



**PERCEPTIONS AND ACCEPTABILITY OF PRENATAL
CONGENITAL ANOMALIES SCREENING AMONG PREGNANT
WOMEN HAVING ANTENATAL CARE FOLLOW UP AT A
TERTIARY HOSPITAL IN ETHIOPIA**

**A RESEARCH THESIS TO BE SUBMITTED TO SAINT PAUL'S
HOSPITAL MILLENNIUM MEDICAL COLLEGE, DEPARTMENT OF
OBSTETRICS AND GYNECOLOGY, AS PARTIAL FULFILMENT FOR
SUBSPECIALTY CERTIFICATE IN MATERNAL FETAL MEDICINE
(MFM)**

PRINCIPAL INVESTIGATOR: DR. ANTENEH MERSHA

(ASSISTANT PROFESSOR OF OBGYN, MFM FELLOW)

ADVISOR: PROFESSOR DEILAYEHU BEKELE

(MFM SUBSPECIALIST, MPH, PROFESSOR OF OBGYN)

ADVISOR: DR. ABDOLFETAH ABDULKADIR

(MFM SUBSPECIALIST, ASSISTANT PROFESSOR OF OBGYN)

**PERCEPTIONS AND ACCEPTABILITY OF PRENATAL
CONGENITAL ANOMALIES SCREENING AMONG PREGNANT
WOMEN HAVING ANTENATAL CARE FOLLOW UP AT A
TERTIARY HOSPITAL IN ETHIOPIA**

PRINCIPAL INVESTIGATOR: *Dr. Anteneh Mersha*

Assistant professor of Obstetrics and Gynecology, MFM fellow

Saint Paul's Hospital Millennium Medical College

ADVISORS: *Professor Deilayehu Bekele*

Professor of Obstetrics and Gynecology, MPH, MFM subspecialist

Department of Obstetrics and Gynecology

Saint Paul's Hospital Millennium Medical College

ADVISOR: *Dr. Abdulfetah Abdulkadir*

Assistant professor of Obstetrics and Gynecology, MFM subspecialist

Department of Obstetrics and Gynecology

Saint Paul's Hospital Millennium Medical College

**(A research thesis submitted to Saint Paul's Hospital Millennium Medical
College, department of Obstetrics and Gynecology as partial fulfillment for
subspecialty certificate in Maternal Fetal Medicine)**

JANUARY, 2023

ADDIS ABEBA, ETHIOPIA

Abstract

Background: Major congenital malformations affect an average of 2 to 3% of all live births which constitute about 3 million fetuses and infants born yearly. Congenital anomalies account for 20 to 25% of perinatal deaths, which is a major marker of quality of health care delivery. Technology and advances in research have made it possible for the fetus to become a patient whose illness can be investigated, diagnosed and treated in utero. There is a scarcity of data about pregnant women's knowledge, perception, preference and acceptability of prenatal congenital anomalies screening in these part of the world. This makes our study findings at most importance that would have further implications for continuing the success of antenatal care programs and reducing complications associated with fetal congenital anomalies in Ethiopia.

Objective: To assess the perceptions and acceptability of prenatal congenital anomalies screening at SPHMMC.

Methodology: Descriptive cross sectional study was conducted among pregnant women who had attended antenatal care services during July 01 to October 31, 2022 at SPHMMC, Addis Ababa, Ethiopia. Data was collected using pretested structured questioner. The data was analyzed using descriptive statistics, chi-square, logistic regression and T-tests in SPSS version 21 statistical software. P-value of less than 0.05 was taken as significant.

Results: A total of 308 pregnant women were interviewed. The mean maternal age was 30.2 ± 4.2 years. Up to 158 (51.30%) had at least secondary school level of education. 55.7% of the respondents had an average knowledge level & only 16.8% demonstrated high knowledge level. 3/4th of participants showed a good perception of prenatal congenital anomalies screening. 88.6% of study participants were willing to accept prenatal screening when offered. Almost all (92.2%) preferred US as prenatal screening method. High knowledge level & Multiparity were associated with increased uptake of prenatal screening tests.

Conclusion: There was a mediocre level of knowledge among the study participants. Most of them showed a good perceptions & a high acceptability of prenatal congenital anomalies screening.

