4) was about the most suitable time for genetic counseling. The correct answer is "when planning for pregnancy," which was chosen by 57% (n=69) of participants. 32.2% (n=39) seemed to think the most suitable time to be in the first trimester of pregnancy, and just 10.7% (n=13) thought the correct answer was directly after delivery.

Question (5) was "is it possible to reduce the incidence of genetic problems?" 81.8% (n=99) answered with yes, and 18.2% (n=22) believed it was not possible.

Question (6) was if "consanguineous marriage increases the incidence of genetic problems" and 99.2% (n=120) answered with yes, it does.

Question (7) was asking whether "the responsibility of transmission of genetic problem is due to" the genes of both parents, which is the correct

answer (85.1%, n=103), the father's genes alone (8.3%, n=10), or the mother's genes alone (6.6%, n=8).

Question (8) was about the "importance of the genetic counseling", and 42.1% (n=51) of parents believed it was only important in the first pregnancy. The correct answer is that it is important in every pregnancy, as 56.2% (n=68) of parents answered. Lastly, 1.7% (n=2) seemed to believe that it is not important at all.

Question (9): was "the relatives with the top priority to undergo DNA analysis to determine the genetic problem of a child are" the parents as 90.1% (n=109) of subjects answered. Some (8.3%, n=10) thought grandparents should also do the analysis, while others (1.7% n=2) thought that cousins also have a priority. None of the subjects (0% n=0) seemed to thinks that there is no need for DNA analysis.

Genetic counseling before marriage is not customary in the Palestinian society, therefore when subjects were asked about the importance of that in **question 10**, nearly half of the answers (48.8% n=59) wrongly chose "treatment of genetic diseases" as the answer, and approximately 44.6% (n=54) chose the correct answer, which is "to control the expansion of genetic disorders in Palestinian society." Meanwhile, 3.3% (n=4) thought "to determine the gender of the baby" is the correct answer, and another 3.3% (n=4) thought it was to avoid infectious diseases.

4.3.3.2 Evaluation and scoring:

The purpose of the previous ten questions was to evaluate parents' knowledge (table 4.4). Each correct answer equals one mark, with a scoring scale ranging from 0 to 10. Scores were classified into three categories: good, moderate, and weak knowledge. There is no literature discussing how to determine a cutoff point for knowledge scores, so the researcher divided the scores into three intervals: good (7-10), moderate (4-6), and weak (0-3). This makes classifying and evaluating knowledge levels easier, and makes it possible to link it with attitudes. In this sample, 5% (n=6) of parents had weak levels of knowledge, 31.4% (n=38) had moderate levels, and 63.6% (n=77) had good knowledge levels.

Table (4.4): Knowledge level

Knowledge Level		Frequency	Percent
	Weak	6	5.0%
	Moderate	38	31.4%
	Good	77	63.6%
	Total	121	100.0%

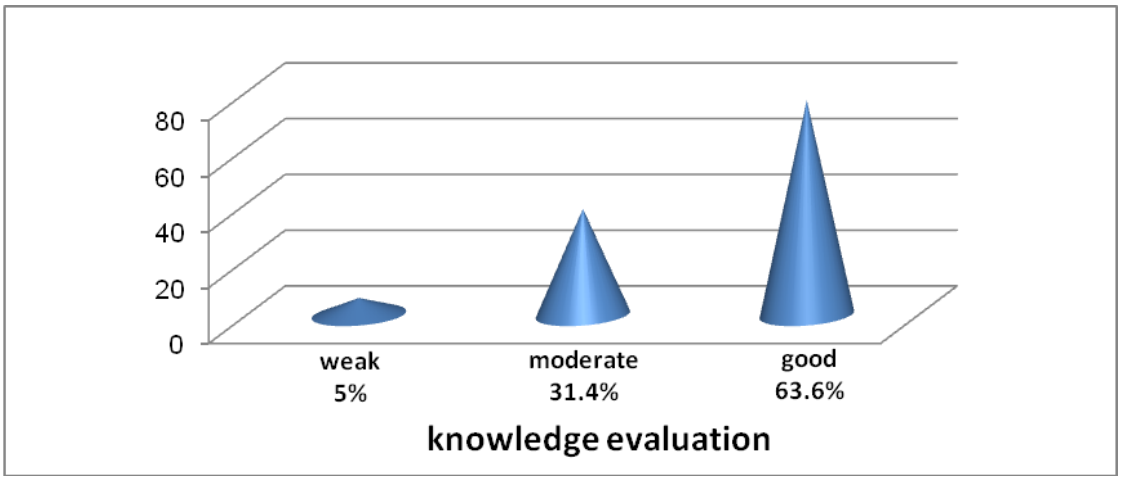

Figure (4.2): knowledge level

4.3.4 Parents' attitude:

Table (4.5) in (annex 2) shows families' attitudes toward genetic counseling and testing. Attitudes were studied using a Likert scale questionnaire, which used five responses to answer questions. These were: strongly agree, agree, undecided, disagree, and strongly disagree. Positive attitudes were indicated by the answers: agree and strongly agree, while

negative attitudes were indicated by disagree and strongly disagree. For questions 6,10, and 11, positive attitudes were determined by answers (disagree and strongly disagree), which were used to avoid bias. A total of 22 questions were used for this evaluation:

Question (1): "Couples have to do genetic testing when they plan to get married": 88.4% (n=107) of participants agreed, and 1.7% (n=2) disagreed, so attitudes toward this question are considered significantly positive.

Question (2): "All pregnant women have to do genetic tests for the fetus": 93.3% (n=113) of the answers were agreed, so attitudes toward this question are considered significantly positive.

Question (3): "Experience of genetic problem in the family will increase their care about genetic counseling": 97.5% (n=118) of couples agreed with this, which indicates positive attitude.

Question (4): "Genetic testing has to be available for people as needed": 99.2% (n=120) of parents agreed, indicating a positive attitude.

Question (5): "Genetic counseling must be available even for families with family history free of genetic problems": 72% (n=91) of families agreed; again, this indicated a positive attitude.

Question (6): "Genetic counseling should never be used because of religious and social reasons." This question was written using negative wording, and 83.5% (n=101) of answers disagreed, indicating a positive attitude.

Question (7): “IVF could be used to avoid defected genes when couples want to have a healthy child”: answers to this question were: disagree (22.3%, n=27), I don’t know (37.2%, n=45), and 40.5% (n=49) said they agree. This is considered a negative attitude.

Question (8): “Genetic testing must be done for all newborns”: 78.5% (n=95) of answers agreed, and that’s positive.

Question (9): “Each person has the right to know if he is at risk of having a genetic problem in the future”: 95.5% (n=116) of parents agreed ,which is considered a positive attitude.

Question (10): “Each person has the right to know the probability of having a child with a genetic problem”: 72% (n=87) of answers were I don't know, which is considered negative attitude.

Question (11): “We have to bow to the genetic problems without interference”: this question was written in negative wording, and 91% (n=110) of answers were 'disagree', which indicates a positive attitude.

Question (12): “Genetic counseling must be avoided because it increases the probability of abortion”: this question was in negative wording, and 79% (n=96) of answers disagreed, which is a positive attitude.

Question (13): “I will take a genetic consultation when I plan for pregnancy in the future”: 86.7% (n=105) of answers agreed, and that’s a positive attitude.

Question (14): “I advise my children to have genetic counseling before marriage”: 95% (n=115) of families agreed, and that’s a positive attitude.

Question (15): “The presence of a genetic disorder in a family may lead them to stop consanguineous marriage”: 86% (n=104) of families agreed, and that’s positive.

Question (16): “Genetic testing helps couples discover their genetic history and may destroy their relationship” 76.5% (n=84) of answers agreed, and that’s positive.

Question (17): “Genetic counseling can lead to avoiding consanguineous marriage”: 92.6% (n=112) of answers agreed, indicating a positive attitude.

Question (18): “Genetic counseling decreases the probability of having a genetic problem”: 74% (n=90) of answers agreed, which is considered a positive attitude.

Question (19): “It is important to consider the Islamic view in making the right decision to marry according to my family health history”: 65.3% (n=79) of answers were agree, which is considered a positive attitude.

Question (20): “My information about genetic counseling is not insufficient”: this question displays the desire of parents for education, 69.4% (n=84) of parents answered agree, which is considered positive.

Question (21): “Laboratories that offer genetic testing service are not available in my country”: this question displays the desire of parents to

have benefits, 91% (n=111) of them answered I agree, and that's a positive attitude.

Question (22): "High cost of genetic counseling may decrease the desire to take it": like the previous question, this question displays the parents' desire to have benefits, and 86% (n=104) of respondents agreed, and that's a positive attitude.

It is clear that most of the attitudes toward previous items were positive (20 out of 22), so it could be considered that parents' attitudes towards genetic counseling and testing are positive. The mean was calculated by taking the sum of positive answers (20) and dividing that by the number of items (22); the mean was 81%.

The following section will examine whether certain factors affect parents' attitudes. Education and the number of sick children are two of the most important factors to discuss.

4.4 Inferential:

4.4.1 Introduction:

To evaluate the relationship between the three categories of knowledge (weak, moderate, and good) and the 22 items for attitudes, a chi-square test was used. Results of significant differences were organized in Table (6), then correlation tests were done for significant results in order to discover the type of the relationship (positive or negative). To study the 2^{nd} and 3^{rd} hypotheses, ANOVA test was used to compare between and within groups.

4.4.2 Chi-square test

Chi-square is a statistical test commonly used to compare observed data with data we would expect to obtain according to a specific hypothesis (Fisher and Yates, 2006). It is used when the researcher has two categorical variables from a single population, and wants to determine whether there is a significant association between the two variables with two or more values (Stat Trek, 2016).

4.4.3 Correlation:

A statistical method that measures the degree to which two variables move in relation to each other. It is computed into what is known as the correlation coefficient, the values of which must fall between -1 and 1 (Invostopedia, 2016)

4.4.4 ANOVA Test:

One-way analysis (ANOVA) or (Analysis of Variance) is used to determine whether there are any statistically significant differences between the means of two or more independent groups (Lund Research, 2013). (ANOVA) is used with one categorical independent variable (attitudes) (total evaluation: positive or negative) and one continuous variable (knowledge evaluation). The independent variable can consist of any number of groups (Richard, 1998). When we compare more than two groups (weak, moderate, and good), based on one factor (independent variable), ANOVA is the most suitable statistical tool (Statistics Solutions, 2013).

