

# **KNOWLEDGE ATTITUDE AND PRACTICE TOWARDS PRE-M ARITIAL/PRENATAL GENETIC TESTING AMONG YOUNG PEOPLE (15-45) YEARS OF AGE IN SAPELE LOCAL GOVERNMENT AREA, DELTA STATE. NIGERIA**

*Article Review by Iweriebor Onoiribholo Bridget, Nigeria  
(MSN, Texila American University)  
Email: - brid\_gets@yahoo.com*

## **ABSTRACT**

This study investigated knowledge, attitude and practice toward premarital/prenatal genetic testing among young people of 15-45years of age in Sapele Local Government Area in Delta State Nigeria. Descriptive survey research design was used. The population of the study consisted of the members of four major communities (Amukpe, Amuogoddo, Okirighwe and Uguanja). The respondents were selected by simple random sampling method. The research instrument was a self-constructed questionnaire. A total of 50 respondents were selected. A total 50 questionnaire were distributed and same retrieved. The objectives of the study were to determine level of knowledge of premarital/prenatal genetic testing among young people, to assess the level of practice and to identify factors influencing their attitude towards premarital/prenatal genetic testing. The rational is to enhance young people's knowledge about premarital/prenatal genetic testing, encourage premarital/prenatal genetic screening and also reduces some of the factors influencing attitudes of young people towards premarital/prenatal genetic testing. Data collected were analyzed using frequency and percentages and were presented using tables and graphs. The study shows that 30% of the respondent level of knowledge of premarital/premarital genetic testing is of high level, 70% of the respondents have low level of knowledge and the source of information was through media (20%), health personnel (40%), friends (6%) etc. The study also showed that the level of practice is low as 80% of the respondent does not practice premarital/prenatal genetic testing, only 20% practiced it. it also shows that there are some factors influencing their attitudes towards premarital/prenatal genetic testing which include lack of knowledge (66%), non affordability (20%), non Accessibility (55) and also as a result of non availabilities of centers (15%) where premarital/prenatal genetic testing should be carried out. In conclusion, lack of basic knowledge, negative attitude and practice has a negative impact on the young people, their family, their community and the society as a whole. It is therefore recommended that effort should be made

by government, parents, and health personnel to improve knowledge, attitude and practice towards premarital/prenatal genetic testing thereby reducing the incidence rate of having children with genetic defect.

## **INTRODUCTION**

Genetic testing is not a single technology rather; it refers to a broad range of methods for gauging the presence, absence or activity of genes in cells. At the relatively low tech, researcher can count the chromosomes in a patient's cells or measures the amount of cells tale proteins in his or her blood. At the most sophisticated level, researchers assay a cell DNA with molecular probes that can find a specific genetic sequence among the three billion base pairs that make up human DNA. Genetic testing cost less than I 500 for a simple blood screening for sickle cell or cost in the 1,500 range for a complicated pre implantation genetic test for Tay sacks disease. There are two extremes of genetic tests with ranging costs (Abuelo, 2005).

Genetic screening has great potential for our society. It has the capability of improving and lengthening human life. If used in an ethical manner, genetic testing can eliminate unforeseen suffering and distress. But, issues such as privacy, absent, discrimination, equity and social engineering are potential barriers that many individuals have *confronted* already. Both legal and personal, family conflicts may arise because of testing of individuals or immediate relatives (Bahado-S. 2008).

Genetic screening uses a variety of laboratory procedures to find out if a person has a genetic condition or disorder or is likely to develop a disease based on his or her genetic makeup. Individuals may be tested if the family shows a history of one specific disease such as hunting's disease or cancer, if the family shows symptoms of a genetic disorder which could be improved by early diagnosis, or if they are planning possibility of passing on a genetic strait to their offspring. This last type of screening can look at the parent's genotype or look at the genotype of the fetus or newborn. This type of screening can also look for a specific disorder or can be done as a general test for common disorder as in prenatal testing or more commonly newborn screening. (Filly. R. 2000).

Genetic tests use techniques to examine genes markers near the genes. Direct testing for diseases such as down syndrome, sickle cell anemia & thalassaemia come from an analysis of an individual's specific genes. A technique called linkage analysis, or indirect testing, is used when the gene cannot be directly identified but can be located within a specific region of a chromosome. This testing requires additional DNA from an affected family member for comparison because each person's DNA is unique except for identical twins. Genetic tests also can be used for individual identification (DNA finger printing). This technique is often used in forensic work, the sample from a crime scene such as blood or semen could be used as indiscriminating or acquitting evidence. (Dweyer 2013).

Carrier identification includes genetic tests used by married people whose families have a history of recessive genetic disorder and who are considering having children. Three common tests include those for cystic fibrosis, achondroplasia, and sickle cell. More tests are common on the market at a very high rate. Norman Frost of the University of Wisconsin-Madison Medical School says, "Potential new genetic tests roll off the conveyor belt of the human genome, project almost once a week" (Bahadon S. 2008).

Pre-implantation Genetic Diagnosis (PGD) combines recent advances in genetics with the well-established techniques of in vitro fertilization (IVF). In IVF, a woman's monthly reproductive cycle is manipulated. She is given hormones that stimulate her ovaries so that many eggs mature at the same time. The eggs are surgically collected and fertilized with her partner's sperm in a lab dish. The resulting embryos are then transferred to the woman's uterus and if all goes well, pregnancy begins. (Lapham E, 2006).

Mass population testing is a large-scale testing usually of a particular ethnic group that shows a high rate of a specific genetic disorder. This type of testing has been both successful and unsuccessful. A voluntary genetic screening program was set up in the early 1970s for Tay-Sachs disease. It has been a huge success. More than a million Jews throughout the world, which Tay-Sachs predominantly affects, have volunteered to be tested to see if they were carriers of this genetic disorder. A carrier is not affected because to develop the disease symptoms, a person must carry two recessive alleles, one from each parent (Armitage P. 2008).

Before the people were tested, they were educated as to what the test would mean and what they could do with the information from the test. Once they were tested, genetic counseling was available to answer any questions about the implications of the tests. The mass genetic test was a huge success, especially to Jews because it gives the individual & the need to plan their family future. (Dweyer J. 2003) This study therefore investigates the knowledge, attitude, and practice of young people of age 15-45 years towards premarital/prenatal genetic testing. This is important because of the relevance of the genetic test to the family, the community, and the society as a whole. There is also a limited study in this area in Nigeria.

## **STATEMENT OF PROBLEM**

Knowledge, attitude, and practice toward premarital/prenatal genetic testing among young people has become a matter of concern worldwide.

Premarital/prenatal genetic testing is one of the ways of combating chromosomal abnormalities in our society today. It has helped in reducing the rate of chromosomal abnormalities e.g. sickle cell disease and thus reducing the rate of maternal and infant mortality.

Information about premarital genetic testing has been disseminated through media, seminars, couple counseling etc, by health personnel.

World Health Organization (WHO), Governmental and Non-Government organizations have also help in disseminating the benefits of premarital genetic testing because of the alarming rate of death from genetic defect. Despite these advantages, benefits and importance of premarital/prenatal genetic testing, the alarming rate of genetic defect is still on the increase. Nigeria is facing a critical problem of children with genetic defects. A survey by the African network for prevention and protection against child deformity and neglect, which was set up in 1988 by some African countries including Nigeria, shows that majority of children having genetic defect is due to "lack of knowledge, and negligence of their parents" This study therefore investigate the knowledge, attitude and practice towards premarital/prenatal genetic testing among young people 15-45 yours of age in Sapele Local Government Area Delta State. This is important because of relevant of the genetic test to the family, the community and the society as a whole. There is also a limited study in this area of Nigeria.

### **OBJECTIVES/PURPOSE OF THE STUDY**

The purpose of this study is to investigate the knowledge, attitude and practice towards premarital/prenatal genetic testing among young people 15-45 yours of age in Sapele Local Government Area Delta State. In line with this, the following objectives will be addressed

1. To determine the level of knowledge among young people. toward premarital/prenatal genetic testing.
2. To assess the level of practices among young people. toward premarital/prenatal genetic testing.
3. To identify factors influencing their attitudes towards premarital/prenatal genetic testing

### **SIGNIFICANCE OF STUDY**

The significant of study is to

1. Enhance people's knowledge about premarital/prenatal genetic testing.
2. Encourage premarital/prenatal genetic screening.
3. Reduce some of the factors influencing attitudes of young people towards premarital genetic testing by encouraging government to provide genetic screening centers
4. The findings will add to the body of knowledge for future studies

### **RESEARCH QUESTIONS**

The key questions that will be answered in this study are;

1. What is the level of knowledge of young people toward premarital/prenatal genetic testing in Sapele local government area?
2. What is the level of practice of young people towards premarital/prenatal genetic testing?
3. What are the factors influencing the attitude of the people towards premarital/prenatal genetic testing of Sapele local government area?

## **SCOPE AND DELIMITATION OF STUDY**

This study covers the knowledge, attitude and practice towards premarital/prenatal genetic testing among young people in Sapele Local Government Area Delta State. It is restricted to young people between the age of 15—45 years in the (4) four communities (Okingve. Amukpe. Amuogodo & Uganja).

## **OPERATIONAL DEFINITION OF TERMS**

- 1 Knowledge: this is the information and skill gained through education or experience.
- 2 Attitude; This is the behaviour towards an action.
- 3 Practice: This is the actions of doing something rather than the theories about it.
- 4 Premarital/prenatal: Preceding marriage and pregnancy.
- 5 Genetic testing: Test done partaking to reproduction or birth or origin.

## **LITERATURE REVIEW**

In this chapter, the literature review would be discussed under the following headings;

- Concept of genetic testing,.
- importance of genetic testing.
- Impact of genetic testing
- factors affecting genetic testing
- Consequences on non genetic testing
- Knowledge of premarital/prenatal genetic testing
- Attitude toward premarital/prenatal genetic testing
- Practices toward premarital/prenatal genetic testing

- Empirical Review
- Theoretical Framework
- Empirical Review
- Appraisal of the literature review.