Acknowledgment

I want to thank SPHMMC and the department of Obstetrics and Gynecology for giving me the opportunity to have a study on this important topic. In addition I would like to thank my Advisors, Professor Deilayehu Bekele and Dr Abdulfetah Abdulkadir for their guidance and very kind full constrictive comments on the title selection and development of this research thesis.

Table of Content

Contents

Abstract	3
Acknowledgment	4
Table of Content	5
List of Tables	7
List of Figures	7
Abbreviations/Acronyms	8
1. Introduction.....	9
1.1. Background	9
1.2 Rationale of the study	11
1.3. Literature review	12
2. Objectives	17
2.1. General objective:	17
2.2. Specific objective:.....	17
3. Methodology	18
3.1 Study area & period:	18
3.2 Study design.....	18
3.3. Populations:.....	18
3.3.1 Source population	18
3.3.2 Study population	19
3.4. Inclusion and exclusion criteria	19
3.5 Sample size determination and sampling procedure	19
3.5.1 Sample size determination	19
3.5.2. Sampling procedure	19
3.6 Data collection:	20
3.7. Variables	20
3.8. Operational Definitions:.....	21
3.9. Data quality assurance and management	22
3.10. Data processing and analysis	22
3.11 Ethical considerations	22
3.12. Disseminations of the result.....	22
4. Results.....	23

4.1. Socio demographic and reproductive characteristics	23
4.2. Knowledge of participants about prenatal congenital anomalies screening	24
4.3 Perceptions of participants regarding prenatal congenital anomalies screening.....	26
4.4. Acceptability of prenatal congenital anomalies screening.....	29
5. Discussion.....	30
Limitations of the study:	32
Strengths of the study.....	32
Conclusion:	32
Recommendations:.....	32
References.....	33
Annexes	37
Annex 1: Consent form.....	37
Annex 2: Questionnaire	39

List of Tables

Table 1: Socio demographic and reproductive characteristics of participants, Addis Abeba, Ethiopia, 2023 GC

Table 2: Variables used to assess prenatal congenital anomalies screening knowledge of participants Addis Abeba, Ethiopia, 2023 GC 22

Table 3: Variables used to assess participants perception of prenatal congenital anomalies screening, Addis Ababa, Ethiopia, 2023 G.C.....

List of Figures

Figure 1: Participants knowledge level of prenatal congenital anomalies screening.....

Figure 2: Perceptions of participants regarding prenatal congenital anomalies screening...

Abbreviations/Acronyms

MFM	Maternal Fetal Medicine
WHO	World Health Organization
CA	Congenital Anomaly
SPHMMC	Saint Paul's Hospital Millennium Medical College
ACOG	American College of Obstetrics and Gynecology
SMFM	Society of Maternal Fetal Medicine
US	Ultrasound
CfDNA	Cell-free DNA
NT	Nuchal Translucency
ANC	Antenatal Care
NIPT	Non Invasive Prenatal Testing

1. Introduction

1.1. Background

The early stages of embryo development are a critical period which may mark vulnerability to disruption by teratogenic agents that lead to congenital anomaly. Congenital anomalies can be defined as structural or functional anomalies that occur during intrauterine life and can be identified prenatally, at birth or sometimes may only be detected later in infancy, such as hearing defect. All races, cultures, and socioeconomic groups are affected (1-4).

CAs are the major cause of new born/infant morbidity, mortality, and disability in addition to adding to the burden of the health care system. It is estimated that about 20–30% of infant deaths occur due to CAs; severe CAs occur in 3% of live and 20% of still births. Every year, an estimated 7.9 million children are born with serious birth defects of genetic or partly genetic origin. Over 1 million more infants are born with serious birth defects of post-conception origin including those that result from maternal exposure to environmental agents such as alcohol, rubella, syphilis, and iodine deficiency that can harm the developing fetus. An estimated 9 million infants, approximately 7% of all births, are born annually with defect that may kill them or results in lifelong disability. About 270,000 newborns die during the first 28 days of life every year from congenital anomalies (5-8).

Low and middle-income countries have been reported to have the highest prevalence and burden of serious birth defects. 94% of children with birth defects are born in low-income countries and 95% of those who die as a result of birth defect also born there. In addition to factors such as the socio-economic conditions of people living in low and middle income countries, a lack of knowledge and education of mothers on genetic diseases and congenital anomalies have been highlighted as major factors which contribute to the huge disparities in incidence between developing and developed countries which do not appear to have undergone much change historically till date. In most developing countries, high percentage of women above 35 years of age give birth without any available community education, medical genetic screening and diagnostic services as well as proper antenatal care (9-11).