4.4.5 Knowledge and attitudes (chi square analysis):

Table(4.5)Chi square significant table(effect of knowledge on attitudes)

Item	Answer	Weak	Moderate	Good	Total	P-value
1.Couples have to do genetic testing when they plan to get married	Disagree	0 0.0%	0 0.0%	2 1.8%	2 1.8%	0.004
	I don't know	2 1.7%	8 6.6%	2 1.7%	12 9.9	
	Agree	4 3.3%	30 24.7%	73 60.3%	107 88.4%	
2. Genetic counseling must available even for families which family history is free of genetic problems	Disagree	3 2.5%	10 8.2%	9 7.4%	22 18.2%	0.02
	I don't know	1 0.8%	2 1.7%	5 4.1%	8 6.6%	
	Agree	2 1.7%	26 21.4%	63 52%	91 75.2%	
3. Genetic counseling has to be avoided for religious and social reasons	Disagree	2 1.7%	29 23.9%	70 57.8%	101 83.4%	0.001
	I don't know	4 3.3%	6 4.9%	7 5.8%	17 14%	
	Agree	0	3	0	3	

		0.0%	2.5%	0.0%	2.5%	
4.Genetic testing must be done for all newborns	Disagree	2 1.7%	6 4.9%	4 3.3%	12 9.9%	0.02
	I don’t know	1 0.8%	6 4.9%	7 5.8%	14 11.7%	
	Agree	3 2.5%	26 21.4%	66 54.5%	95 78.5%	
5.We have to bow to the genetic problems without interference	Disagree	4 3.3%	33 7.3%	73 60%	110 91%	0.01
	I don’t know	0 0.0%	2 1.7%	0 0.0%	2 1.7%	
	Agree	2 1.7%	3 2.5%	4 3.3%	9 7.4%	
6. Genetic counseling must be avoided because it increases the probability of abortion	Disagree	3 2.5%	25 20.6%	70 57.8%	96 79.3%	0.01
	I don’t know	2 1.7%	7 5.8%	3 2.5%	12	
	Agree	1 0.8%	8 6.6%	4 3.3%	13 10.7%	

7. Genetic counseling leads to avoiding consanguineous marriage	disagree	0 0.0%	4 3.3%	0 0.0%	4 3.3%	0.04
	I don't know	0 0.0%	3 2.5%	2 1.7%	5 4.1%	
	Agree	6 4.9%	31 25.6%	75 61.9%	112 92.5%	
8. Genetic counseling decreases the probability of having a genetic problem	Disagree	0 0.0%	12 9.9%	6 4.9%	18 14.8%	0.01
	I don't know	2 1.7%	3 2.5%	6 4.9%	11 9%	
	Agree	4 3.3%	23 19%	63 52%	90 74.4%	

Table (4.6) shows the relationship between knowledge and attitudes. A total of eight items had a significant relationship with knowledge (1, 5, 6, 8, 11, 12, 17, and 18). In Table (4.6) the first item, "couples have to do genetic testing when they plan to get married," has a significant relationship with knowledge (P-value= 0.016). The fifth item, "genetic counseling must be available even for families whose family history is free of genetic problems", the difference between the three groups was

significant (P-value= 0.04). The correlation test shows that this is a positive relationship.

Item 6, “genetic counseling has to be avoided for religious and social reasons”, had a negative significant difference between the groups (P-value= 0.001). This item was written in negative framing, so a negative relationship means positive attitudes.

For Item 8, “genetic tests must be done for all newborn children”, the difference between three groups is considered significant (P-value= 0.02). The correlation test revealed this relationship to be positive.

The P-value for Item 11 “we have to bow to the genetic problems without interference,” was 0.02, indicating a significant difference between groups. The correlation test indicates a negative relationship between knowledge and attitudes towards this item; however, this item was worded negatively, so a negative relationship means positive attitudes.

As for Item 12, “genetic counseling must be avoided because it increases the probability of abortion”, the difference between the three groups was also significant (P-value= 0.01). The correlation test indicates a negative relationship between knowledge and attitudes towards this item, but this item was worded negatively, so a negative relationship means positive attitudes.

Item 17, “genetic counseling leads to avoiding consanguineous marriage”, showed a significant difference between the three groups (P-value= 0.04).

The correlation coefficient shows there is a positive relationship between knowledge and attitudes towards this item.

Lastly, the P-value for Item 18, “genetic counseling decreases the probability of having a genetic problem”, was 0.01, indicating a significant difference between groups. The correlation test revealed a positive relationship between knowledge and attitudes towards this item.

There were 14 items with no significant relationship between knowledge and attitudes. These items were: 2, 3, 4, 7, 9, 10, 13, 14, 15, 16, 19, 20, 21, and 22 (annex 3).

These items and their respective P-values were: “all pregnant wom\en have to do genetic tests for the fetus”, (P-value= 0.7); “Genetic tests must be available as needed”, (P-value= 0.1); “Experience of genetic problem in the family will increase their care about genetic counseling”, (P-value= 0.3); “IVF could be used to avoid defective genes when couples want to have a healthy child”, (P-value= 0.1); “Each person has the right to know the risk of having a genetic problem in the future”, (P-value= 0.3); “Each person has the right to know the probability of having a child with a genetic problem”, (P-value= 0.6); “I will take a genetic consultation when I plan for pregnancy in the future”, (P-value= 0.7); “I advice my children to have genetic counseling before marriage”, (P-value= 0.2); “The presence of genetic disorder in a family may lead them to stop consanguineous marriage”, (P-value= 0.1); “Genetic testing helps couples to discover their genetic history and may destroy their relationship”, (P-value= 0.9); “It is

important to clarify the Islamic view before making the right decision to marry according to my family's health history", (P-value= 0.3); "My information about genetic counseling are not insufficient", (P-value= 0.1); "Laboratories that offer genetic testing service are not available in my country", (P-value= 0. 3); and "High cost of genetic counseling may decrease the desire to take it", (P-value= 0.6). All these P-values indicate that there is no significant difference between groups for any of these items.

As discussed in the section about parents' attitudes, attitudes were clearly significantly positive (in 20 items from 22), however as can be seen from the results of the correlation test (table 4.7), only eight of these positive attitudes had a positive correlation with parents' knowledge levels.

Table (4.6) Correlations: to discover the relationship between knowledge and attitudes:

Item	Sig.	Correlation	Person's Coefficient	Correlation
Couples have to do genetic testing when they plan to get marry	0.016	Positive	0.220	Positive
Genetic counseling must be available even for families which family history	0.04	Positive	0.272	Positive

free of genetic problems				
Genetic counseling had been never used for religious and social causes	0.001	Negative	-0.330	Negative
Genetic testing must be done for all newborns	0.02	Positive	0.324	Positive
We have to bow to the genetic problems without interference	0.01	Negative	-0.228	Negative
Genetic counseling must be avoided because it is increase the probability of abortion	0.01	Negative	-0.296	Negative
Genetic counseling leads to avoiding consanguineous marriage	0.04	Positive	0.191	Positive

The first hypothesis of this research was that parents who have high knowledge about genetic testing and counseling are expected to have more

positive attitudes towards testing and are more likely to use it. The previously-mentioned results allow the researcher to accept this hypothesis.

4.4.6 Number of sick children and parents' knowledge and attitudes:

To study the relationship between the number of children suffering from genetic disorder and parents' knowledge and attitudes, an ANOVA test was performed at the significance level of ($\alpha \leq 0.05$) with total (positive or negative) attitude evaluation (Table 4.7).

Table (4.7) ANOVA Test: Number of sick children and attitudes and knowledge:

Item		Df	Mean Square	F	Sig.
Attitudes	Between Groups	2	0.002	0.023	0.977
	Within Groups	118	0.101		
	Total	120			
Knowledge	Between Groups	2	0.364	1.058	0.350
	Within Groups	118	0.344		
	Total	120			

This table shows that there are no differences between the means at a significance level of ($\alpha = 0.05$). The difference in attitudes between the different groups (parents with one child with a genetic disease, parents with

two children, and parents with three children) has a significance value of 0.977, which is much higher than the significance level (α= 0.05), and indicates an insignificant difference. Similarly for knowledge, the difference between groups had a significant value of 0.350, which is again much higher than the significance level and indicates an insignificant difference.

These results suggest that there is no significant difference in parents' knowledge and attitudes towards genetic counseling and testing based on the number of children with genetic diseases that they have.

Based on these conclusions, the second hypothesis, which states that "Parents who have more children with genetic diseases have more knowledge and more positive attitudes towards genetic counseling" can be rejected and the null hypothesis can be accepted instead.

4.4.7 Number of lost children and parents' knowledge and attitudes:

To investigate the relation between the number of children who have died due to genetic disorders and their parents' knowledge and attitudes towards genetic testing and counseling, an ANOVA test was performed at the

($\alpha \leq 0.05$) significance level.

4.4.8 Parents' educational level and their knowledge evaluation and attitudes:

To study the relationship between parents' educational level and their knowledge and attitudes, another ANOVA test was done, again with a significance level of (α= 0.05).

Table (4.8): ANOVA Test: Number of deceased children and attitudes and knowledge:

Item		Df	Mean Square	F	Sig.
Attitudes	Between Groups	1	0.190	1.929	0.167
	Within Groups	119	0.099		
	Total	120			
Knowledge	Between Groups	1	0.009	0.025	0.875
	Within Groups	119	0.347		
	Total	120			

This table shows that there are no significant differences between groups at the 0.05 significance level. The significance value for differences in attitudes between the different groups (parents with one deceased child, parents with two deceased children, parents with three deceased children, and parents with six deceased children) is 0.167, which is higher than the significance level, and indicates an insignificant difference. Additionally, the differences in knowledge between the different groups had a significance level of 0.875, again indicating an insignificant difference.

These results suggest that there is no significant difference in parents' knowledge and attitudes towards genetic testing and counseling based on the number of children they've lost due to genetic disorders.

Therefore, the third hypothesis stating that "parents who lost more children due to a genetic problem have more knowledge and more positive attitudes towards genetic counseling" can be rejected, and the null hypothesis is accepted

Table (4.9): Parents' educational level and their knowledge and attitudes.

Item		Sum of Squares	Df	Mean Square	F	Sig.
Attitudes	Between Groups	0.374	4	0.093	0.938	0.445
	Within Groups	11.552	116	0.100		
	Total	11.926	120			
Knowledge	Between Groups	6.753	4	1.688	5.663	0.0003
	Within Groups	34.585	116	0.298		
	Total	41.339	120			

The table above shows that there are no significant differences between the attitudes of different groups (elementary education, middle school, secondary education, diploma education, or higher academic education)

toward genetic testing and counseling. The significance value for differences in attitudes was 0.445, which is higher than the significance level of 0.05, and indicates an insignificant difference. On the other hand, the table shows that there is a significant difference in knowledge levels between the different groups, with a significance value of 0.003, indicating a significant difference.

4.4.9 Parents' income and knowledge:

To study the relationship between parents' income and their knowledge, an ANOVA test was done at the 0.05 significance level.

Table (4.10): Parents' income level and their knowledge evaluation

Item		Sum of Squares	Df	Mean Square	F	Sig.
Knowledge	Between Groups	6.753	3	1.488	5.663	0.29
	Within Groups	34.585	115	0.398		
	Total	41.339	122			

This table shows that there is no significant difference in knowledge between the different income groups. The significance value for this difference is 0.29, which is larger than 0.05 and indicates an insignificant difference. This suggests that family income does not affect parents' knowledge about genetic testing and counseling.