## **CONCEPT OF GENETIC TESTING**

A genetic test is the analysis of human Deoxyribonucleic acid (DNA), ribonucleic acid (RNA), chromosomes and proteins to detect heritable disease related genotypes, mutations, phenotypes or karyotypes (standard pictures of the chromosomes in a cell). For the purpose of diagnosis, treatment and other clinical decision making, most genetic testing is performed by drawing a blood sample and extracting deoxyribonucleic acid (DNA) from white blood cells (Bogart Mit 2007).

Genetic test may detect mutations at the chromosomal level, such as additional absent or rearranged chromosomal material, or even subtler abnormalities such as a substitution in one of the bases that make up the DNA. There is a broad range of techniques that can be used for genetic testing. Genetic tests have diverse purposes, including screening for and diagnosis of genetic disease in newborn children and adults. The identification of future health risk, the prediction of drug responses and the assessment of risks to future children. (Abuelo 2001).

There is a difference between genetic tests performed to screen for disease and testing conducted to establish a diagnosis. Diagnostic tests are intended to definitely determine whether a patient has a particular problem. They are generally complex tests and commonly require sophisticated analysis and interpretation. They may be expensive and are generally performed only on people believed to be at risk such as patients who already have symptoms of a specific disease.

Bahado, (2008) stated that genetic screening has great potential for our society. It has the capability of improving and lengthening human life, if used in an ethical manner, genetic testing can culminate unforeseen suffering and distress. But issues such as privacy. Consent, discrimination, equity and social engineering are potential barriers that many individuals have confronted already. Both legal and personal family conflicts may arise because of testing of individuals or immediate relatives.

There are thousands of genetic diseases such as sickle cell, anemia, cystic fibrosis and Tay-sachs disease, that may be passed from one generation to the next. Many tests have been developed to help screen parents at risk of passing on genetic disease to their children as well as to identify embryo, fetuses and newborns who suffer from genetic disease.

Carrier identification is the term for genetic testing to determine whether a healthy individual has a gene that may cause disease it passé on to his or her offspring. It is usually performed on

people considered to be at higher than average risk such as those of Ashkenazi Jewish descent, who have a slim 24 chance of being Tay-sachs. Carriers (in other populations, the risk is 1 out of 250) according to the National Tay-sachs and Allied Diseases Association (2007)

Testing is necessary because many carriers have just one copy of a gene for an autosomal recessive trait and are unaffected by the trait or disorder. Only someone with two copies of the gene will actually have the disorder. So while it is widely assumed that everyone is an unaffected carrier of at least one autosomal recessive, it only presents a problem in terms of inheritance when two parents have the same recessive gene. It only presents a problem if both are carriers. In this instance the offspring would each have a one in four chance of receiving a defective copy of the gene from each parent and developing the disorder. Reports that Genetic tests exist for more than 1,600 conditions and that the national institutes of registry to share information about Genetic testing.

Despite improvements in medical technology, surgically invasive techniques to test for conditions like down syndrome still cause approximately 1 percent of mother receiving the tests to miscarry, reports (the Guardian, 2011).

Today, the U.S department of Health and Human services (HHS) reports that there are over 4,000 genetic diseases that can be passed down from generation to generation within a family.

As of 2011, fetal sex can be determined by a Non-invasive genetic test as early as seven weeks into the pregnancy, allowing for less use of invasive test to determine sex-specific genetic disorders. The tests were, on average, 95.4 percent successful at identifying a male fetus and 98.6 percent successful at identifying a female fetus.

Prenatal Genetic testing reported by CNN highlights the ongoing political controversies of prenatal genetic with candidates in the 2012 presidential election claiming that such testing encouraged more abortions. Studies conducted between the late 1990s and 2005 found that a majority of women would consider terminating their pregnancies- If tests indicated that the child would have a condition like Down syndrome.

## **IMPORTANT OF GENETIC TESTING**

A genetic test is the analysis of human Deoxyribonucleic acid (DNA), ribonucleic acid (RNA), chromosomes and proteins to detect heritable disease — related genotypes, mutations, phenotypes or karyotypes.

Genetic testing, examines the genetic information contained inside a person's cells called DNA, to determine if the person has or will develop a certain disease or could pass a disease to his or her offspring.

Genetic tests also determine whether or not couples are at a higher risk than the general population for having a child affected with a genetic disorder.

## *IMPORTANCE OF TESTING FOR GENETIC DISORDERS*

Genetic disorders can easily be prevented by genetic testing. Genetic testing can thereby control the occurrence of genetic diseases. Genetic tests can screen fetuses for possible genetic diseases. Genetic testing can help in conception and pregnancy. Read on to know more about the importance of genetic testing.

The importance of genetic testing is magnanimous. There are a lot of diseases that have their roots hidden in our genes. Once we get to know them, the doctors will be better equipped to prescribe an effective cure and even prevent them. Timely precautionary measures play a great role in maintaining the well-being of an individual. The main purpose of the genetic tests is to search for possible genetic disorders. There are almost over nine hundred varieties of genetic tests that are prescribed by doctors to determine the condition of their patients. Genetic tests are carried out on blood or any other tissue samples.

## *CONDITIONS FOR GENETIC TESTING*

Given below are some of the common conditions where doctors suggest a genetic test:

- In order to find out whether the unborn baby has any possibility of contracting a genetic disease
- In order to find whether the individual is a carrier of a disease and thereby determine whether or not he or she can pass on the said genetic disease to their offspring
- Genetic tests are suggested for screening the fetuses for any possible disease
- There are a number of diseases that are present in our system but their symptoms are hidden as they don't get manifested. Through a genetic test, the presence of the same can be determined and a course of treatment can be charted out before it is too late.
- Genetic tests are also suggested to confirm a disease. Doctors presume the disease after studying the symptoms but when there is any element of doubt due to various other associated complications, a genetic test always clears the doubts.

## *WHY IS GENETIC TESTING IMPORTANT?*

It is the prerogative of the doctor to decide and conclude on whether a particular genetic disease can be prevented or treated after coming across a gene alteration in the genetic tests. It all depends on the final and latest research condition regarding the treatment of the disease along with the status of the patient when the results were obtained. There can well be no treatment for certain diseases.



The importance of genetic testing lies in the fact that the person finds himself equipped to take certain vital life decisions. This can pertain to opting for an immediate insurance coverage, making a career choice or go for family planning. A genetic counselor is the best person to help you make an informed decision after adequately understanding the results and ramifications of the genetic tests.

### *SIGNIFICANCE OF GENETIC TESTING*

The importance of genetic testing is defined by the following conditions:

**Diagnostic Testing** – Certain symptoms of diseases have their roots in genetic alterations. The suspected disorder can be correctly determined only through genetic testing. For example, a genetic testing can confirm diseases like polycystic kidney disease or the Chariot-Marie-Tooth disease.

**Presymptomatic Testing** – Also known as predictive testing, the members of the direct family tree are tested in order to ascertain whether a certain suspected genes runs in the family or not. That way the doctors can plan out the treatment even prior to the appearance of the symptoms.

**Carrier Testing** – Genetic testing is important here when you plan to start a family. When you and your partner get tested before conception, you can ascertain whether any of are a carrier to a genetic condition that is liable to be passed on to your child. It is vital to note here that you or your partner may not contract the said disease, but your carrying the altered genes can pose a threat to the unborn child.

**Prenatal Screening** – Genetic conditions like Spinal bifida and Down's syndrome can be detected through this genetic tests conducted on the genes of the fetus.

**Pharmacokinetics** – When an individual is already suffering from a certain disease, this type of genetic testing helps the doctor to determine the exact type of medicine and dosage that will yield the best results. This is a sort of customized treatment that guarantees effectiveness.

Carrier testing is offered to individuals who have family members with a genetic condition, people with family members who are identified carriers and members of racial and ethnic groups known to be at high risk. Figure 6.2 shows how carrier testing would be used for a family affected by cystic fibrosis and among African-Americans who may carry the gene for sickle cell anemia.

### *PRE IMPLANTATION GENETIC DIAGNOSIS*

Pre implantation diagnosis is a newer genetic test that enables parents undergoing in vitro. Fertilization (fertilization that takes place outside the body) to screen an embryo for specific genetic mutation when it is no larger than six or eight cells and before it is implanted in the uterus to grow and develop. Figures 6.3 show how pre implantation genetic diagnosis performed.

## **PRIMARITAL/PRENATAL TESTING**

Premarital genetic testing enables physicians to diagnose disease in the individual. Most genetic tests examine blood or other tissue to detect abnormalities. An example of a blood test is the triple marker screen. This test measures levels of Alpha Feta Protein (AFP). Human chorionic gonadotropin identifies some birth defects such as Down syndrome and neural tube defects. (Two of the most common neural tube defects are an encephala-absence of most of the brain -of the back and spine). The fetal yolk sac and the fetal Liver make AFP, which is continuously processed by the fetus and excreted into the amniotic fluid. A small amount crosses the placenta and can be found in maternal blood. Maternal screening for AFP levels is based on maternal age, fetal gestation, and the number of fetuses the mother is carrying elevated levels of AFP are associated with conditions such as spinal bifida and low levels are found with down syndrome. Because AFP levels alone may not always adequately detect disorders, two other blood serum tests have been developed. Human chorionic gonadotropin is a glycoprotein produced by the placenta. Normally HCG is elevated at the time of implantation, but decrease at about eight weeks of gestation, and then drops again at approximately twelve weeks of gestation. Elevated level of HCG is found with 'DOWN SYNDROME' The placenta also produces unconjugated estriol. As with AFP, lower unconjugated estriol maternal serum levels are also found with down syndrome. Triple marker screen results are usually available within several days and women with abnormal results are often advised to undergo additional diagnosis testing such as chorionic villous sampling (CVS) amniocentesis, or percutaneous umbilical blood sampling (withdrawing blood from the umbilical cord).