The children who survive go on to face higher chances of physical, cognitive and social disabilities all through life which place huge financial, emotional, psychological and social burdens on their families. Research has documented that birth defects are responsible for miscarriages, pre-term deliveries and stillbirths and therefore constitute a significant drawback to the achievement of global health goals (12).

Prenatal care is one of the most widely used methods of preventive healthcare in the world and has been viewed as a strategy to improve pregnancy outcomes for more than a century. Within the ambit of prenatal care, genetic risk assessment includes surveillance of genetic disease and birth defects through prenatal screening (13). Prenatal testing refers to elective tests that are done during pregnancy to either screen for or diagnose a birth defect. Prenatal testing is designed to assess whether a patient is at increased risk of having a fetus affected by a CA with the aim of providing pregnant women and their family information to make deliberate informed choices and decisions (14). The ACOG and SMFM endorse healthcare providers caring for pregnant women to offer prenatal genetic testing to all women regardless of known risk factors. WHO also recommends all pregnant women to have at least one sonographic scan during second trimester of pregnancy (15).

Screening tests for fetal anomalies include a combination of maternal serum biochemical markers (triple/quad/penta screen) in the second trimester that includes unconjugated estriol, human chorionic gonadotropin, alpha fetoprotein, and Inhibin A. This screening test assesses for Trisomy 18, Trisomy 21, and neural tube defects. Other non-invasive screening tests for fetal aneuploidy that can be done in the late first or early second trimester include cfDNA in circulating maternal blood and fetal ultrasound to assess NT or nuchal-fold thickness (16).

Studies have shown racial and ethnic differences regarding the acceptance of prenatal testing. These differences are associated with factors such as cultural and religious beliefs and attitudes toward miscarriage, pregnancy termination and childhood disability. It might also reflect differences in society's attitude toward screening (i.e. if the screening is private or public, if it is self-paid or insurance-dependent) and in the individual's attitude (17).

In Africa prenatal diagnosis and screening for congenital defects is at the stage of infancy as the personnel and facilities are few and in most places nonexistent, where available accessibility and

affordability becomes an issue. US prenatal diagnostic technique coverage in sub-Saharan Africa is <10% where as biochemical & invasive prenatal diagnosis accounts for <5% and <2% respectively. Prenatal diagnosis has positively impacted on our knowledge of congenital anomalies that is why it is essential even in low-income countries. As there are no established screening programs in Africa, diagnosis of congenital defects is opportunistic and happens by chance. Malformation detection rates do not exceed 20% (18, 19).

1.2 Rationale of the study

Similar to developing countries, the prevalence of CAs in Ethiopia is also raising. Evidence showed that the proportion of birth defects in Ethiopia ranges from 1.14% during 2010 to 2.83% in 2014. Another studies conducted in Ethiopia showed that the prevalence of CA ranges from 1.61% to 1.99% and congenital malformation is one of the direct causes of under-five mortality (4%) in Ethiopia (20, 21).

In Ethiopia, a significant number of babies are born with CAs, but the causes of these CAs have never been studied. In fact, whether the causes are environmental or genetic factors or interactions between environmental and genetic factors are not known. In addition there are no established prenatal screening programs and preventive strategic plans to reduce or control the occurrence of these problems at the national level. Although US have been widely used in the current clinical practice, the availability of biochemical and invasive prenatal screening and diagnostic techniques is limited to only few private set ups. Very few studies regarding prenatal congenital abnormalities screening had been carried out in this part of world. In Ethiopia, specifically in the study area, there were no documented data regarding the perception and acceptance of prenatal screening for the congenital abnormalities among pregnant women and their families. The data obtained from this study is going to help us to assess the awareness and preference of women on prenatal screening methods which in turn provides evidence crucial to our obstetric practice and also helps the policy makers to develop and implement health programs aimed at prevention, early detection and management of congenital abnormalities among pregnant mothers (22).