4.5 Summary:

Data collected in this study was analyzed using SPSS Version 19. The first section of the survey collected general and demographic data, which showed that 75% of subjects were mothers, and 25% were fathers. Additionally, 79.3% of subjects had one child with a genetic condition, 19% had two, and only 1.7% had three. The genetic diseases that children suffered from were classified according to body systems impacted: 28.1% of children had metabolic disorders, which are considered the most common in Palestine.

The most common associated factors for genetic problems were: ignoring premarital genetic tests, early motherhood, consanguineous marriages, and a family history of genetic problems.

Parents' knowledge was evaluated using a quiz of ten questions, with a possible score ranging from 1 to 10. Scores were classified into three categories based on three score intervals: good (7-10), moderate (4-6), and weak (0-3). In this sample, 5% of parents had weak knowledge, 31.4% scored moderately, and 63.6% had scores indicating good knowledge.

Parents' attitudes towards genetic testing and counseling were overwhelmingly positive; respondents agreed with 20 out of 22 items on the attitudes part of the questionnaire, which reflects a positive attitude.

Different relationships and correlations were investigated in order to study the following hypotheses:

Hypothesis (1): Parents who have high knowledge about genetic testing and counseling are expected to have more positive attitudes toward and are

more likely to use it. To study this hypothesis, a chi-square test was used to compare attitudes between groups. The chi-square test results suggest knowledge affects attitudes positively, which allows for the first hypothesis to be accepted.

Hypothesis (2): Parents who have more sick children have more knowledge and more positive attitudes towards genetic counseling. To investigate this, an ANOVA test was used. The results showed that there is no relationship between the number of sick children and parents' knowledge and attitudes towards genetic counseling and testing. Based on these results, the second hypothesis was rejected.

Hypothesis (3): Parents who have lost more children to genetic problems have more knowledge and more positive attitudes towards genetic counseling. An ANOVA test was used again, and the results indicated that there is no relationship between the number of deceased children and parents' attitudes. However, there was a relationship between the number of deceased children and parents' knowledge. The third hypothesis was also rejected based on these results.

Chapter (5)

Discussion

5.1 Introduction

Results of this study were compared with other national and international studies, some of which were previously mentioned Chapter 2. The results of this study were sometimes similar and sometimes different from the articles in the literature review. In the following section, the different aspects of this study will be discussed in detail while comparing this study to other published works. The purpose of this is to discover how different socio-demographic factors affect knowledge and attitude data.

5.2 Socio-Demographic characteristics

Out of a total of 121 subjects, 35% (n=42) were in PMC, while the rest were in Al-Najah University Hospital. Moreover, 75% (n= 91) of them were females (mothers) and 25% (n=30) were males (fathers). Most subjects (48.8%, n= 60) lived in villages, whereas 30% (n=37) lived in cities, 14.9% (n=18) lived in camps, and only 5.8% (n=6) were Bedouin nomads. It is worth mentioning that consanguineous marriages, which are considered a significant risk factor, are more common in villages.

Unfortunately, only a few epidemiological population studies were conducted to investigate the prevalence of genetic disorders among Palestinians (Abu Lebdeh and Teebe, 2010).

The educational level of participants was as follows: 26.4% (n=32) had higher academic education, 52% (n=64) went to middle and high school, and 6.6% (n=8) only finished primary education. The results of this study suggest that parents' educational level positively affects their knowledge levels. The significance value (P-value) was 0.003, indicating a significant relationship.

As for the income of the subjects, 15.7% (n=19) of families had very low income (less than 1,500 shekels a month), 27.3% (n=33) had an income between 3,500-4,000 shekels, which is considered a middle-class income level. However, only 7.4% (n=9) had an income of 4,000 shekels or more, which is what's considered as 'good' or 'high' income. This study found no relationship between parents' income and their knowledge (P-value= 0.29). However, a study in Ohio (2014) found a significant association between parents' knowledge and household income (Fitzgerald-Butt et al., 2014). Other Arab countries had similar demographic distributions; however, studies done in Ohio, USA, showed very different distributions. This is possibly because the USA is a developed country, and often has higher income levels than Arab countries.

5.3 Associated risk factors:

Early marriages are common in Arab countries; therefore, the mother's age was studied as a risk factor for genetic diseases. In this study, 35.5% (n=43) of mothers had their first child when they were 20 years old or younger, 63% (n=76) when they were between 21-31 years of age, 1.7%

(n=2) when they were between 31 and 40 years old, and no subjects had a child after the age of 40. The high percentage of subjects with early motherhoods suggests that early marriage is, indeed, a risk factor in this study.

Another significant risk factor is consanguineous marriages, which are very common in Arab countries in general, and in Palestine in particular. Most parents in this study (71%, n=86) were married to their relatives, 40% (n=48) of which were first-degree relatives. A study by Tadmori et al. (2009) mentioned that consanguineous marriages, especially among first cousins constitute about 25-30% of marriages in Arab countries.

Although more than half of the subjects (55.4% n=67) had a family history of genetic problems (relatives suffering genetic problems), less than 1% (n=1) of the subjects did genetic counseling before marriage. This is the most significant risk factor. Additionally, lack of laboratories, high costs, and lack of awareness are considered obstacles that prevent families from undergoing premarital genetic testing.

Pollution was not significant as a risk factor, as only 6.6% (n=8) of families lived in industrialized areas or near a factory. However, it is important to take into consideration that Palestine in general is not an industrialized country.

To summarize, early marriage and motherhood, consanguineous marriage, and neglecting premarital genetic test are the most significant risk factors

for genetic problems in Palestine, while pollution was not a significant factor in this study.

5.4 Parents' knowledge

Parents were asked about the meaning of genetic testing, genetic problems, its causes, methods of transmission, and prevention methods. Each of these questions were scored, and constituted the knowledge evaluation part of this study. Only 5% (n=6) of parents had weak knowledge, 31.4% (n=38) had moderate knowledge, and 63.6% (n=77) had good knowledge.

These results are better than the results of an interventional study (educational program: pre and post exams) which was conducted in Saudi Arabia among university students, where knowledge levels about genetic counseling and testing were low (Ibrahim et al., 2011).

Another cross-sectional study in Netherland examined the knowledge and attitudes of patients with chronic diseases towards genetics and genetic testing using a questionnaire and a DNA test. The study found that genetic knowledge was low for older and lower educated patients (Morren and Rijken, 2006). This is consistent with the findings of this study which suggest that higher education is indicative of higher levels of knowledge (P-value= 0.003).

Another knowledge and attitude study conducted in Ohio (US) in 2014 among parents of children with congenital heart defect revealed that parents' knowledge was good, with 73.8% of parents answering questions correctly (Fitzgerald-Butt et al., 2014). Meanwhile, a study conducted in

Australia in 2013 among Parkinson's disease patients to assess their knowledge and attitudes towards genetic testing found that the level of knowledge was relatively low (37% correct responses) (Scuffham et al., 2013).

It is clear that the subjects of this study had good knowledge levels about genetic testing and counseling. Different studies investigated various segments of society; including university students and chronic disease patients, both of which scored low on the knowledge evaluation. However, studies conducted among parents (like this study) seemed to have more knowledgeable subjects. It is possible that being a parent of a patient may push the individual to becoming more educated and aware about genetic issues, as well as genetic testing and counseling.

5.5 Parents' attitudes:

Attitudes toward genetic counseling and testing had been studied by a Likert scale questionnaire which used five aspects: (strongly agree, agree undecided, disagree, and strongly disagree), positive attitude was determined by the items (agree and strongly agree) and the negative counted by (disagree and strongly disagree).

(20) items from (22) had high percentage of (agree and strongly agree) and just (2) had high percentage (more than 50%) of (disagree and strongly disagree), generally this result consider parents might have positive attitudes towards genetic counseling, which looks similar to many studies as shown below.

A cross sectional study in Netherland used questionnaire and DNA test, to examine knowledge of patients with chronic diseases and their attitudes towards genetics and genetic testing, found that attitudes toward genetics were positive and higher levels of genetic knowledge were associated with more positive attitude towards genetic counseling (Morren and Rijken, 2006).

Another knowledge attitude study conducted in Ohio (US) in (2014) among parents of congenital heart defect children showed attitudes towards the genetic testing were positive with (57%) agreeing that genetic testing would be used for managing health care and finding cures for disease (Fitzgerald-Butt et al., 2014).

Parkinson disease patients were population for a study in Australia, their attitudes towards genetic testing and counseling were positive: the vast majority (97%) supported diagnostic testing while (90%) would undertake a genetic test themselves, support for predictive test was lower (78%) and prenatal genetic testing had the least support (58%) (Scuffham et al., 2013).

All of above seems different from the study by University of Central Lancashire conducted in 1997 in the UK which studied the attitudes of deaf adults toward genetic testing for hereditary deafness. The study found negative attitudes and they said that they prefer to have deaf children (Middleton and Hewison, 1997). This is an old study; the tool was a questionnaire which was filled by delegation, which may have led to a lack of communication or misunderstanding, especially considering that the

population were deaf individuals. In general it is normal for any person to prefer to improve health and avoid having a genetic problem.

5.6 Knowledge and attitudes:

This section is to discuss the relationship between knowledge and attitudes; knowledge evaluation classified participants into three groups: good, moderate and weak.

Attitudes had been measured by the Likert scale and considered positive in general.

But when the three groups compared by Chi square, it is found that some significant results determined by which group had the positive results and if knowledge affecting attitudes **(Table 4.6).**

In the item (Couples have to do genetic testing when they plan to get married) there is a significant effect of good knowledge to have positive attitudes (p. value: 0.016).

A study conducted in Palestine by **(Thawabteh, et al. 2005):** families of Thalassemia mutation shows very good acceptability for prenatal diagnosis in b-Thalassemia afflicted families.

Both results are similar, both conducted in Palestine, so may culture affects their attitudes.

And regarding to the fourth item (Genetic counseling must be available even for families whose family history is free from genetic problems) it also has a significant positive attitude by the group of good evaluation (p.

value: 0.04). As mentioned before all of subjects had history of genetic problems and wants to stop that in the society.

The item (Genetic counseling has to be avoided for religious matters) is built in negative framing, so the answer 'disagree' expresses positive attitudes which significantly affected by the group of good knowledge (P.value:0.001).

Actually no studies in Arab or Moslem societies discussed attitudes according to religion, but in this study, although Palestinian society is conservative, religion was not considered as a barrier.

If (genetic test must be done for all newborns), it was a significant positive relationship between knowledge and attitudes (P. value: 0.02).

As mentioned before , this study and other literatures found that parents' attitudes towards testing were positive, especially those who had good knowledge.

(We have to accept to the genetic problems without interference) this item had a significant negative relationship between knowledge and attitudes towards this item, but this item had written in negative framing, so negative relationship mean positive attitudes.