Chromosome 21 is the genetic disease most often identified using this technique. Down syndrome is rarely inherited; most cases result from an error in the formation of the ovum (egg) or sperm, leading to the inclusion of an extra chromosome 21 at conception. As with prenatal diagnosis for most in limited genetic disease, this use of genetic testing is focused on reproductive decision making.

The most invasive prenatal procedure for genetic testing is periumbilical blood sampling. Table 6.1 describes the technique periumbilical blood sampling poses the greatest risk to the unborn child, one in fifty miscarriages occurs as a result of this procedure. It is used where a diagnosis must be made quickly. For example, when an expectant mother is exposed to an infection agent with the potential to produce birth defects, it may be used to examine fetal blood for the presence of infection.

Until 2006 it was thought that women undergoing CVS were more likely to have miscarriage than those who had AMNIOCENTESIS. However Aaron, Cagney, Linda, Hopkins, and Norton, in "Chorionic Villous sampling compared with amniocentesis and the difference in the rate of pregnancy loss (Ostetrics and Gynecology. September 2006) refute this notion. Cagney, Hopkins, and Norton analyzed the outcomes of nearly 10,000 CVS and 32,000 amniocentesis procedures and found that CVS was no more likely than amniocentesis to lead to pregnancy loss.

They attribute previously reported higher rates of miscarriage resulting from most genetic disorders are treated using more than one type of treatment, in keeping with their complex and varied symptoms. For example, children with cystic fibrosis usually take pancreatic enzymes to help digest food and inhale the main aim of prenatal genetic testing is to prevent fetal abnormality and death.

## **STEPS TO PREVENT BIRTH DEFECT**

Awareness and education are the steps to preventing birth defects. The immediate step following awareness and education is taking action.

There are a number of things you can do to increase the probability of having pregnancy and a healthy baby. Some are more challenging than others because they require that you break habits, but it is worth your effort.

Here are a variety of tips you can use to prevent birth defects as you contemplate adding to your family.

- ❖ TIP 1: The first and foremost tip is maintaining preconception health, eating well balanced and nutritional meals and taking a multivitamin daily that includes the recommended 400mcg of folic acid and other essential B vitamin.
- ❖ TIP 2: If you are sexually active and pregnancy is a possibility, make sure you take a multivitamin daily which includes the recommended 400mcg of folic acid and other essential B vitamins.
- ❖ TIP 3: Avoid all activities that could potentially lead to birth defects including alcohol, tobacco, illicit drugs and caffeine.
- ❖ TIP 4: Seek an annual gynecological and wellness exam.
- ❖ TIP 5: Obtain genetic counseling and birth defect screening particularly if you are 35 years of age or older
- ❖ TIP 6: Help your family or friends who might be considering parenthood by informing them that January is Birth defects prevention month

Other birth defects preventing tip include setting up a birth defects prevention campaign in your company, preimplantation genetic diagnosis.

## **THE IMPACT OF PRENATAL GENETIC TESTING ON FAMILY PLANNING SERVICES**

At the same time that legislatures around the country are planning and establishing programs to enable women through genetic screening and prenatal diagnosis to avoid conceiving or bearing

affecting children a trend toward restricting a woman's right to decide to abort an affected fetus is evident. It seems likely, in view of recent Supreme Court decisions, that individual state legislatures will have increasing power to define the circumstances under which abortion will be legally available. If access to abortion is significantly, one really must ask just what kind of choices prenatal genetic testing offers. How much benefit is knowledge in the absence of meaningful options?

Although many are currently optimistic that abortion will remain a legal option in this country, women are still faced with significant limitations on the accessibility of abortion services both in financial terms and in terms of the number and geographical distribution of facilities offering abortion procedures. Women facing the termination of a desired pregnancy based on an abnormal result from prenatal testing may have even more difficulty because they must locate facilities that offer termination of second-trimester pregnancies.

### **THE IMPACT OF PREMARITAL/ PRENATAL GENETIC TESTING ON A WOMAN'S RELATIONSHIPS WITH FAMILY AND WITH HER FUTURE CHILD**

The decisions a woman is required to make regarding prenatal genetic testing can be very stressful ones for her and for her partner. For many couples, the stress comes at a time when their relationship is already being redefined by the expectation of a child. The woman's partner may want prenatal diagnosis more than she does, and may be less anxious about it (Keenan, Basso, Goldkrand, & Butler, 20012) potentially leading the woman to experience a sense that "he'll blame 192 ELENA A. GATES me if the child has diagnosable abnormality that we don't find out about," or he'll blame me if we have an amniocentesis complication.' If the fetus is affected by a genetic disorder, the woman and her partner may also feel different about the prospect of abortion. Those differences may impact a couple's relationship far into the future. Regardless of the decision they ultimately make. The disagreement may furthermore affect their relationship with the child, if the pregnancy is continued. The integrity of these relationships is clearly important to women's overall health. Little work has been done in terms of delineating the effects of decisions about prenatal diagnosis on a woman's family relationships. It will be important to clarify such ramifications before widespread testing is initiated.

Taken as a whole, investigation of amniocentesis's impact suggests that anticipation of the procedure and its results may lead to disruption of an otherwise normal adjustment to pregnancy. Studies have revealed that women undergoing amniocentesis may experience a "suspension of commitment to pregnancy" while awaiting test results (Beeson & Golbus, 2009); Spencer and Cox 2008) Beesen and Goibus (200 observed that this was reflected both in social spheres, such as in not telling others about the pregnancy, and in personal domains, such as in avoiding thinking about the pregnancy. Rnthman (2006 noted a greater frequency of women not feeling movement until after the 18 week among those undergoing aminocentesis. In contrast. Dixson

(2001) could demonstrate no significant differences between amniocentesis and non amniocentesis groups in the timing of selecting names or in willingness to talk about the pregnancy. Furthermore, (Phipps & Zinn 2006) found that amniocentesis patients in a United States sample showed a greater increase in fetal attachment over the course of pregnancy than did non tested controls.(Caccia,2001) demonstrated that maternal-fetal attachment increased significantly for amniocentesis and CVS patients once normal results were received. No non tested controls were included. It has also been noted that attachment may be enhanced by viewing the fetus on ultrasound, a technology used in conjunction with amniocentesis (Fletcher, 2003). If suspension of commitment does occur for some women during the early months of pregnancy and if it 193 does testing benefit women? It involves decreased compliance with suggested regimes such as good nutrition and abstaining from alcohol use, long- term adverse effects might result. Further investigation could clarify which women are at risk for this type of response to prenatal testing and could lead to meaningful interventions.

Jeffrey Botkin (2000) states that “a fundamental aspect of parenting is the recognition of the unique and independent nature of our children’s personalities and lives. Try as we might, they rarely fit the molds that we design for them. Knowledge that our intrinsic personal characteristics were the intentional product of our parents’ designs would have a profound influence on the parent-child relationships’. Abby Lippman (2001) points out that ‘prenatal diagnosis does approach children as consumer objects subject to quality control” Those observations will be important to consider as the use of prenatal genetic testing expands. It will be important to clarify our understanding of women’s expectations in relation to their children, as they depart from the illusion that they actually have some control over the ‘equality” of the infants they bear.

## **FACTORS AFFECTING PREMARITAL/PRENATAL GENETIC TESTING**

Abuelo, (2001) maintains that several factors such as:

(1) Need for more scientific information. (2) Positive attitudes toward genetic testing, (3) non-affordability of the cost of the conducting the test. (4) non- accessibility of medical facilities in health centre’s, (5) non-availability of screen centers and (6) lack of knowledge of the relevance of undergoing genetic testing. These factors is influence their willingness to embark on such all important exercise.

Consequently, Burton (2008) in agreement with Abuelo (2001) believes that non-affordability of the enormous cost of undergoing genetic testing is yet a major factor influencing its access by many pregnant women in Nigeria and the world over. This implies that the provision of medical facilities in health centre’s across the country is a necessary measure that must be taken towards improving the health services delivery in Nigeria. It must be emphasized that the Nigeria as at now lacks adequate medical centers for effective genetic testing.

In the same vein, Croyle (2005) stated that poor attitudes of pregnant lades in our society today tend to impact negatively on their consistent access o i7t51 genetic testing in Nigeria. According

to Croyle, unless this disorder attitude of our expectant mothers is corrected via adequate information on the relevance of this test this wrong notion will continue to affect their behaviour towards carrying this test.

In addition, Bogart (2007) argues that it is being quite amazing today that the level at which medical practitioners neglect the issue of genetic testing to the detriment of the timid pregnant women is dangerous to the actualization of quality health for all in the year 2021) according to the World Health Organization (WHO 2001). Bogart (2007) therefore opines that doctors, and nurses must ass a matter of priority devout much of their time and energy toward the conduct of prenatal genetic testing for the common good of both the expectant mother and their child.

Evans (2008) has continually argued that our society today is characterized with falsehood and the spread of unverified information by the media which no doubt hinder that understanding of the need for prenatal genetic test. According to Evans, accurate and up-to-date information on how to obtain genetic testing should be channeled to health personnel such as nurses & doctors rather than relying on information being peddled around by uninformed individuals in the medical field.

Palomaki, (2006) maintain that inadequate level of knowledge by pregnant women goes a long way to affect their access to genetic testing in health centre's across the country Nigeria. According to Palomaki, (2006) less rigorous pregnant women tended to be mere in favour of prenatal tests as a result of their interest and up-to-date knowledge on prenatal genetic test and how to undertake such tests. This preliminary study provides genetic counselor and policy makers with a clearer picture of their clients motives and attitudes behind the decision - making process of prenatal genetic testing, contributing to improving both the communication process between counselors and their clients and the organization of genetic services.