Families want to stop suffering and live in a healthy society, so did not agree to bow to the genetic problems without interference.

Regards to Item 12 (Genetic counseling must be avoided because it increases the probability of abortion). The difference between the three

groups was negatively significant (P-value: 0.01). By correlation test it was a negative relationship between knowledge and attitudes towards this item, but this item was written in negative framing, so negative relationship mean positive attitudes, that similar to the finding of a study by **(Thawabteh, et al. 2005)** families of Thalassemia mutation show very good acceptability for prenatal diagnosis in b-Thalassemia afflicted families, and all couples with affected fetuses opted for abortion, this study was conducted in Palestine. While a study about prenatal testing by qualitative interviews found that parents' decisions around selective termination were not being made by unknown others, but by members of their own family **(Boardman, 2014)** that mean they may accept abortion for abnormal or sick fetus.

Otherwise abortion is not an easy decision, but may families refer that to religious and medical opinions.

(Genetic counseling leads to avoid consanguineous marriage): this Item had a significant positive association between knowledge and attitudes towards this item (P-value: 0.04). In the section of knowledge evaluation question (6) was if the consanguineous marriage increases the incidence of genetic problems (99.2% (n=120) think yes it increases that (which was the correct answer).

So good knowledge about consanguineous marriage and genetics affects attitudes positively. On the other hand, consanguinity in this study considered as one of the associated risk factors.

The item (Genetic counseling decreases the probability of having genetic problems) most of subjects were agree and their evaluation was good.

A study in Germany to discuss the different aspects of genetic counseling in the infertile couples underwent chromosome analysis prior IVF couples referred to genetic testing and genetic counseling before intracytoplasmic sperm injection, the finding was high rate of chromosomal abnormalities in female patients **(Kaiser and Kiesel, 1997).** The aim of the study was to discuss the different aspects of genetic counseling in the infertile couples, but it could be useful to support this study because the genetic testing discovered serious genetic problems could be avoided.

Generally this study reflects that good knowledge significantly associated with positive attitudes towards genetic testing and counseling, and there are many literatures supported our result.

That is like a cross sectional study in Netherlands found patients of higher levels of genetic knowledge were associated with a more positive attitudes towards genetic counseling **(Morren and Rijken, 2006).**

To insure this idea other literatures found that the highly specific information provided about genetic testing can empower both clinicians and patients to target their efforts on behavioral strategies that will have the greatest impact on reducing disease morbidity and mortality **(Tercyak, et al, 2002).**

Another cross sectional study in Netherlands used questionnaire and DNA test found attitudes toward genetic testing were positive and higher levels

of genetic knowledge were associated with a more positive attitude towards genetic counseling **(Morren and Rijken, 2006)**, also in Netherlands knowledge and attitude follow up study conducted over two years from (2002 to 2004) among patients of asthma, diabetes mellitus and cardiovascular disease, and found that the perceived knowledge on DNA-testing has not increased since 2002, and attitudes towards genetic testing also were rather consistent. Less perceived medical genetic knowledge and more perceived social genetic knowledge were found predictive for a more reserved attitude towards genetic testing **(Calsbeek, et al,2007)**

And finally there is a study conducted in Australia in (2013) among Parkinson's disease patients to assess their knowledge and attitudes towards genetic testing found that the level of genetic knowledge was relatively low (37% correct responses), but their attitudes were positive **(Scuffham, et al, 2013).**

As discussed above most of studies found an association between knowledge and attitudes towards genetics, but it is essential to note that most of studies had good knowledge of subjects and found an association between that and positive attitudes, but the final one recorded low knowledge evaluation and also positive attitudes so it is obvious that people want to stop genetic problems.

5.7 Number of sick or lost children and attitudes (experience and attitudes):

All of sample subjects had experienced a genetic problem in the family, some of them had one sick child and some had more, while (29%) of them lost a child or more, in table (4.9) it is found that no significant relationship between number of lost children because of genetic problem and parents knowledge about genetic counseling (P-value: 0.8) also no significant relationship between the number of lost children and parents' attitudes toward that (P-value: 0.16),

In table (4.8) there is no significant relationship between number of sick children because of genetic problem and parents' knowledge about genetic counseling (P-value: 0.3) also no significant relationship between number of sick children and parents' attitudes toward that (P-value: 0.9)

While a study in America in (2007), shows that subjects who are known as history of genetic mutation their communication about genetic was strongly positive among counseling and testing **(Ellington and Maxwell, 2006),** that seems different from the study by University of Central Lancashire in 1997 in UK, which studied the attitudes of deaf adults toward genetic testing for (hereditary deafness), that showed negative attitudes and they said that they preferred to have deaf children **(Middleton and Hewison, 1997).**

So when a family is suffering the problem from all dimensions, it is normal to refuse live that again, and to have positive attitudes towards genetic counseling, but deaf subjects who had negative attitudes towards genetic counseling, may lack of communication affect their answers.

5.8 Attitudes towards prenatal testing and abortion:

Subjects attitudes towards prenatal testing were positive (93%) of them answered agree and strongly agree on (All of pregnant women have to do genetic analysis for the fetus), it is mentioned before that all of subjects had family history and experience of genetic disorders, and when asked if (Genetic counseling must be avoided because it increases the probability of abortion) (96%) of them disagreed. That means that subjects had positive attitudes towards prenatal testing and abortion, which is similar to the finding of Thawabteh et al. (2005) that families of Thalassemia mutation show very good acceptability for prenatal diagnosis in Thalassemia-affected families, and all couples with affected fetuses opted for abortion; this study was conducted in Palestine. Another study about prenatal testing by qualitative interviews found that parents' decisions around selective termination were not being made by unknown people, but by members of their own family **(Boardman, 2014).** Abortion is not an easy decision, but may families base their decision on religious and medical beliefs and knowledge.

5.9 Attitudes towards using the IVF to avoid affected gene:

IVF could be used to avoid defected gene when couples want to have a healthy baby, (60%) of parents inform negative attitudes, without significant differences between groups evaluations

A study conducted in the United Kingdom about pre-implantation diagnosis and other reproductive options in (IVF) to study attitudes of male

and female carriers of recessive disorders , the result shows that .the majority of the sample did not feel that it was the most useful option in their situation especially those who would not consider a termination **(Snowdon and Green, 2000).** Attitudes were negative among two different countries, which may be according to culture in Palestine, but according to fear of termination in the UK.

5.10 Conclusion:

The first hypothesis: Parents who have high knowledge about genetic testing and counseling expected to have positive attitudes toward s using it.

This hypothesis had been accepted and the good knowledge evaluation parents had also positive attitudes towards genetic counseling and testing, chi square had been used to compare groups.

The second hypothesis: Parents who have more sick children have more knowledge and more positive attitudes towards genetic counseling.

This hypothesis had been rejected because it is found that no differences between the means and statistically no significant values, this is clear from the value of α which reach (0.167).

The third hypothesis: Parents who lost more children have good knowledge evaluation and more positive attitudes towards genetic counseling.

It is found that parents' attitudes were not affected by the number of lost children, (P-value: 0.875), so this hypothesis had been rejected.

5.11 Recommendations

1- The Ministry of health has to organize educational programs to increase people's awareness towards genetic problems and genetic counseling.

2- Adopt an initiative to start on inserting genetic tests in diagnostic process.

3- Expand the limitation of premarital tests to cover more genetic items.

4- Provide complementary laboratory services to cover genetic tests.

5- Recruit genetic counselors in primary health care centers.

6- Use media to publish awareness campaigns about consanguineous marriage and genetic problems, and about prenatal genetic exams.

7- Insert the genetic counseling in the process of antenatal care.

5.12 Summary :

In the West Bank governmental and private hospitals especially in pediatric wards there are no statistics about mortality rate of children who suffer from genetic disorders. In some occasions, many members from the same family have been diagnosed with the same disorder. From the researcher's own experience, there is a new child from the same family suffering from the same disease in the year after without any genetic counseling or any tool of prevention.

Unfortunately, only few population epidemiological studies were conducted to discover the incidence of genetic disorders among

Palestinians (Abu Lebdeh and Teebe, 2010), Except for thalassemic and hemophiliac patients (PHIC, 2013).

Sometimes, health professionals are unable to use a name to a genetic condition because it is newly appeared in some family. When this happens, physicians will say that a patient has an undiagnosed or rare genetic condition (NIH, 2011).

A quantitative descriptive cross sectional prospective survey had been used in this study using a questionnaire. The aim of the study was to describe the parents' knowledge about genetics and how it affects these attitudes toward genetic counseling and testing

The study was conducted in two hospitals in the West Bank: Al-Najah National Hospital in Nablus: pediatric ward and pediatric clinic (65%) of subjects, and Palestine Medical Complex (PMC) in Ramallah: Pediatric suit (Neonate ICU, Pediatric ICU and Pediatric ward) (35%) of subjects.

The questionnaire was built according to a literature review by the researcher and the supervisor with help from many experts in research and heredity. Data was collected from (15\2\2016 to 15\9\2016) the questionnaire contains four sections: Demographic data, associated risk factors, the section of knowledge; it is like a quiz to evaluate the awareness of parents, and the section of attitude to evaluate parent’s attitudes toward genetic counseling and what their plan in the future to avoid it having other children with the same or other genetic problem is likert scale questionnaire

had been used in five aspects: (strongly agree, agree, undecided, disagree, strongly disagree).

Sample size (121) subjects, data analyzed by SPSS vergion 19.

Independent variables: education, address, age, number of children, income and Knowledge

Dependent variable: parents attitudes toward genetic testing and counseling

There is a filter question (How many children with genetic disorders do you have?) this will help us to analyze the data.

In risk factors most risks were: Neglect the premarital genetic testing, consanguineous marriage and early marriage of mothers.

Ten questions had been used to evaluate parents' knowledge which was classified into three categories (good, moderate, and weak), (5%) of parents had weak evaluation, (31.4%) of them their evaluation was moderate, and good knowledge evaluation was (63.6%). People who had good knowledge had also positive attitudes towards genetic counseling and testing, chi square had been used to compare groups, then correlation was tested. Hypothesis 2 and 3: if number of lost or affected children affects parents knowledge and attitudes had been refused and there is no significant relationship.

According to the previous results it is recommended to increase people's awareness about genetic problems and genetic counseling especially

premarital and prenatal prevention, and to insert genetic testing in diagnostic process in national hospitals.