Several other factors that seem to influence genetic testing by pregnant women are:

- (1) Population-Based Risk - A young, healthy woman may believe that because her population-based risk for chromosome abnormalities is small that she is not at any risk for an abnormality. Women over age 35 may look to screening as a way to avoid the risks of invasive testing. This is the age group most likely to refuse amniocentesis after a positive serum screening test fails to remove them from the at-risk category (Fitzgerald, Streets, & Priest, 2002). The nurse can help the family explore the potential outcome of the decision to accept or decline screening.
- (2) Effects of Exposures to Medications- Concern about any harmful effects of exposures to medications or environmental agents may lead some women to accept screening. It is important to clarify what is known about specific agents so that the testing is not being accepted hoping to gain information that screening cannot provide. There are resources that help the practitioner provide this information but it may be necessary to refer some families to specialists for adequate evaluation and counseling.

- (3) Specific Family History Factors- For specific family history factors, it may be more appropriate to forego screening and refer the woman for more in- depth evaluation and consideration of diagnostic testing. It is optimal to assess family and personal health before pregnancy so that appropriate diagnostic tests and complex evaluations can be completed. This is not always possible, as some women do not address these risk factors until they are pregnant. Early prenatal visits for review of history and health problems may prevent missed opportunities for early screening or diagnosis. It also gives the woman time to discuss testing with her partner and others who may be important in the decision to accept screening

## **CONSEQUENCES ON GENETIC TEST**

### *POSITIVE AND NEGATIVE ASPECTS OF GENETIC TESTING*

#### *POTENTIAL BENEFITS*

There are many potential benefits which can arise as a result of genetic testing. Individuals identified as carrying potentially harmful genetic alterations can receive regular medical check-ups and be eligible for screening to enable early detection of cancer (although these options are also available to individuals who have not been tested but who do have a strong family history of cancer); they may also choose to undergo preventative surgery. This can potentially lead to a reduction in cancer incidence and mortality.

Individuals who are found not to carry a harmful gene alteration which is known to run in their family may feel that they are less anxious and have a better quality of life; they may also benefit from the knowledge that they have not passed a gene alteration on to their children. Also, because such individuals do not require the same regular checkups as do people who carry the gene, resources can be targeted to benefit those people who do have a higher risk of developing cancer.

Despite the significant advantages of genetic testing, there are also, however, several disadvantages which any individual considering undergoing testing should be aware of (these include the limitations of the genetic testing technique which were discussed in the previous section.)

#### *POTENTIAL DISADVANTAGES*

Because genetic alterations generally need to be identified in a family member who has already developed cancer this can lead to distress and difficult family relations, for example if there are no surviving family members who are able to undergo diagnostic genetic testing, or if an individual is reluctant to undergo testing he/she may be subject to pressure from other family members. A positive genetic test can also lead to an increased level of anxiety and individuals

may feel guilty for having potentially passed a gene alteration on to their children. There may also be issues for individuals wishing to obtain health and life insurance.

Receiving a negative genetic test can also affect family relations, with many individuals feeling 'survivor guilt', for example if they have a brother or sister who has been shown to carry that gene alteration, they may feel guilty at having escaped the increased cancer risk, while their sibling is still at risk.

Some people with a strong family history of cancer believe they would find it too difficult to receive a positive genetic test result. They may feel that knowing they are definitely a carrier of a harmful alteration will lead to increased levels of anxiety throughout their life. They choose, instead, to undergo regular medical check-ups, and screening, to enable early detection of cancer without ever having to know their genetic status.

### *ADDITIONAL INFORMATION*

It is very important that genetic testing is always accompanied by pre- and post-test counselling so that individuals are able to make an informed choice about whether or not to undergo testing, and have access to extra support if needed. Below we have provided a few links to UK-based websites which can provide further information on the issues discussed in the Genetics and Cancer and Genetic Testing sections:

- Cancerbackup ([www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)) is Europe's leading cancer information charity, and has over 4,500 pages of up-to-date cancer information. They have a comprehensive section on genetics and cancer, and provide advice for individuals who are worried about cancers running in families.
- In the UK there is currently a voluntary ban which prevents companies who are members of the Association of British Insurers from being able to access the results of genetic tests (apart from those for Huntington's disease). This ban is due to be reviewed in 2014. For more information please refer to the Association of British Insurers' (ABI) leaflet 'Insurance and Genetic Tests: What you need to know' which can be accessed through the ABI's website.

### *ATTITUDE, KNOWLEDGE PRACTICE TOWARD GENE TESTING*

Attitude is a psychological construct which expresses one's disposition towards an issue. One's behavior can be inferred from his or her disposition to situations. In other words, knowledge about an issue determines attitude towards it which in turn influence the behavior. Al Sulaiman. (2008) found that there was positive attitude of Saudi population towards pre-marital screening and the majority of participants agreed that the program should apply to all couples in all regions of Saudi Arabia.



Best practice guidelines for genetic testing are recommendations describing techniques or methods to perform a specific test in the best way possible. It provides professionals with a standard to perform the tests. This promotes uniformity in testing and results in a higher quality in terms of accuracy of results and interpretation.

These guidelines are usually drafted after best practice meetings with experts from the field. EuroGentest has actively participated in and organized many of these meetings in molecular genetics, biochemical genetics and (molecular) cytogenetics- (EuroGentest 2014)

## **EMPIRICAL REVIEW**

The following two empirical studies illustrate how nurses can provide care for prenatal patients undergoing screening Each empirical study will be followed by a discussion.

### *EMPIRICAL STUDY 1*

An empirical survey conducted by Mennuti (2006) in UI3TH Benin city titled 'Neural tube defects: issues in prenatal diagnosis and counseling' the genetic unit distributed 120 questionnaires to some randomly selected patients. Mean maternal age was 36 +/- 4 years. The study revealed that access to prenatal genetic counseling was mainly patient's own initiative, or 'self-referral'. Most self-referred patients (87%) considered that 'receiving accurate information' was the main issue. Eighty-one percent of all couples contacted knew that TOP because of fetal anomalies was not legal. In case of a serious anomaly, 68.2% of patients would contemplate TOP, in spite of the risk of being exposed to an unsafe abortion.

A similar empirical, survey conducted by Bahado-Singh, Ozgur, Oz. Tan, Hunter,, Copel, & Mahoney (2008) selecting 40 patients in 3 local health centers Jos. The study showed that in many countries, prenatal genetic testing is offered, but TOP is not available. The study showed that Mary V. is a 38 year old woman who begins prenatal care early in the first trimester of her second pregnancy. Her first pregnancy ended at 8 weeks with a spontaneous abortion. After several years of trying to conceive, Mr. and Mrs. V. sought infertility treatments and have achieved a pregnancy after In Vitro fertilization. The treatments cost over \$10,000 and the couple comment on more than one occasion that after spending so much money to conceive they will not subject the pregnancy to avoidable risk. They feel certain that they would not terminate a pregnancy because of Down syndrome but remain concerned about the risks of other fetal chromosome abnormalities related to maternal age. They also desire to experience a pregnancy that is as normal as possible and want to deliver in their local community.

Their primary care provider is knowledgeable about the risk for chromosome problems related to maternal age and about the common methods of prenatal diagnosis. The information about some of the newer screening tests for chromosome abnormalities is not a familiar and the patient is referred to a prenatal center with expertise in pregnancy screening and diagnosis. The V's elect to have n nuclear translucency measurement at 11 weeks. The measurement is not increased and

the risk for Down syndrome is determined to be less than the patient's age-related risk. She chooses to forgo invasive testing at this time but elects to have second trimester serum screening to further evaluate risk.

Although the Quad test is only available in a few selected areas of the country, a laboratory is located and blood is sent for evaluation. The result of this test is reported as screen positive with a risk for Down syndrome of 1/148 that is still less than her age related risk of 1/99 Mrs. V. again declines invasive testing. After discussion with the consultants an ultrasound evaluation of the fetal heart and other organs is scheduled as a final evaluation. When this exam is normal the V.'s continue the pregnancy without further evaluation and deliver a healthy baby at term.

### *DISCUSSION OF EMPIRICAL STUDY 1*

This family demonstrates the approach and attitude of many women who are looking to screening to avoid the risks of invasive diagnostic testing. The only birth defects that increase in incidence with maternal age are chromosome abnormalities. If a woman is otherwise healthy and does not have medical conditions such as hypertension or diabetes, the pregnancy is likely to progress normally. There is a decline in fertility in this age group and many women seek evaluation and treatment from infertility specialists in order to conceive. It is not uncommon for couples in this situation to be very well informed about the newest and latest modalities for testing and screening.

The nurse may learn about how these tests perform through this special group of patients. Insurance coverage may also become an issue, as newer tests may not be covered under every benefit package. During the pregnancy, the nurse in the primary care center can provide support for Mrs. V. and her husband as the couple goes through the screening process.

### *EMPIRICAL STUDY 2*

In 2001, the American College of Obstetricians and Gynecologists and the American College of Medical Genetics introduced guidelines for prenatal and preconception carrier screening for cystic fibrosis. The American College of Obstetricians and Gynecologists' Committee on Genetics has updated current guidelines for cystic fibrosis screening practices among obstetrician-gynecologists.