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Annex (1) Questionnaire:

كلية الدراسات العليا

برنامج ماجستير الصحة العامة

استبيان

المعرفة والموقف تجاه الاستشارة الوراثية بين آباء الأطفال الذين يعانون من أمراض وراثية في الضفة الغربية/ فلسطين

اعداد الطالبة: فلسطين ياسين

المشرف: الدكتورة ايمان الشاويش

معلومات حول الدراسة:

معلومات أهالي الأطفال المصابين بأمراض وراثية عن الاستشارة الوراثية والفحص الجيني، وما رأيهم في اللجوء إليها

سيدي المشارك/ سيدي المشاركة:

أنا الباحثة فلسطين ياسين طالبة ماجستير صحة عامة في جامعة النجاح الوطنية يسرني أن أدعوكم الى المشاركة في بحثي عن:

(معلومات أهالي الأطفال المصابين بأمراض وراثية عن الاستشارة الوراثية والفحص الجيني، وما رأيهم في اللجوء اليها)

مع العلم أن لديك الحق في قبول أو رفض المشاركة في البحث و أخذ الوقت الكافي للتفكير في المشاركة أو عدمها كما لديك الحق في طلب تفسير السؤال الذي لا تفهمه.

نضمن لك الحفاظ على سرية المعلومات المتعلقة بك ولن نطلب منك ادراج اسمك أو معلومات خاصة.

بامكانك الانسحاب من المشاركة في أي وقت دون الحاجة لأن تبدي أي عذر أو تبرير.

الهدف من الدراسة:

نهدف من خلال هذه الدراسة الى وصف مدى معلوماتكم حول الاستشارة والفحص الجيني ومدى تأثير ذلك على آرائكم تجاه استخدامها فيا لمستقبل، لذلك نرجوا من حضرتكم مسادتنا في تعبئة

هذه الاستبانة حيث سيتم طرح السؤال عليكم وتعبئة الجواب من قبل الباحث حيث من المتوقع أن تأخذ من وقتك خمسة عشر دقيقة حيث تتكون من أربعة أقسام:

تتكون الاستبانة من ثلاثة أقسام:

القسم الأول : معلومات عامة عنكم

القسم الثاني : أسباب وجود المرض الوراثي

القسم الثالث : أسئلة لاختبار معلوماتكم حول الاستشارة الوراثية والفحص الجيني عليكم اختيار اجابة واحدة فقط لكل سؤال.

القسم الرابع : أسئلة تكشف رأيكم في اللجوء الى الاستشارة الوراثية والفحوصات الجينية حيث يتم الجواب على هذه الأسئلة باختيار :(أرفض بشدة ، أرفض ، لا يهم ، أوافق، أوافق بشدة)

كما أن مشاركتك في هذا البحث ستساهم في دعم الوضع الصحي في الوطن ومحاولة انجاب جيل جديد خال من الأمراض الوراثية.

اختيار المشاركين:

سيتم اختيار ذوي المرضى المصابين بأمراض مشخصة بأنها وراثية وقد تم إدخالهم إلى قسم الأطفال بسببها وذلك في مستشفى النجاح الوطني (قسم الأطفال)، و مجمع فلسطين الطبي (قسم العناية المكثفة بالأطفال الخدج وقسم العناية المكثفة بالأطفال، وقسم الأطفال).

معلومات عن الباحثة:

الاسم : فلسطين على حسين ياسين

العنوان: عصيرة القبلية/ نابلس

البريد الالكتروني: falasteen-yaseen@hotmail.com

رقم الهاتف: ٠٥٩٨٠٩٥٣٢٣

المشرف على البحث: الدكتورة إيمان الشاويش

إن كنت موافقا على المشاركة في الدراسة نرجو من حضرتك التوقيع في الأسفل

التوقيع: .....

القسم الأول : معلومات سكانية عامة (أرجو وضع رقم الإجابة في المكان المخصص للإجابة)

الرقم	السؤال	خيارات الإجابة	الإجابة
١.	مكان السكن	١. مدينة ٢. قرية ٣. مخيم ٤. بادية	☐
٢.	الجنس	١. ذكر ٢. أنثى	☐
٣.	العمر	.....	☐
٤.	الحالة التعليمية	١. لا شيء ٢. ابتدائي ٣. إعدادي ٤. ثانوي ٥. دبلوم متوسط ٦. بكالوريوس فأعلى	☐
٥.	العمل	١. يعمل ٢. لا يعمل	☐
٦.	دخلك الشهري	١. ١٥٠٠ شيكل فأقل ٢. ١٥٠١- ٢٥٠٠ شيكل ٣. ٢٥٠١- ٣٥٠٠ شيكل ٤. ٣٥٠١- ٤٠٠٠ شيكل ٥. أكثر من ٤٠٠٠ شيكل	☐

٧.	عدد الأطفال	ذكور ☐☐ إناث ☐☐ المجموع ☐☐	
٨.	عدد الأطفال المصابين بمرض وراثي	ذكور ☐☐ إناث ☐☐ المجموع ☐☐	
٩.	نوع المرض الذي يعاني منه طفلك	١. تشوهات في القلب ٢. سكري ٣. أعصاب ٤. حموضة الدم ٥. تكسر الدم الوراثي ٦. هضمي ٧. جلدي ٨. عظمي ٩. مرض آخر، اذكره	☐
١٠.	هل فقدت طفلا أو أطفالا بسبب مرض وراثي؟	١. نعم ٢. لا	☐
١١.	إن كان جوابك نعم . كم عددهم	ذكور ☐☐ إناث ☐☐ المجموع ☐☐	

القسم الثاني: العوامل المساعدة لظهور المرض الوراثي

(أرجو وضع رقم الإجابة في المكان المخصص للإجابة)

الرقم	السؤال	خيارات الإجابة	الإجابة
١.	كم كان عمر الأم عند الزواج ؟	.....	☐
٢.	عمر الأم عند إنجاب الطفل الأول	.....	☐
٣.	هل يوجد قرابة بين الأم والأب؟	١. نعم ٢. لا	☐
٤.	إذا كان الجواب نعم ما درجة القرابة؟	١.أولى ٢. ثانية ٣. ثالثة	☐
٥.	هل تم إجراء أي الفحوصات الوراثية قبل الزواج؟ (بالإضافة إلى فحص التلاسيميا)	١. نعم ٢. لا	☐
٦.	ماذا كانت النتيجة؟	١.سلبية ٢. ايجابية	☐
٧.	هل لديكم أقارب مصابون بمرض وراثي ؟	١. نعم ٢. لا	☐
	إذا كان نعم ، ما هو نوع المرض ؟	١.تشوهات في القلب ٢. سكري ٣. أعصاب ٤. حموضة الدم ٥. تكسر الدم الوراثي ٦. هضمي ٧. جلدي ٨. عظمي ٩. مرض آخر اذكره	☐
٨.	هل تقطنون في منطقة صناعية أو منطقة قريبة من إشعاعات (مفاعل ديمونا)؟ (الآن أو في السابق)	١. نعم ٢. لا	☐
٩.	هل قامت الأم خلال الحمل بعمل صورة تلفزيونية للجنين (فحص الأعضاء) ؟	١. نعم ٢. لا	☐

	إذا كان الجواب نعم كم كان عمر الحمل (الجنين)؟	١. أقل من أربعة أشهر ٢. أربعة أشهر أو أكثر	☐
١٠ .	هل سبق أن قدمت لك معلومات عن الأمراض الوراثية وطرق انتقالها، والحد من انتشارها ؟	١. نعم ٢. لا	☐
	إن كان نعم ما هو مصدر المعلومة ؟	١. مركز صحي ٢. وسائل الإعلام ٣. مدرسة ٤. الأسرة ٥. رجال الدين ٦. ندوة صحية ٧. من الناس المحيطين حولك	☐

القسم الثالث: معلوماتك عن الاستشارة الوراثية والاختبارات الجينة

(اختر الجواب الذي تعتقد أنه صحيح)

الرقم	السؤال	خيارات الإجابة	الإجابة
١.	الفحص الوراثي هو .....:	١. فحص الجينات الوراثية للأم والأب ٢. فحص الحمض النووي للكشف عن صفة وراثية معينة ٣. الكشف عن الكروموسومات التي تحمل الجينات المصابة بالمرض ٤. كل ما ذكر صحيح	☐
٢.	المرض الوراثي ينتقل عن طريق.....:	١. الجينات ٢. العدوى بالملامسة ٣. الماء والهواء الملوثان ٤. لا ينتقل	☐
٣.	الهدف الرئيسي من الاستشارة الوراثية هي.....:	١. التقليل من أطفال مصابين بأمراض وراثية ٢. إجهاض الجنين المصاب بالمرض الوراثي ٣. علاج الطفل المصاب بالمرض الوراثي	☐
٤.	الوقت المناسب للاستشارة الوراثية..... :	١. عند التخطيط للحمل ٢. في الأشهر الأولى للحمل ٣. في الأشهر الأخيرة للحمل ٤. بعد الولادة مباشرة	☐
٥.	يمكن التقليل من الإصابة بالأمراض الوراثية.....:	١. نعم ٢. لا	☐
٦.	زواج الأقارب يزيد من احتمالية الإصابة بمرض وراثي.....:	١. نعم ٢. لا	☐

٧.	من السبب برأيك في انتقال المرض الوراثي .	١. الأم ٢. الأب ٣. كلاهما	☐
٨.	الاستشارة الوراثية ضرورية ... :	١. في أول حمل فقط ٢. عند كل حمل ٣. ليست ضرورية	☐
٩.	الأفراد الذين يجب إخضاعهم للاستشارة الوراثية إلى جانب الطفل المصاب هم	١. الأم والأب ٢. الجد والجدة ٣. أبناء العمومية ٤. لا داعي للفحص	☐
١٠.	برأيك ما أهمية الاستشارة الوراثية قبل الزواج .....:	١. علاج الأمراض الوراثية ٢. التحكم في انتشار بعض الأمراض الوراثية في المجتمع ٣. تحديد جنس المولود ٤.تجنب التعرض للأمراض المعدية	☐
	التقييم	١. ضعيف ٢. متوسط ٣. جيد	☐

القسم الرابع: رأيك في اللجوء إلى الاستشارة الوراثية والفحوصات الجينية قبل الإنجاب

أرجو وضع إشارة (√) أسفل الكلمة التي تعبر عن رأيك:

الرقم	السؤال	أعارض بشدة	أعارض	لا رأي	أوافق	أوافق بشدة
١.	ينبغي على الأفراد عمل فحوصات وراثية عند اختيار الزوج/الزوجة					
٢.	ينبغي على كل النساء الحوامل عمل فحوصات وراثية للجنين					
٣.	ينبغي أن يكون الفحص الوراثي متاحا لأي شخص يحتاجه					
٤.	يجب أن تتوفر الاستشارة الوراثية حتى للعائلة التي ليس لديها تاريخ في الأمراض الوراثية					
٥.	الاستشارة الوراثية لا يجب اللجوء إليها نهائيا لأسباب دينية واجتماعية					
٦.	تستخدم تقنيات أطفال الأنابيب لاختيار الجين السليم عند الرغبة في الإنجاب.					
٧.	يجب عمل فحص وراثي لكل المواليد الجدد					
٨.	من حق كل فرد أن يعرف قابليته للتعرض للأمراض الوراثية خلال حياته.					
٩.	من حق كل فرد أن يعرف احتمالية إنجاب أطفال مصابين بأمراض وراثية.					
١٠.	يجب التسليم بالمرض الوراثي دون تدخل.					