Cystic fibrosis (CF) is the most common life-threatening autosomal recessive condition in the non-Hispanic white population. It is a progressive, multisystem disease that primarily affects the pulmonary, pancreatic, and gastrointestinal systems but does not affect intelligence. The current median survival is approximately 37 years, with respiratory failure as the most common cause of death. Approximately 15% of individuals with CF have a mild form of the disease with a median survival of 56 years (1). More than 95% of males with CF have primary infertility with obstructive azoospermia secondary to congenital bilateral absence of the vas deferens. Cystic

fibrosis is caused by mutation in this gene cause CF. the disease incidence is 1 in 2,500 individuals in the non-Hispanic white population and considerably less in other ethnic groups

Prenatal and preconception carrier screening for CF was introduced into routine obstetric practice in 2001 (2). The goal of CF carrier screening is to identify couples at risk of having a child with classic CF, which is defined by significant pulmonary disease and pancreatic insufficiency. Cystic fibrosis is more common among the non-Hispanic white population compared with other racial and ethnic populations; however, it is becoming increasingly difficult to assign a single ethnicity to affected individuals. It is reasonable, therefore, to offer CF carrier screening to all patients. The sensitivity of the screening test varies among different ethnic groups, ranging from less than 50% in those of Asian ancestry to 94% in the Ashkenazi Jewish population (3). Therefore, screening is most efficacious in non-Hispanic white and Ashkenazi Jewish populations. Because testing is offered for only the most common mutations, a negative screening test result reduces, but does not eliminate, the chance of being a CF carrier and having an affected offspring. Therefore, if a patient is screened for CF and has a negative test result, she still has a residual risk of being a carrier.

Preconception carrier screening allows couples to consider the most complete range of reproductive options. Knowledge of the risk of having an affected child may influence a couple's decision to conceive or to consider preimplantation genetic diagnosis, prenatal genetic testing or the use of donor gametes. Generally, it is more cost effective and practical to perform initial carrier screening for the patient only.

The study shows that Cheryl M. a 19-year-old early in her first pregnancy. She is single, lives at home and is engaged to the father of the baby. The pregnancy is unplanned but both she and her boyfriend are happy. She lives in a small town and is seen for her pregnancy at a clinic established for low-income woman. An ultrasound is done around 10 weeks gestation because of an episode of vaginal bleeding. The ultrasound establishes her due date but offers no explanation for the bleeding. The bleeding continues off and on for the next two weeks and Cheryl is concerned that it may indicate a problem with the baby.

She accepts screening hoping that the test will provide reassurance that all is well with the baby. The initial blood test comes back with a striking elevation of APP and she is referred to a prenatal center for evaluation. The ultrasound at the center shows a fetus with an abdominal wall defect called gastroschisis. Cheryl is counseled about the condition and additional appointments are made with pediatric surgeons who will repair the defect when the baby is born. Delivery at the tertiary center is recommended because of the need for immediate treatment when the baby is delivered. Cheryl will continue her care in her local area and will return for ultrasounds and additional visits to the prenatal center as the time for delivery is near.

## *DISCUSSION OF EMPIRICAL STUDY 2*

Gastroschisis is an explanation for an elevated maternal serum AFP. This is a repairable defect that will most often have a good outcome. This problem is seen more often in younger women (Rankin, Dillon. & Wright, 2009). It is not yet clear what factors may explain the increased incidence in this age group. The infant will, however, require major surgery and high risk care in the neonatal period. Much of the prenatal care can be provided in the local community with some visits to a medical center where the delivery will be planned. The visits often include referrals to the pediatric specialists who will care for the baby after birth. Parents often tour the pediatric units as well as the delivery room to prepare themselves and their family for the birth.

“Genetics is becoming central to the delivery of health care and preventive services. Changes are occurring in the delivery of genetic services, with a gradual move from university-based genetics clinics to satellite genetics clinics and primary care settings. As these services move beyond specialized roles and settings, nurses in a variety of general practice areas have already or soon will confront the implications of the current advances in genetic science and technology” (p. 9). The importance of genetics in nursing practice and the desire for information about evolving genetic screening and technology makes accurate information necessary for nurses in many practice settings. Nurses who understand the screening process can help women make informed decisions about participating in screening. They can provide appropriate information and support throughout the testing process and help to interpret results. When results are abnormal or confusing the nurse can clarify when possible and identify resources to manage the stress and anxiety. Marteau, et al. said it best, “One of the greatest challenges for those involved in the screening process is to inform people of low probability but serious events without alarming them unduly or reassuring them falsely” (2002, p. 13). This skill will be increasingly important as additional screening tests are developed and introduced into practice.

In the present study, although most of the couples who decided to undergo prenatal genetic testing were aware of this, they still chose to perform prenatal diagnosis. The main reason given was to obtain reliable information about fetal condition. Finally, if a fetal chromosomal abnormality were detected, most of them would consider TOP.

Among the ethical issues confronting maternal-child nurses are questions surrounding genetic testing, contraception and sterilization, infertility/assisted reproductive technology, and equality in balancing maternal-fetal needs. This article explores these issues, reviews the literature currently available, and discusses nursing clinical implications for each as well as representative case studies.

The types of support needed by childbearing families who are facing ethical issues require emotional and physical support. Informational support and advocacy support. The role of the nurse in educating women about the ethical implications of their choices cannot be overestimated. When women have been educated about the implications of their decisions and

are therefore empowered to make informed decisions about their lives and their pregnancies, clinical nurses who practice ethically respect those decisions and support the women in their choices. Nurses support childbearing families in the face of multiple ethical issues, and are called upon to provide emotional and physical support, informational support, and advocacy support.

## **THEORETICAL FRAMEWORK**

The theoretical orientation of this study is the theory of knowledge by (Karl Marx 2009). Structural equation modeling was used to describe the dynamic interplay between knowledge, beliefs, attitudes and health — related behaviour such as prenatal genetic testing. Following the Theory of reasoned action, three dimensions predict the intention to undergo prenatal genetic testing: the need for more scientific information a positive attitude towards genetic testing and the inclination to terminate pregnancy after receiving a positive test result.

This theory is built on the premise that since this study involves knowledge and practice of prenatal genetic testing therefore tends to depend on knowledge of the individual adolescent as regards what abortion is all about. The theory of knowledge is a theory of social or existential determination of knowledge thought and the social structure in which they emerged. The theory explains why there are variations in thought and perception from one place to another.

The theory of knowledge is a theory of social or existential determination thinking. It also concerns with the procedure by which the socio-historical selection of ideational contents is to be studied. It is being understood, that the contents themselves are independent of socio-historical causation and thus inaccessible to sociological analysis. According to a (Mannheim, 2003) all knowledge is bound to a location within the social process. Also, Mannheim believed that different social groups vary greatly in their capacity thus to transcend their own narrow position. At a particular time, a particular group can have fuller access to the understanding of a social phenomenon than other groups, but no group can claim to have a total access to it.

Thought is therefore, culturally relative and time specific. Thus, it can be very interesting to want to know the views attitudes and implication of these adults or the youth will be in another environment and at a later date and time may be next century. But this is not provided for in this research work.

Karl Marx (2009) attempted in his early writings to establish a connection between philosophic and the social structures in which they emerged and more specifically, he was concerned with analyzing the ways in which systems of ideas appeared to be dependent on the social position, more particularly the class position of their proponent. Marx thus attempted to functionalize ideas of individuals to their social roles and to the class position they occupy in society. To him, it is not the consciousness of men that determine their existence but on the contrary the social existence determines their consciousness. Man's thought is concerned with human activity consequent upon this submission the attitudes and beliefs of an adult Doctor/Nurse may tend to oppose an abortion as practice but the attitude of a rural farmer may support it since they might

not be aware of the dangers of abortion and are only thinking of the impact the unwanted pregnancy can have on their image if not terminated especially as unwanted pregnancy before marriage is more often than not the reason for abortion. These variations are as a result of the type of Social roles they play within the structure.

Wright maintains that less religious women tend to be more in favour of prenatal tests and in undertaking such tests. This preliminary study provides genetic counselor and policy makers with a clearer picture of their clients motives and attitudes behind the decision-making process of prenatal genetic testing, contributing to improving both the communication process between counselors and their clients and the organization of genetic services.

In the general practice of medicine, it is important to consider not only therapeutic results, but also the no clinical implications of what is done to or for patients. This is particularly imperative when one considers prenatal genetic screening and testing and its application to broad populations of women. A few basic questions need to be asked: Do we know whether prenatal genetic testing is a good thing for women, children, or society? Does prenatal genetic testing go beyond merely providing more information about a woman's pregnancy to actually improving her health? The term health is used broadly in this context, a 183184 ELENA A. GATES described by Dorland's illustrated Medical Dictionary (2008) as a "state of optimal physical, mental, and social well-being, not merely as the absence of disease and infirmity."

While it is clear that prenatal genetic testing is very useful for identifying a particular chromosomal or genetic abnormality in a fetus, and that it can offer meaningful choices to families at risk for specific genetic disorders, less evidence exists to indicate whether the widespread application of testing to pregnant women will succeed in achieving the broader goal of improving the health and well-being of obstetric patients. Indeed, several goals can be postulated for a broadly applied program of prenatal genetic testing.

The notion that individual women should be offered or encouraged to undergo prenatal genetic testing in order to spare society the expense of coping with diseased or disabled offspring has been put forward (Shaw, 2004). Viewed in terms of medical economics, the burden of genetic diseases on society is significant. "Genetic disorders account for about 20 percent of pediatric hospital admissions and for an even higher percentage of long term admissions" (Simpson, 2006). Widespread application of prenatal genetic testing, if accompanied by treatment or by termination of pregnancy, would decrease the social burden of genetic disease, at least in economic terms. Currently, however, most diagnosable conditions are not treatable prenatally. Furthermore, access to abortion, even for diagnosed genetic conditions, may be limited, either legally, and deformity and these are likes which are inherent and not extern and again those which are caused by external fortune as sovereignty, nobility, obscure, birth, riches, want, magistracy, prosperity adversity and the life (Bncen, 2002).

This shows that an individual is affected in the way he sees things in the society. This might be due to a number of reasons including environmental influences, personality make-up and societal values. This theory of knowledge therefore concerns itself with the social construction or reality. It concerns itself with everything that pauses for “knowledge in the society”. The attitudes and believes of an individual about anything at all, especially the issue of abortion will largely depends on his socio-economic status. There are things that will guide the adults in building an attitude or having a belief about abortion. To some, the fear of death may influence their lack of support for it or it might even be ignorant about the hazard involved in abortion that will determine other attitudes.

## **METHODOLOGY**

This chapter deals with and gives light into the research method and procedures used for this project. And it was discussed under the following sub-headings;

- Research design.
- Research setting
- Target population
- Sample /Sampling Technique
- Instrument for data collection.
- Validation of Research instrument
- Reliability of Data collection
- Method of Data Analysis.
- Ethical consideration.

**DESIGN OF STUDY** The researcher adopted descriptive survey method. This design was used because the study deals with analysis of information that will enable the researcher to investigate knowledge, attitude and practice towards premarital/prenatal genetic testing among young people in Sapele local government area of delta state.

## **SETTING OF STUDY**

The study was carried out in Sapele Local Government Area of Delta State. The local government is made up of four communities which include:

- Okirighiwe
- Amuogodo

- Amukpe
- Uguanja

The people of Sapele local government area are fishermen, traders, civil servant and students, they have had a formal education while some informal education. Their main language is Urhobo and Itsekiri. Most of them are Christians though here are also pagans.

Sapele local Government Area have good roads, 13 government owned primary health centers. 7 government primary and secondary schools, one general hospital (referral centers) and some private hospitals (one man enterprise) Sapele Local Government are have one government company and 3 non-governmental company, one school of midwifery. The local government area is about 60 kilometer to Warri school of Nursing.

## **TARGET POPULATION**

The target population consists of young people of age 15- 45 years.

## **THE ACCESSIBLE POPULATION**

The accessible population for this study is 100 young people in Sapele in the following proportions.

- Okirighwe -20 young people.
- Amuogodo-36 young people.
- Amiikpe -14 young people.
- Uguanja -30 young people.

## **SAMPLE**

The sample was obtained from 50% of the population of each of the community as follows:

1. Okirighiwe

$$\frac{50}{100} \times \frac{20}{1} = 10$$

2. Amuogodo

$$\frac{50}{100} \times \frac{36}{1} = 18$$



3. Amukpe

$$\frac{50}{100}x\frac{14}{1} = 10$$

4. Uguanja

$$\frac{50}{100}x\frac{30}{1} = 10$$

Total = 50 young people

### **SAMPLING TECHNIQUE**

A probability sampling method was used where simple random sampling method were used for the selection of subject, because the method ensure that every element of the population has an equal opportunity of being selected, fallowing method was used to get the sample in order to prevent falsification.

### **INSTRUMENT FOR DATA COLLECTION**

The data was collated through the use of questionnaires designed by the researcher to elicit the responses on knowledge attitude and practice toward premarital/prenatal genetic testing among young people in Sapele Local Government Area. The questionnaire was given out by the researcher to the respondents to answer while those of low educational level were guided by researcher's assistant.

The questionnaire has four Sections. section A was on socio demographic data, section B on knowledge of premarital/prenatal genetic testing, section C on the practice of premarital/prenatal genetic testing and section D on the factors that influences young people's attitudes towards premarital/prenatal genetic testing and it is consist of open ended and close ended questions.

### **VALIDITY OF INSTRUMENT**

The self structured questionnaire was submitted to the supervisor with three other professional in the field health science for content and face validation they all critically and constructively examined the items on the questionnaire, based on their recommendations necessary corrections were effected on the instrument. The instrument was constructed in such a way that if administered by another individual given the same condition the finding will remain constant.

## **RELIABILITY OF INSTRUMENT**

Pilot study was carried out by choosing 15 respondents outside the sample and offered questionnaire which they answered, returned and data analyzed and found to answer the research question based on that the instrument was found to be reliable.

## **PRE-TEST/PILOT STUDY**

Before proceeding to the field to administer the research questionnaire to the sample subjects consisting of 50 young people with genetic defect in Sapele LGA. The researcher embarked on a pre-test exercise/pilot test using 40 young people with genetic defect in Sapele LGA in the following proportions. Okirigwe-10 young people with genetic defect, Amuogodo-10 young people with genetic defect, Arnukpe-10 young people with genetic defect and Uguanja -10 young people with genetic defect.

These persons were not part and parcel of the actual sample elements. This was done in order to further determine the reliability or otherwise of the research instrument. Analysis of the result of the pilot test was done using Pearson Moment Correlation Co-efficient. The result of the reliability test yielded 0.75 which signifies a positive outcome indicating that the pilot test or the research instrument was reliable.

## **METHOD OF DATA COLLECTION**

50 Young people were randomly selected (50%) from the four communities (Amukpe, Amuogodo, Okirighiwe and Uguanja) of Sapele local government area (LGA). Questionnaires were distributed to them and their co-operation solicited. Those of low educational level were guided on how to fill the questionnaire, in the language they understand. The questionnaires were all retrieved and thoroughly examined to ensure that none of them were improperly filled.

## **METHOD OF DATA ANALYSIS**

The data collected from the survey was analyzed using simple percentage and histogram after presenting them on frequency distribution table. The respondents were given options to participate on their own accord without force after through explanation of what the research is all about. The percentage reveals the different opinion of respondents.

## **ETHICAL CONSIDERATIONS**

The respondents were assured of confidentiality of information given and that such will be strictly used for academic purpose. The researcher also ensured that the respondents participate voluntarily without coercion.

The information in this was genuinely obtained from the respondents. It is meant to protect the research subjects from any physical, mental or social harm and this maintain their integrity.

## DATA ANALYSIS

This chapter deals with the analysis of data based on the result of questionnaire and interview conducted in 4 communities (Aukpe, Amuiogodo, Okirighiwe and Ugunja) of Sapele Local Government Area of Delta State.

## PRESENTATION OF RESULT / FINDINGS

Analysis is done using simple percentile table, bar charts and histogram

**Table 1: socio-demographic data**

Variables	Frequency	Percentage
15-25	10	20%
26-35	25	50%
36-45	15	30%
<b>Sex</b>		
Male	35	70%
Female	15	30%
<b>Marital status</b>		
Married	30	60%
Single	15	30%
Others	5	10%
<b>Ethnic group</b>		
Itsekiri	10	20%
Urhobo	22	44%
Ijaw	8	16%
Igbo	7	14%
Others	3	6%
<b>Educational status</b>		

Formal education	15	30%
Informal education	35	70%
<b>Occupational status</b>		
Fishermen	12	24%
Traders	8	16%
Students	5	10%
Applicant	8	16%
Civil servant	10	20%
Others	7	14%
<b>Religion</b>		
Christianity	40	80%
Muslim	3	6%
Pagan	2	4%
Others	5	10%

Results: from the table above majority (50%) of the respondents are aged 26-35 while the least (20%) are within the range 15-25. concerning sex: majority of the respondents are male (70%) while (30% female).

Concerning marital status: majority (63%) are married while the least is 10%. Concerning ethnic group: Majority of the respondents (44%) are Urhobo while the least 6%). Concerning educational status: majority (70%) have had formal, education while the least (30%) have no formal education.

Concerning occupational status: Majority (24%) are fisher men while the least (19%). Concerning religion: majority of the respondents (80%) are Christians while the least (4%) pagan.

Table 2: to showing the level of knowledge of prenatal/pemarital genetic testing among young people.

**Table 2: frequency distribution on the level of knowledge of prenatal genetic testing.**

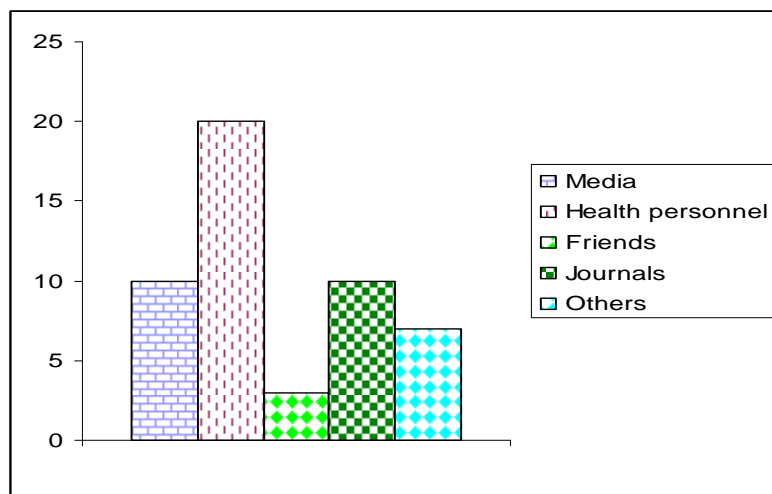
Level of knowledge	Frequency	Percentage (%)
Yes	15	30%
No	35	70%
Total	50	100

The table 2 above shows that 30% of the respondents level of knowledge of premarital genetics testing is positive while 70% of the respondent have a negative level of knowledge.

**Table 3: frequency distribution on the source of information**

Source of information	Frequency	Percentage (%)
Media	10	20%
Health personnel	20	40%
Friends	3	6%
Journals	10	20%
Others	7	14%
Total	50	100%

From table 3 above, it is seen that 20% of the respondents got their information through the media, 20% health personnel, 40% through friends, 6% through journals and 14% others.