الرقم	السؤال	أعارض بشدة	أعارض	لا رأي	أوافق	أوافق بشدة
١١.	يجب تجنب الاستشارة الوراثية لأنها تزيد من احتمالية الإجهاض					
١٢.	سألجأ إلى الاستشارة الوراثية عند التخطيط لإنجاب طفل في المستقبل.					
١٣.	أنصح أبنائي في المستقبل باللجوء إلى الاستشارة الوراثية قبل الزواج					
١٤.	ظهور المرض الوراثي يمنع من الاستمرار في زواج الأقارب في العائلة.					
١٥.	تجربة الإصابة بمرض وراثي داخل الأسرة تزيد من الاهتمام بالاستشارة الوراثية					
١٦.	الفحوصات الوراثية تساعد على كشف الوضع الصحي للمقبلين على الزواج وإلحاق الضرر بهم					
١٧.	الاستشارة الوراثية تساعد على الابتعاد عن زواج الأقارب.					
١٨.	الاستشارة الوراثية تقلل من احتمالية إصابة أحد أفراد الأسرة بمرض وراثي					
١٩.	من المهم توضيح رأي الشرع في اتخاذ القرار المناسب في الزواج حسب التاريخ الصحي لعائلتي المخطوبين					
٢٠.	المعلومات المقدمة لي عن الاستشارة الوراثية غير كافية.					

الرقم	السؤال	أعارض بشدة	أعارض	لا رأي	أوافق	أوافق بشدة
٢١.	المختبرات التي تقدم خدمة الفحص الوراثي غير متوفرة في منطقتي.					
٢٢.	التكاليف المرتفعة للاستشارة الوراثية تشكل عائق في اللجوء إليها.					

Annex (2): Tables

Table (4.5): Attitudes

Attitudes			
Attitude		N	%
1. Couples have to do genetic testing when they plan to get marry	disagree	2	1.7
	I don't know	12	9.9
	Agree	107	88.4
2. All of pregnant women have to do genetic test for the fetus	disagree	5	4.1
	I don't know	3	2.5
	Agree	113	93.3
3.Experience of genetic problem in the family will increase their care about genetic counseling.	disagree	1	.8
	I don't know	2	1.7
	Agree	108	97.5
4. Genetic testing have to be available for people as needed.	disagree	0	0
	I don't know	1	.8
	Agree	120	99.2
5. Genetic counseling must be available even for families which family history free of genetic problems.	disagree	22	18.2
	I don't know	8	6.6
	Agree	91	75.2
6. Genetic counseling had been never used for religious and social causes	disagree	101	83.5
	I don't know	17	14.0
	Agree	3	2.5
7. IVF could be used to avoid defected gene when couples wont to	disagree	27	22.4
	I don't know	45	37.2

have a healthy baby.	Agree	49	40.5
8.Genetic testing must be done for all of new born.	Disagree	12	9.9
	I don't know	14	11.6
	Agree	95	78.5
9. Each person have the right to know if he is risky to have a genetic problem in the future	Disagree	4	3.7
	I don't know	1	.8
	Agree	116	95.9
10. Each person have the right to know the probability to have a child with genetic problem	Disagree	5	4.1
	I don't know	87	71.9
	Agree	29	23.9
11.We have to bow to the genetic problems without interference	Disagree	110	90.9
	I don't know	2	1.7
	Agree	9	7.4
12.Genetic counseling must be avoided because it is increase the probability to abortion	Disagree	96	79.3
	I don't know	12	9.9
	Agree	13	10.8
13. I will take a genetic consultation when I plan for pregnancy in the future	Disagree	10	8.2
	I don't know	6	5.0
	Agree	105	86.7
14.I advice my children to have genetic counseling before marriage	Disagree	3	2.5
	I don't know	3	2.5
	Agree	115	95
15. The presence of genetic disorder in a family may lead them to stop consanguineous Marriage.	Disagree	9	7.5
	I don't know	7	5.8
	Agree	105	86.8

16. Genetic testing help couples to discover their genetic history and may destroy their relationship	Disagree	21	17.3
	I don't know	16	13.2
	Agree	84	96.5
17. Genetic counseling lead to avoid consanguineous marriage	Disagree	4	3.3
	I don't know	5	4.1
	Agree	112	92.6
18. Genetic counseling decrease the probability of having genetic problem	Disagree	18	14.8
	I don't know	13	10.7
	Agree	90	74.3
19. It is important to clarify the Islamic view in making the right decision to marry according to my family health history	Disagree	8	6.6
	I don't know	34	28.1
	Agree	79	65.3
20. My information about genetic counseling are not insufficient	Disagree	32	26.5
	I don't know	5	4.1
	Agree	84	69.4
21. Laboratories that offer genetic testing service is not available in my country	Disagree	8	6.6
	I don't know	3	2.5
	Agree	111	90.9
22. High cost of genetic counseling may decrease the desire to take it	Disagree	11	9.1
	I don't know	6	5
	Agree	104	86

Annex(3) Chi-square analysis (relationship between knowledge and attitudes)

Attitude		Knowledge evaluation			Total	P–value
		weak	moderate	good		
1. Couples have to do genetic testing when they plan to get marry	Strongly disagree	0 0%	0 0%	0 0%	0 0%	0.004
	Disagree	0 0%	0 0%	2 100%	2 100%	
	I don't know	2 16.7%	8 66.7%	2 16.7%	12 100.0%	
	Agree	4 4.8%	26 31.0%	54 64.3%	84 100.0%	
	Strongly agree	0 .0%	4 17.4%	19 82.6%	23 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
2. All of pregnant women have to do genetic analysis for the fetus	Strongly disagree	0 0%	0 0%	0 0%	0 0%	0.47
	Disagree	0 0%	1 20%	4 80.0%	5 100.0%	
	I don't know	0 0%	2 66.7%	1 33.3%	3 100.0%	
	Agree	6 6.3%	32 33.3%	58 60.4%	96 100.0%	
	Strongly agree	0 0%	3 17.6%	14 82.4%	17 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
3.Experience of genetic problem in the family will increase their care about genetic counseling	Strongly disagree	0 .0%	0 0.0%	0 .0%	0 0.0%	0.07
	Disagree	0 .0%	1 100.0%	0 .0%	1 100.0%	
	I don't know	0 .0%	2 100.0%	0 .0%	2 100.0%	
	Agree	5 5.6%	28 31.1%	57 63.3%	90 100.0%	
	Strongly agree	1 3.6%	7 25.0%	20 71.4%	28 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
4. Genetic testing have	Strongly disagree	0 0%	0 0%	0 0%	0 0%	0.06

to be available for people as needed	Disagree	0 0.0%	0 0.0%	0 0.0%	0 0.0%	
	I don't know	0 0.0%	0 0.0%	1 100.0%	1 100.0%	
	Agree	6 6.0%	35 35%	59 59%	100 100.0%	
	Strongly agree	0 0%	3 15.0%	17 85.0%	20 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
5.Genetic counseling must be available even for families which family history free of genetic problems	Strongly disagree	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0.02
	Disagree	3 13.6%	10 45.5%	9 40.9%	22 100.0%	
	I don't know	1 12.5%	2 25.0%	5 62.5%	8 100.0%	
	Agree	2 2.6%	23 29.9%	52 67.5%	77 100.0%	
	Strongly agree	0 .0%	3 21.4%	11 78.6%	14 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
6. Genetic counseling had been never used for religious and social causes	Strongly disagree	1 2.3%	9 20.5%	34 77.3%	44 100.0%	0.001
	Disagree	1 1.8%	20 35.1%	36 63.2%	57 100.0%	
	I don't know	4 23.5%	6 35.3%	7 41.2%	17 100.0%	
	Agree	0 .0%	3 100.0%	0 .0%	3 100.0%	
	Strongly agree	0 00.0%	0 00.0%	0 00.0%	0 00.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
7. IVF could be used to avoid defected gene when couples wont to have a healthy baby	Strongly disagree	0 .0%	2 33.3%	4 66.7%	6 100.0%	0.18
	Disagree	1 4.8%	9 42.9%	11 52.4%	21 100.0%	
	I don't know	3 6.7%	17 37.8%	25 55.6%	45 100.0%	
	Agree	1 2.5%	9 22.5%	30 75.0%	40 100.0%	
	Strongly agree	1 11.1%	1 11.1%	7 77.8%	9 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
8. Genetic testing must	Strongly disagree	0 0.0%	0 0.0%	0 0.0%	0 0.0%	0.02

be done for all of new Born	Disagree	2 16.7%	6 50.0%	4 33.3%	12 100.0%	
	I don't know	1 7.1%	6 42.9%	7 50.0%	14 100.0%	
	Agree	3 4.0%	24 32.0%	48 64.0%	75 100.0%	
	Strongly agree	0 .0%	2 10.0%	18 90.0%	20 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
9. Each person have the right to know his risk to have a genetic problem in the future	Strongly disagree	0 .0%	0 .0%	2 100.0%	2 100.0%	0.16
	Disagree	0 .0%	1 50.0%	1 50.0%	2 100.0%	
	I don't know	0 .0%	1 100.0%	0 .0%	1 100.0%	
	Agree	6 6.6%	33 36.3%	52 57.1%	91 100.0%	
	Strongly agree	Strongly agree	0 .0%	3 12.0%	22 88.0%	
	Total	Total	6 5.0%	38 31.4%	77 63.6%	
10. Each person have the right to know the probability to have a child with genetic problem	Strongly disagree	0 .0%	0 .0%	1 100.0%	1 100.0%	0.3
	Disagree	0 0%	0 0%	0 0%	0 0%	
	I don't know	0 .0%	1 25.0%	3 75.0%	4 100.0%	
	Agree	6 6.9%	33 37.9%	48 55.2%	87 100.0%	
	Strongly agree	0 .0%	4 14.3%	24 85.7%	28 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
11. We have to bow to the genetic problems without interference	Strongly disagree	1 1.8%	16 28.1%	40 70.2%	57 100.0%	0.01
	Disagree	3 5.7%	17 32.1%	33 62.3%	53 100.0%	
	I don't know	0 .0%	2 100.0%	0 .0%	2 100.0%	
	Agree	2 25.0%	2 25.0%	4 50.0%	8 100.0%	
	Strongly agree	0 .0%	1 100.0%	0 .0%	1 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	