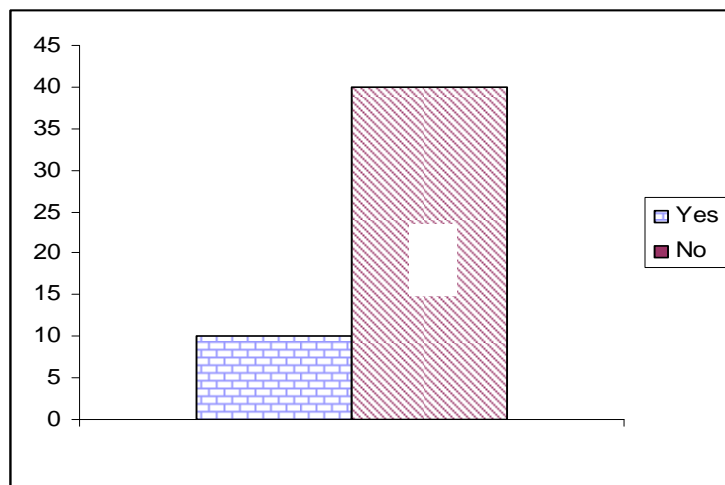
**Figure 1: Sources of Information**

The graph above shows that 20% of the respondents got their information from the media, 40% health personnel, 6% friends, 20% journals and others 14%.

**Table 4: frequency distribution on the level of practice of premarital genetic testing**

Level of knowledge	Frequency	Percentage (%)
Yes	10	20%
No	40	80%
Total	50	100

The table 4 above shows that 20% of the respondents practiced premarital/prenatal genetic testing while 80% did not.



**Figure 2: Practice of premarital/prenatal genetic testing**

The above graph shows that 20% of the respondents, practice premarital/prenatal genetic testing while 80% do not practiced it.

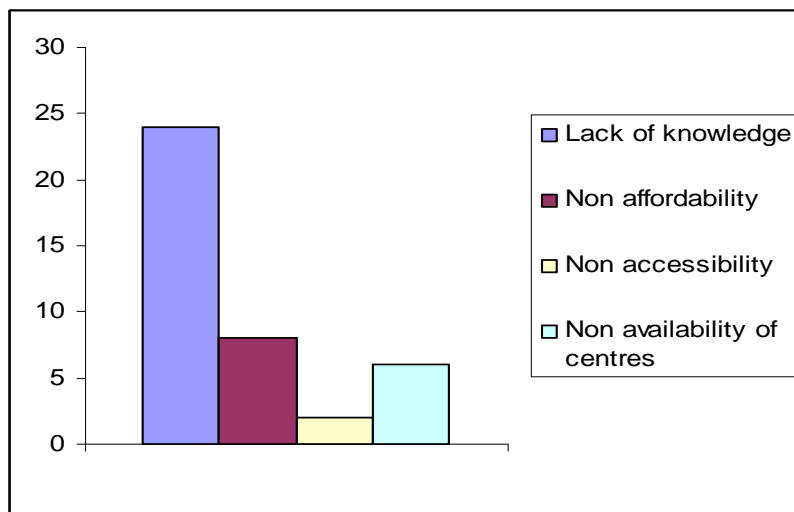
**Table 5: Frequency distribution on factors influencing young people’s attitudes towards premarital genetic testing.**

Factors influencing their attitude	Frequency	Percentage (%)
Lack of knowledge	24	60%
Non affordability	8	20%
Non accessibility	2	5%

Non availability of centers	6	15%
Others	0	-
Total	50	100%

The table 5 above shows that 60% of the respondent are as a result of lack of knowledge 20% due to non affordability, 5% non accessibility and 15% as a result of non availability of centre's where prenatal genetic testing is been carried out.

This can also be represented with the use of histogram



**Figure 3: Factors influencing their attitude**

The histogram above shows that (24) 60% of the respondents are as a result of lack of knowledge, (8) 20% due to non affordability, (2) 5% non accessibility and (6) 15% due to non availability of centers where pre marital genetic testing is done.

**Table 6: Frequency distribution on when prenatal genetic testing should be done**

When it should be done	Frequency	Percentage (%)
Before marriage	14	28%
Before pregnancy	6	12%
During pregnancy	28	56%
Others	2	4%
Total	50	100%

From table 6 above, it shows that 28% of the respondents say before marriage 12% before pregnancy, 56% during pregnancy while others 4%.

## **ANSWERING OF RESEARCH QUESTIONS**

According to table 2 which shows that 70% of the respondents does not have positive knowledge of premarital/prenatal. Genetic testing and 30% of the respondents have positive knowledge of prenatal genetic testing. This therefore shows that majority of the respondent are not aware of prenatal genetic testing. This answer research question 1.

According to table 4 which show that 20% of the respondents do practice premarital genetic test and 80% do not practice it as it is seen in figure 2. It therefore seen that young people of Sapele local government area, level of practice of premarital/prenatal genetic testing is very low. This therefore answered research question 2.

According to table 5, 60% of the respondents lack of knowledge, influences their attitude towards premarital/prenatal genetic testing, 20% due to non affordability, 5% non accessibility and 15% due to non availability of centers where prenatal genital testing is earned out.

As it is seen in figure 3 which reveals 60% of the respondents is due to lack of knowledge, 20% non affordability, 5% non accessibility and 15% due to non availability of centers.

According to statistics, it shows that young people in Sapele local government area of delta state have limited knowledge negative attitude and low level practice of premarital/prenatal genetic testing. It is also discovered that lack of knowledge. non affordability, non accessibility and non availability of centers influences their attitudes towards premarital genetic testing. It is a multi-multi furious problem that requires multi-sect oral approach.

## **DISCUSSION OF FINDINGS**

This chapter deals with discussion of major findings of the study / relationship with other related findings conclusion, summary implications for nursing, limitation of the study, recommendation and suggestion for further studies.

## **DISCUSSION OF FINDINGS RELATIONSHIP WITH OTHER RELATED FINDINGS**

Objective 1: to determine the lvel of knowledge towards premarital/premarital genetic testing among young people. Question 1 table 2: Frequency distribution on the level of knowledge of premarital genetic testing. The results shows that 30% of the respondents have adequate level of knowledge of premarital/premarital genetic testing while 70% of the respondents have no knowledge of premarital genetic testing.

It could be seen that a greater number of the people are not aware of premarital/prenatal genetic testing.



Results of similar study conducted by Palornaki. (2006) shows that inadequate level of knowledge by pregnant women goes a long way to affect their access to genetic testing in health centers across the country Nigeria. According to Palomaki, (2006) less religious pregnant women tended to be more in favor of premarital/prenatal genetic tests as a result of their interest and up-to-date knowledge on premarital genetic test and how to undertake such tests. This preliminary study provides genetic counselor and policy makers with a clearer picture of their clients motives and attitudes behind the decision-making process of premaritalpremarital genetic testing, contributing to improving both the communication process between Question 2.

Table 3: Frequency distribution on the source of information.

The table shows 20% of young people who have adequate knowledge of premarital genetic testing heard about it through the media, 40% through health personnel. 6% through friends, 20% from the journals while 14% others. This correspondent with the study conducted (Evans 2008) have continually argued that our society today is characterized with falsehood and the spread of unverified information by the media which no doubt hinder that understanding of the need for prenatal genetic test. According to Evans, accurate and up-to-date information on how to obtain genetic testing should be channeled to health personnel such as nurses & doctors rather than relying on information being peddled around by uninformed individuals in the medical field.

*OBJECTIVE 2: TO ASSESS THE LEVEL OF PRACTICE OF PREMARITAL/PRENATAL GENETIC TESTING.*

Table 4: Frequency distribution on the level of practice of premarital/prenatal genetic testing. This reveals that 20% of the respondents practiced premarital genetic testing while 80% of the respondent do not.

This falls in line with the survey on the need to boast medical practices on genetic test in Nigeria conducted by Bogart (2007) who argues that it is being quite amazing today that the level at which medical practitioners neglect the issue of genetic testing to the detriment of the timid pregnant women is dangerous to the actualization of quality health for all in the year 2020 according to the World Health Organization (WHO 2001). Bogart (2007) therefore opines that doctors, and nurses must assess a matter of priority devout much of their time and energy toward the conduct of prenatal genetic testing for the common good of both the expectant mother and their child.

*OBJECTIVE 3: TO IDENTIFY FACTOR INFLUENCING THEIR ATTITUDE TOWARDS PREMARITAL GENETIC TESTING.*

Table 5: Frequency distribution on factors influencing young people's attitudes towards premarital/prenatal genetic testing.

This shows that 60% is due to lack of knowledge/need for more scientific information as well as a positive attitude towards genetic testing, 20% non affordability, 5% non accessibility and 15% as a result of non availability of centers. This finding is in line with a study conducted by Green, (2000) who stated that three dimensions predict the intention to undergo prenatal genetic testing: the need for more scientific information, a positive attitude towards genetic testing And the inclination to terminate pregnancy after receiving a positive test result. This implies that despite the increase in popularity of premarital/prenatal genetic testing relatively little is known about the role psychological factors play in the decision — making process. This correspondent with study conducted by Croyle (2005) who stated that poor attitudes of pregnant ladies in our society today tend to impact negatively on their consistent access to premarital genetic testing in Nigeria. According to Croyle, unless this disorder attitude of our young people is corrected via adequate information on the relevance of this test this wrong notion will continue to affect their behaviour towards the test.

## **CONCLUSION**

From the analysis of the result it could be established that young people have limited knowledge of premarital/prenatal genetic testing and negative attitude and practice towards the premarital genetic testing as a result of lack of knowledge non affordability, non accessibility and non availability of health centers with premarital genetic testing equipment.

The study has shown that despite the increase in popularity of premarital/prenatal genetic testing relatively little is known about the role psychological factors play in the decision — making process.

## **IMPLICATION FOR NURSING**

The knowledge gained from this research work will help the Nurse to know the different types of genetic abnormalities.

It also create an avenue for nurses to health educate the young people on what remarital/prenatal genetic testing is all about, and how to prevent it, what to do and how to do it, and how to avoid member of the community from being affected.

Further, the research work serves as an eye opener for members of the community on the different genetic abnormalities and what to do to prevent it.

## **LIMITATIONS OF THE STUDY**

The extent of this research is constraint by a number of factors. This includes:

1. Time constraint: Time factor was a limitation the researcher would have loved to cover other area of the community but could not because the time allocated to the work was short.

2. Respondents: Due to inability of some of the respondents to read & write, the researcher spent time and energy explaining to them and getting them to fill the questionnaire correctly.

## **RECOMMENDATIONS**

Based on the findings on the research work, it is noted that the knowledge, attitude and practice toward premarital genetic testing among young people in Sapele local government, among the selected community is low, so with this result, the research recommends that;

1. Government should provide screening centers among the people
2. Young people should be encouraged to be involved in premarital/prenatal genetic testing to prevent congenital abnormalities of their offspring.
3. Every January, the community members in Sapele Local Government should go for genetic testing, and counseling.
4. Women of reproductive age especially the pregnant one's should be encouraged to be involved in prenatal genetic testing to prevent congenital abnormalities.
5. For couples in which both partner are carriers, genetic counseling is recommended to review prenatal testing and reproductive options.
6. Every unmarried young people should assess their genetic status before marriage
7. Efforts should be made by government and health workers to improve their knowledge, attitude and practice toward genetic testing and its abnormalities, thus reducing genetic disorder in the society.

## **SUGGESTIONS FOR FURTHER STUDIES**

1. Causes, effect and remedy of poor premarital/prenatal genetic testing among young people in Sapele Local Government Area.
2. The effect of prenatal genetic testing on young people in Nigeria.
3. Implication and cost benefit analysis of prenatal genetic testing among couples.

## **REFERENCES**

1. Abby Lippman (2001): The View from de Womb, Genetics: Ethics to Order Remain a Pipe dream. Newsletter. 8 November 2003. p.64.
2. Abuelo, D. N., Hopmann, M. R., Barsel-Bowers, G. & Goldstein, A. (2001). Anxiety in Women with Low Maternal Serum Alpha-Fetoprotein Screening Results. *Prenatal Diagnosis*. 11, 381-385.

3. Armitage, P., & Colton, T. (eds.) (2008). *Encyclopedia of Biostatistics Volume 5*. Boston: John Wiley & Sons.
4. Bacon, A.L (2002): Prevention of the first Occurrence of Neural Tube Defects by Periconceptual Vitamin Supplementation. *The New England Journal of Medicine*, 119, 327.
5. Bahado-Singl R, Ozgur. D., Oz. U. Tan, A. Hunter. D. Copel, J., & Mahoney, M. J. (2008). An Alternative for Women initially Declining Genetic Amniocentesis: Individual Down Syndrome Odds on the basis of Maternal Age and Multiple Littrasonographic Markers. *American Journal of Obstetrics and Gyhecology*. 179: 5 14-9.
6. Beeson, J. & Golbus, 0 (2009): Who's for Amniocentesis? The Politics of Prenatal Screening. In H. Homans (ed,) *The Sexual Politics of Reproduction*. London: Gower. (pp. 96-177).
7. Bogart, M. H., Pandian. M. R. Jones O. W. (2007). Abnormal Maternal Serum Chorionic Gconadotrophin: Levels in Pregnancies with fetal Chromosome Abnormalities. *Prenatal Diagnosis*. 7, 1 97-200.
8. Boss, B.K (2012): Elevated Maternal Serum Alpha-Fetoprotein (MSAFP): Interpretation and Follow-up. In R. M. Pitkin. Jr. & J. R. Scott (eds), *Clinical Obstetrics and Gynecology*. 31. 293-205.
9. Caccia J.H (2011) Screening of Maternal Serum for Fetal Down's Syndrome in the First Trimester. *New England Journal of Medicine*, 338, 955-961.
10. Croyle, R. T. (2005). Introduction. In R.T. Croyle (ed). *Psychosocial Effects of Screening for Disease Prevention and Detection*. (pp. 3-7).
11. Dixson, H (2011) Combining Inhibin A with Existing Second-Trimester Markers in Maternal Serum Screening for Down's Syndrome. *Prenatal Diagnosis*, 16: 1095-1 100.
12. Dorland's (2008) *Psychosocial Aspects of Prenatal Screening and Diagnosis*. In T. Marteau and M. Richards (eds) *The Troubled Helix: Social and Psychological Implications Of The New Human Genetics*. New York: Cambridge. (pp.140-163).
13. Dweyer, J. M., (2013). Scientific Criteria for adopting Health Screening Measures. *Pediatric Nursing*. May/June. 195-197.
14. Eriferi M. T. (2011), Knowledge and practice of prenatal genetic testing among married couple.(unpublished work).
15. Evas. MI. Bottoms. S.F., Carlucci. T. Grant, J., Belsky. R. L., Solyom, A. E., Quigg, M. H., & Laferla. J. (200). Determinants of Altered Anxiety after Abnormal Maternal Serum Fetoprotein Screening. *American Journal of Obstetrics and Gynecology*. 159: 1501-4.

16. EuroGentest (2014) <http://www.eurogentest.org/index.php?id=645>
17. Filly, R. A. (2010). Obstetrical Sonoaraphy: The Best way to Terrif, a Pregnant Woman. *Journal of Ultrasound in Medicine*, 19. 1-5.
18. Fitzgerald, J., Streets, K. & Priest. J. (2012). Maternal Serum Screening Risk for Down Syndrome is Considered Positive if a Triple-Maker-Derived Risk Exceeds the Age-Specific Risk: Use of this Definition for Women Aged 35 and over. *Prenatal Diagnosis*. 13,2. 152-153.
19. Fletcher, B. (2003) Low Second Trimester Maternal Serum Unconjugated Oestriol in Pregnancies with Down syndrome. *British Journal of Obstetrics and Gynecology*, 95, 330-333.
20. Genes on the Line (2007), <http://www.tav.sachs.org/taysachs.php>.
21. Genes on the Line (<http://www.geiieticailiance.org>)
22. Genes on the Line (<http://ww.dines.com>.Retrived march 2012).
23. Genes on the Line (<http://ww.encyclpedia.com>. 2012).
24. Genes on the Line ([www.Google.com](http://www.Google.com), retrieved 14th October 2012).
25. Genetic Unit, Department of Obstetrics and Gynecology. Centro de Education Medical Investigations Clinics CEMIC, Institutur Universities IUC. Buenos Aires, Argentina.
26. Green, J.M. (2000). Prenatal Screening and Diagnosis: Some Psychological and Social Issue. *British Journal of Obstetris and Gynecolohy*, 97. 1074-(70).
27. Gucudian (2011): Congenital Anterior Abdominal wall Defects in the North of England, 2006-2006: Occurrence and Outcome. *Prenatal Diagnosis*, 19(7): 662-8.
28. Jeffiey Botkin (2000) *Medical Progress. Congenital Malformations: Etiologic factors and their Role in Prevention. Part I.* *New England Journal of Medicine*. 308 (8): 424-1.
29. Karl Marx (2009) *Medical Progress. Congenital Malformations: Etiologic factors and their Role in Prevention. Part II.* *New England Journal of Medicine*. 308(9): 491-7.
30. Keena D., Basso V., Goldkrand P. & Butler S. 2001): *The Genetic Screening of Target Populations.* In *Backdoor to Eugenics*. New York: Routledge.
31. Lapham, E. Virginia; Kozma, Chahila: Weiss, Joan 0. *Genetic Discrimination. Perspectives of Consumers Science* Vol 274. 24, Oct 2006. pp. 621-624.

32. Main, D. M., & Mennuti, M.T.(2006). Neural Tube Defects: Issues in Prenatal Diagnosis and Counseling. *Obstetrics and Gynecology*, 67, 1-16.
33. Mannheim, A (2003). Prenatal Detection and Diagnosis. in *Clinical Genetics in Nursing Practice*. (pp. 271-293'). New York: Springer Publishing Company.
34. Marteau, T. M. (2009). Psychological Costs of Screening. *British Medical Journal*, 299, 527.
35. Marteau, T.M., Johnston, M. Kidd J., Michie, S. Cook. R Slack J. & Shw, R\V. (2002). Psychological Models in Predicting Uptake of Prenatal Screening. *Psychology and Health*. 6, 1 3-22.
36. Palomaki, G. E. (2006). Collaborative Study of Down Syndrome Screening using Maternal Serum Alpha-Fetoprotein and Maternal Age. *The Lancet*, December 10-27. 1460.
37. Palomaki, G. E., Williams, J. & Haddow. J. E.(2009). New England Regional Genetics Group Prenatal Collaborative Study of Down Syndrome Screening: Combining Maternal Serum Alpha-Fetoprotein Measurements and Age to Screen for Down Syndrome in Pregnant Women Under Age 35. *American Journal of Obstetrics and Gynecology*, 160; 578-581.
38. Phipps and Zinn (2006) Psychological Consequences for Parents of False Negative Results on Prenatal Screening for Down's syndrome: Retrospective interview Study. *British Medical Journal*, 320: 407-412.
39. Rankin, Dillon, E., & Wright, L. (2009). Prenatal Diagnosis in the 2000s. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 23; 506-5 15.
40. Rothman D. (2006): Alpha-Fetoprotein in the Antenatal Diagnosis of Anencephaly and Spina Bifida. *Lancet* 2. 770, 197-200.
41. Shaw, G (2004). Sensitivity arid specificity of Ultrasound for the Detection of Neural Tube and Ventral Wall Defects Population. *Obstetrics and Gynecology*, 4. 562-566.
42. Simpson, O. (2006). Fetal Nuchal Translucency: Ultrasound Screening for Chromosomal Defects in the First Trimester of Pregnancy. *British Medical Journal*, 304, 867-869.
43. Spencer, P and Cox D. (2008): Prenatal Screening for Down Syndrome with the use of Maternal Serum Markers. *New England Journal of Medicine*, 327, 588-593.