12. Genetic counseling must be avoided because it is increase the probability to abortion.	Strongly disagree	0 .0%	14 29.8%	33 70.2%	47 100.0%	0.01
	Disagree	3 6.1%	9 18.4%	37 75.5%	49 100.0%	
	I don't know	2 16.7%	7 58.3%	3 25.0%	12 100.0%	
	Agree	1 9.1%	7 63.6%	3 27.3%	11 100.0%	
	Strongly agree	0 .0%	1 50.0%	1 50.0%	2 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
13. I will take a genetic consultation when I plan for pregnancy in the future	Strongly disagree	0 .0%	0 .0%	1 100.0%	1 100.0%	0.5
	Disagree	1 11.1%	3 33.3%	5 55.6%	9 100.0%	
	I don't know	1 16.7%	1 16.7%	4 66.7%	6 100.0%	
	Agree	2 2.6%	28 36.4%	47 61.0%	77 100.0%	
	Strongly agree	2 7.1%	6 21.4%	20 71.4%	28 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
14. I advice my children to have genetic counseling before marriage	Strongly disagree	0 .0%	0 .0%	1 100.0%	1 100.0%	0.7
	Disagree	0 .0%	1 50.0%	1 50.0%	2 100.0%	
	I don't know	2 66.7%	1 33.3%	0 .0%	3 100.0%	
	Agree	2 2.5%	30 37.5%	48 60.0%	80 100.0%	
	Strongly agree	2 5.7%	6 17.1%	27 77.1%	35 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
15. The presence of genetic disorder in a family may	Strongly disagree	0 .0%	0 .0%	2 100.0%	2 100.0%	0.3
	Disagree	0 .0%	5 71.4%	2 28.6%	7 100.0%	
	I don't	2	4	1	7	

lead	know	28.6%	57.1%	14.3%	100.0%	
them to stop consanguineous marriage	Agree	4 4.8%	24 28.6%	56 66.7%	84 100.0%	
	Strongly agree	0 .0%	5 23.8%	16 76.2%	21 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
16. Genetic testing help couples to discover their genetic history And may destroy their relationship	Strongly disagree	0 .0%	0 .0%	4 100.0%	4 100.0%	0.2
	Disagree	1 5.9%	6 35.3%	10 58.8%	17 100.0%	
	I don't know	1 6.3%	5 31.3%	10 62.5%	16 100.0%	
	Agree	4 5.6%	24 33.8%	43 60.6%	71 100.0%	
	Strongly agree	0 .0%	3 23.1%	10 76.9%	13 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
17. Genetic counseling lead to avoid consanguineo	Strongly disagree	0 .0%	0 0.0%	0 0.0%	0 00.0%	0.04
	Disagree	0 .0%	4 100.0%	0 .0%	4 100.0%	

us marriage	I don't know	0 .0%	3 60.0%	2 40.0%	5 100.0%	
	Agree	5 5.4%	27 29.0%	61 65.6%	93 100.0%	
	Strongly agree	1 5.3%	4 21.1%	14 73.7%	19 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
18. Genetic counseling decrease the probability of having genetic problem	Strongly disagree	0 .0%	0 .0%	1 100.0%	1 100.0%	0.01
	Disagree	0 .0%	12 70.6%	5 29.4%	17 100.0%	
	I don't know	2 15.4%	3 23.1%	6 61.5%	11 100.0%	
	Agree	4 5.2%	21 27.3%	52 67.5%	77 100.0%	
	Strongly agree	0 .0%	2 15.4%	11 84.6%	13 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
19. It is important to clarify the	Strongly disagree	0 .0%	0 .0%	0 0.0%	0 0.0%	0.4
	Disagree	0	3	5	8	

Islamic view		.0%	37.5%	62.5%	100.0%	
in making the right decision to marry according to my family health history	I don't know	2 5.9%	14 41.2%	18 52.9%	34 100.0%	
	Agree	3 4.3%	19 27.5%	47 68.1%	69 100.0%	
	Strongly agree	1 10.0%	2 20.0%	7 70.0%	10 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
20. My information about genetic counseling are not insufficient	Strongly disagree	0 .0%	0 0.0%	3 100.0%	3 100.0%	0.6
	Disagree	0 .0%	10 34.5%	19 65.5%	29 100.0%	
	I don't know	0 .0%	1 20.0%	4 80.0%	5 100.0%	
	Agree	4 6.3%	18 28.1%	42 65.6%	64 100.0%	
	Strongly agree	2 10.0%	9 45.0%	9 45.0%	20 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
21.Laboratories that offer	Strongly disagree	0 .0%	0 .0%	0 00.0%	0 00.0%	0.8

genetic testing service is not available in my Country	Disagree	0 .0%	0 .0%	8 100.0%	8 100.0%	
	I don't know	0 0.0%	0 0.0%	3 100%	3 100.0%	
	Agree	1 1.8%	20 35.7%	35 62.5%	56 100.0%	
	Strongly agree	5 9.3%	18 33.3%	31 57.4%	54 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	
22. High cost of genetic counseling may decrease the desire to take it	Strongly disagree	1 50.0%	0 .0%	1 50.0%	2 100.0%	0.6
	Disagree	0 .0%	1 11.1%	8 88.9%	9 100.0%	
	I don't know	0 .0%	2 50.0%	2 50.0%	4 100.0%	
	Agree	1 2.2%	16 35.6%	28 62.2%	45 100.0%	
	Strongly agree	4 6.8%	18 30.5%	37 62.7%	59 100.0%	
	Total	6 5.0%	38 31.4%	77 63.6%	121 100.0%	

Annex (4): Table of Literature Review

Author, year and Title	Methodology Aim, Study design and tool	Population and Sample	Finding
(Felicity.Kate Boardman, 2014) UK(The expressivity objection.to prenatal.testing: The.experiences of Families.living with.genetic disease)	Cross sectional Tool: Qualitative interview (over the telephone (75%), via email (17%) and face-to-face (8%). Aim: to explore the role that experiential knowledge of SMA played in reproductive decision-making and attitudes towards having children with SMA	Population: Families.and individuals. living with a genetic .disease in UK sample: stratified sample 61 subject	idea that such screening and selective termination decisions are made in the context of ignorance, or even prejudiced ideas, about the reality of that particular condition. Indeed, for families living with inheritable diseases such as SMA, these decisions around selective termination were not being made by unknown others, but by members of their own family.

ABALI,A. AYAYDIN, H20014, turkey (An examination of the symptoms of anxiety and parental attitude in children with hemophilia)	Cross sectional State-Trait Anxiety Scale Aim: To assess symptoms of anxiety in children with hemophilia and parental attitude towards children with hemophilia.	Families of hemophilic patients Sample: Forty-two male patients between the ages of 7 and 16 diagnosed and followed as hemophiliac.	There were positive correlations between overprotective mothering and marital conflict. Also, another positive correlation was obtained between marital conflict and strict discipline. Fifteen mothers showed significant anxiety disorder
Ibrahim, N. Al-Bar, H. Al-Fakeeh,A 2012, KSA (An educational program about premarital screening for unmarried female students in	Interventional study. Tool: Questionnaire before education And another after education program Aim: present study was conducted	Unmarried female students In King Abdul-Aziz University Sample: Multi-stage stratified random sample method was used with recruitment of 1563 students	This study highlights that knowledge of female uni- versity students about the PMS program was low before the educational campaign. On the other hand, there was general positive

King Abdul- Aziz University, Jeddah	to assess knowledge and attitude of unmarried female students in King Abdul-Aziz University (KAU) towards premari-tal screening (PMS) program, to determine predictors of high students' knowledge scores and to improve their knowledge about PMS through conduction of an educational campaign.		attitude towards the importance of the PMS. Our educational program was successful in improving students' knowledge about PMS. There is certainly a need for more information and education about the program.
Awatif A. Alam 2006 ksa (perception of female students of	Cross sectional KAP survey Tool: Questionnaire	Population: female students of King Saud University	The students in the present study demanded the extension of PMS to

king saud university towards premarital screening	Aim: To in assess the attitudes of university students in Abha, KSA, in 2002 towards premarital counseling.	sample: simple random sampling method 135 students	investigate and screen for other diseases especially sexually transmitted diseases likely to adversely affect the health of individuals and the community.
(Hietala,M & Hakonen,A & Aro, A & Peltonen,L & Aula, P.2000) Finland (Attitudes toward Genetic Testing among the General Population and Relatives of Patients with a Severe Genetic Disease: A Survey from Finland)	A case control study using self reported questionnaire Aim: explore the attitudes of the Finnish population toward genetic testing	The population: 1)Normal finland population 2)Relatives of pt.s with genetic disorders Sampling: 2 stratified samples -control group: (1169 subjects) -case group: (82 subjects	survey indicated that the Finnish population in general, and family members of patients with AGU in particular, have a positive attitude toward genetic testing in risk determination for a variety of genetically determined disorders.

(Snowdon, C. & Green, J. 2000) UK (Preimplantation diagnosis and other reproductive options: attitudes of male and female carriers of recessive disorders)	A cross sectional questionnaire passed study. Aim: describes in detail the attitudes of carriers of recessive disorders to pre–implantation Diagnosis (PID). In IVF	Population: Couples carrying a recessive disorder whom recorded in four genetics centers in the UK. Sample: The couple were still together; they were of an age where they may still be considering (more) children.	The majority of the sample did not feel that it was the most useful option in their situation Those who would not consider a termination were also those most likely to choose PID, and it is for this group that PID may really offer something new.
Ellington, L. Maxwel, A. 2006 USA Genetic counseling communication with an African American BRCA1 kindred	Pre and post test protocol Tool : Interview analyzed By RAIS scale Aim: to open the ‘‘black box’’ of genetic counseling communication	Population: African American kinder have a genetic mutation Sample: 87 participants that underwent genetic testing, 85 participated in the post-test session and 46 participants’ pre-	when providers were informing clients that they were mutation carriers, they provided more Biomedical information and Psychosocial communication (which includes

		and post-test sessions	discussion of results with family members) and asked more psychosocial questions than when they talking with non-carriers.
(Awwad, R 2007) Palestine (Culture and Acculturation Influences on Palestinian Perceptions of Prenatal Genetic Counseling)	A cross sectional comparative study Tool: Demographic form and interview Aim: To investigate influences of culture and acculturation on prenatal decision making processes of native Palestinians and Palestinian Americans.	Population: Tow group population 1)Native Palestinian 2)American Palestinian Sample: 17 native Palestinians and 14 Palestinian Americans	Several similarities and differences in native Palestinian and Palestinian American responses were obtained. Similarities appear to be due to common cultural roots, while differences may be due to acculturation.

(Wertz,D. Janes,S, 1992) Israel (Attitudes toward the Prenatal Diagnosis of Cystic Fibrosis: Factors in Decision Making among Affected Families)	A cross sectional study Tool: Anonymous survey questionnaires Aim: to explore psychosocial factors underlying decisions about use of prenatal Diagnosis for cystic fibrosis (CF), among parents of affected children.	Population: All parents who visited CF centers within 4 mo of a center's entry into the study were asked to participate. Sample: 318 families receiving questionnaires, 227 (71 %) responded.	Attitudes toward prenatal diagnosis-and the decisions that it may present-may be related to fundamental perceptions of the affected child that go beyond the child's present health status or the parents' Many parents in this study said that, after seeing retarded or severely disabled children in their visits to pediatric clinics, they considered themselves fortunate to have a child with CF.
(Rantanen,A. 2014) Finland (Expectations, frames and practices of genetic ounseling	Tool: Literature review Aim: to review the kinds of expectations that are concentrated on genetic	Population: international guidelines and recommendations, produced mostly by international ounselingns such as	On the basis of the analysis of all perspectives, the ideal genetic ounseling seems to consist of information about the

in different contexts of genetic testing)	ounseling, and the different conceptions of genetic information that lie behind those expectations.	the WHO and professional associations. Which naturally occurring data that interestingly reflect the ideals of genetic ounseling. Sample: The 56 documents produced by 29 different organizations.	test, the condition, the risks and their management; and of support in adjusting to this information and in decision-making concerning the test and its result.

Meiser,B & Halliday,j 2002(What is the impact of genetic ounseling in women at increased risk of developing hereditary breast cancer? A meta-analytic review)	A meta-analytic review Aim: to determine the impact of genetic ounseling on women with a family history of Breast cancer.	Published studies about heredity breast cancer and genetic counseling	This review highlighted that most research so far focused on generalized distress and anxiety and accuracy of perceived risk, to the exclusion of other, perhaps equally Important types of outcomes.

(Middleton, A. Hewison, J 1998) UK(Attitudes of Deaf Adults toward Genetic Testing for Hereditary Deafness)	Tool: questionnaire Aim: to document the attitudes of deaf adults toward genetic testing for deafness.	Population: There were 140 delegates in the auditorium; completed questionnaires were collected from 124 British individuals (response rate 89%), 83 of whom considered themselves “deaf” and 4 of whom considered themselves “hearing impaired.” Sample : 87 individuals in 46 (53%) considered themselves culturally Deaf, and 37 (43%) identified equally with the Deaf and hearing communities;	The sample group as a whole had a negative attitude toward genetics and genetic testing for deafness.

(Afifi, H. Al-robe, F 2010) Egypt (The most encountered Group of genetic disorders in Giza Governorate, Egypt	A prevalence study Tool: Medical files Aim: To present the prevalence of genetic disorders in Al-Giza ,Egypt	Population: -visitors of outpatient clinic in Al-Giza -NICU in Al-Giza Governmental Hospital Sample: 73260 pt	A high prevalence of genetic disorders among Egyptians with frequencies comparable with other Arab areas
(Dolev, Y. Weiner, N 2008) (New reproductive technologies, genetic ounseling and the standing of the fetus: views from Germany and Israel)	a cross-national comparative study tool: interviews aim: to compare between Israeli and Germany morals in the use of genetic technology and genetic counseling	Population: Two groups of Israeli and Germany counselors Sample: 18 Israeli and 14 German genetic counsellers	interviewees from these two groups share similar knowledge concerning the fetus, and face similar moral dilemmas in their professional practice, they employ different ethical reasoning in their considerations of the fetus.
(MORREN, M. and RIJKEN, R . 2006) (Perceived genetic	Cross sectional study Questionnaire and	Population: Respondents of the ‘Panel of Patients	It was found that while chronically ill patients indicate they

knowledge, attitudes towards genetic testing, and the relationship between these among patients with a chronic disease)	DNA testing. Aim: to examine to what extent patients with chronic diseases perceive to have genetic knowledge and what their attitudes towards genetics and genetic testing are.	with Chronic Diseases' (PPCD) in Netherlands. Sample: 1916 patients. Age at least 15 years, living independently, being aware of the diagnosis, being mentally and physically fit to participate.	know little about genetic testing, their general view is positive, although they also expressed some fears and worries. In addition, older and less educated patients perceived to have relatively little genetic knowledge and found it more difficult to form an opinion about genetics. We also investigated the relationship between knowledge and attitudes among chronic patients.

(Brunger, J. and Murray, G 2000) USA(Parental Attitudes toward Genetic Testing for Pediatric Deafness)	Cross sectional Tool: Questionnaire Aim: To investigate parents attitudes toward deaf genetictesting .	Population: Parents of deaf children Sample: 328 surveys distributed, 96 were completed and returned.	Population's strong interest in genetic testing for deafness, it is found that they had a very poor understanding of genetics and the inheritance of deafness.
(Thawabteh, N. Abu-Libdeh, B. Ayesh, S. 2005) (Prenatal diagnoses of Beta-Thalassemia in the West- Bank and Gaza)	Cohort study: (1999-2005) Tool: DNA analyses and interview couples Aim: This study focuses on the genetic aspect of b-thalassemia among risk couples from the Westbank and Gaza, and the attitude of these couples toward prenatal diagnosis and its outcome asa preventive method	Population: all the -thalassemia prenatal diagnoses performed in the Molecular Genetics Lab at Al-Makassed Hospital in Jerusalem between January 1999 and July 2005. Sample: All positive carriers	very good acceptability for prenatal diagnosis in b-thalassemia afflicted families. All couples with affected fetuses opted for abortion

(Tercyak, K and Hamann, H 2002) (Genetic Testing: Psychological Aspects and Implications)	Literature review Aim: To highlight the kinds of concerns, decisions, and emotional sequelae that clinicians may encounter in patients who are members of families with inherited disease.	Population: the behavioral science literature concerning genetic testing in the following three primary domains: prenatal testing, carrier testing, and predictive testing.	The highly specific information provided by genetic testing can empower both clinicians and patients to target their efforts on behavioral strategies that will have the greatest impact on reducing disease morbidity and mortality.

(Siani and Assaraf, 2015) (University Students' Attitudes towards Genetic Testing: A Comparative Study)	Comparative study Tool: Likert scale questionnaire Aim: To examine the attitudes of undergraduate Israeli students toward genetic issues and learn how these are affected by the field they study, their religious affiliation and their gender.	Population: Undergraduate students from a variety of higher education institutes throughout Israel. Sample: 490 students	the most influential is the students' religious affiliation. Religious students, especially those who do not study life sciences (LS), place less trust in genetic tests than secular Students of LS show more critical thinking towards genetic testing than others. Gender was least influential, showing a mixed trend of.
(Fitzgerald-Butt, et al, 2014) (Genetic Knowledge and Attitudes of Parents of Children with Congenital Heart Defects)	Cross sectional study Tool: Likert scale questionnaire Aim: To measure the demographics,	Population: parents of children with CHD who previously consented to participate in a separate research study of the genetic etiology of left	Genetic knowledge was assessed on an adapted measure on which themean percent correct was 73.8%. Educational attainment and household income

	genetic knowledge, and attitudes towards genetic testing of parents of children with CHD .	ventricular outflow tract malformations (LVOT). Sample:287 participants.	were directly and significantly associated with genetic knowledge)
(Scuffham, et al, 2013) (Knowledge and attitudes towards genetic testing in those affected with Parkinson's disease)	A cross-sectional study Tool: Questionnaire Aim: To determine knowledge and attitudes toward genetic testing for those affected with Parkinson's Disease.	Population: patents those affected or at risk of Parkinson's Disease Sample: Participants were selected from a registry of people affected with PD living in Queensland, Australia.	Patients with PD have strong interest in genetic testing for themselves with support for diagnostic testing but less support for predictive and prenatal testing. Genetic knowledge was unrelated to testing attitudes
Calsbeek, et al,2007) (Knowledge and Attitudes Towards Genetic Testing: A	Follow up study Tool: Questionnaire Aim: To assess the	Population: All patients with asthma, diabetes mellitus type 2 (DM),and sever cardiovascular	The finding that more perceived social genetic knowledge results in more reluctance can

Two Year Follow-Up Study in Patients with Asthma, Diabetes Mellitus and Cardiovascular Disease)	genetic knowledge and attitude towards genetic testing of patients with asthma, diabetes mellitus type II and cardiovascular diseases	diseases (CVD) were selected from the Panel on the basis of the patient's first diagnosis according to the followingcodes of the International Classification of Primary Care. Sample: 577 patients responded: 299 patients with asthma, 144 with diabetes mellitus type 2, and 134 with cardiovascular disease	be considered an indicator for the necessity of social debates on genetic testing.

An-Najah National University
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جامعة النجاح الوطنية
كليـــة الطب وعلوم الصـــحة
دائرة الدراسات العليا

IRB Approval letter

Study title:
"Knowledge and attitude toward genetic counseling and testing among parents of children with genetic disorder in the West bank Palestine"

Submitted by:
Falasteen Ali Hussain Yaseen.

Date Reviewed:
February 4, 2016

Date approved:
February 8, 2016

Your study titled: "Knowledge and attitude toward genetic counseling and testing among parents of children with genetic disorder in the west bank Palestine"
with archived number 123/February /2015 , was reviewed by An-Najah National University IRB committee and was approved on February 8, 2016

Hasan Fitian , MD

IRB

IRB Committee Chairman,
An-Najah National University

جامعة النجاح الوطنية

كلية الدراسات العليا

المعرفة والموقف تجاه الاستشارة الوراثية بين آباء الأطفال الذين يعانون من أمراض وراثية في الضفة الغربية/ فلسطين

إعداد

فلسطين ياسين

إشراف

الدكتورة إيمان الشاويش

قدمت هذه الأطروحة استكمالاً لمتطلبات الحصول على درجة الماجستير في الصحة العامة بكلية الدراسات العليا، في جامعة النجاح الوطنية، نابلس- فلسطين.

٢٠١٧

المعرفة والموقف تجاه الاستشارة الوراثية بين آباء الأطفال الذين يعانون من أمراض وراثية في الضفة الغربية/ فلسطين

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إشراف

د. ايمان شاويش

الملخص

تزداد الحالات المصابة بالأمراض الوراثية في الضفة الغربية بشكل لافت دون تدوين هذه الحالات أو عمل أبحاث عليها، لاسيما وأن العائلة الواحدة تعاني من إصابة أكثر من طفل بنفس المرض دون اللجوء إلى طريقة للحد من ذلك، هذا دفع الباحثة لدراسة معلومات أهالي الأطفال المصابين بالأمراض الوراثية عن الاستشارة الوراثية، وتأثير ذلك على رأيهم في اللجوء إليها.

تم استخدام دراسة مقطعة وصفية للبحث بوساطة استبيان مكون من اختبار لقياس للمعلومات ومقياس ليكرت لقياس الرأي والموقف، وتمت تغطية كل المتغيرات في الاستبيان.

معلومات الأهالي كانت جيدة بشكل عام حيث حصل (٦٣%) منهك على تقييم جيد لمعلوماته، أيضا الموقف كان ايجابي حيث حصل ٢٠ عنصر على نتيجة ايجابية من أصل ٢٢ من عناصر دراسة الموقف، وعند دراسة العلاقة كان لمعلومات الأهالي أثر ايجابي على مواقفهم تجاه الاستشارة الوراثية.

لذلك نوصي وزارة الصحة الفلسطينية بزيادة وعي الأهالي تجاه الاستشارة الوراثية، ثم شمول الفحص الجيني في تشخيص الأمراض بشكل عام.