1.3. Literature review

Major congenital malformations affect an average of 2 to 3% of all live births which constitute about 3 million fetuses and infants born yearly. ACOG & SMFM recommend offering prenatal genetic screening and diagnostic tests for all pregnant women during prenatal care. WHO has outlined a set of recommendations to address congenital anomalies and genetic disease referred to as Community Genetics. Community Genetics aims to provide services to individuals while working to reduce the incidence of congenital anomalies and genetic diseases at the population level (23).

A descriptive, exploratory study was used to investigate Hispanic women's perceptions and knowledge of prenatal testing and how it influences their uptake at Texas A & M University College of Nursing, USA 2019. Women's understanding and knowledge of prenatal testing was limited, specifically regarding its purpose, how it works, the benefits and why it was recommended by their provider. The majority of the participants (85%) found out about prenatal testing from their doctors or nurses. 70% indicated that they were unaware of genetic tests names or types. 60% of women took prenatal testing 'to be on the safe side' and accept it. Obstacles to prenatal testing mentioned are; financial barriers, healthcare providers using complex medical terms, Lack of clarity about why they should take the test and its risks for them and their babies, religious beliefs (24).

The result from retrospective cohort study conducted at Erciyes University obstetric clinic perinatology unit, Turkey done at 2015 showed; among 291 women offered prenatal screening, 143 (49.1%) opted for testing. The only demographic parameter that affects the uptake of invasive testing was location; and women who were living in rural areas had a higher rate of uptake. No statistically significant difference was detected for the uptake of test with respect to age, educational level and previous pregnancy loss (25).

A cross-sectional study including 530 pregnant women carried out at south east region of Romania during April–September 2016 revealed; The mean knowledge score was 10.9 (range 0 to 22, SD = 4.77). None of the respondents obtained the maximum score, whilst 2.9% (N= 8) had no knowledge of prenatal screening tests. More than half of the participants (57.1%) had an average level of knowledge about this tests. knowledge increased significantly; by undergoing

prenatal testing, due to a follow-up with an obstetrician, accessing private services, using teaching aids and urban location. The mean attitude score was 20.36 (range 0 to 22, SD = 3.39). More than three quarters had a positive attitude to prenatal screening, almost quarters were neutral, and only 0.7% had negative attitude. Better knowledge slightly increased the positive attitude tendency (26).

Pregnant women's attitudes towards fetal congenital anomalies screening and diagnosis were assessed by the study conducted among 1170 pregnant women who attended a routine US examination at Oslo university hospital and Akershus university hospital, Norway from august to November 2019; most participants (78.4%) thought that fetal screening and diagnostics should be offered by the public health service to all pregnant women, while 8.2% thought this should not be a public offer and 13.4% were uncertain. 52.2% thought pregnant women had to decide for herself whether she wanted to accept the offer. Of women who did not want prenatal screening; half (49.5%) thought this diagnostics would contribute to a sorting society, 33.7% that cost is expensive and 22.1% that other diseases were more important. Women with religious outlook on life most often answered no to prenatal screening while women born in a non-Nordic country and primigravidas most often answered yes (27).

A multicentre prospective cohort study carried out in Netherland revealed; of 5216 participants, 23% had the combined test and 90% had the fetal anomaly scan, with uptake rates ranging from 4% to 48% and 62% to 98% respectively. Increasing age, non-Dutch ethnicity and higher income had an independent positive impact on the uptake while protestant, multiparous and being from the eastern region had negative impact (28)

According to a descriptive cross-sectional study conducted in teaching hospital, Sri Lanka; higher proportion of the participants; 92(61%) , 88(56.7%) and 123(82%) had good knowledge on the risk factors, prenatal screening and on preventive actions related to birth defects respectively. Significant proportion (26.7%) had poor knowledge regarding birth defects. There are 143 (95.3%) of the participants interested to know more information on birth defects, 72% believed birth defects were due to evil spirits. 87.3% of pregnant mothers had positive and satisfactory attitudes towards prenatal screening of birth defects. There was a significant association between maternal level of knowledge and attitudes on birth defects $p=0.001$ (29).

Using well structured questionnaire 95 women were interviewed regarding their attitudes towards prenatal testing for a range of congenital disorder at university of California from September 2010 to May 2012; in exploring attitudes toward prenatal testing, 81% of the participants reported somewhat or strongly agreeing with the statement, “Having prenatal testing is a way to make me less anxious during my pregnancy”. In addition, 85% somewhat or strongly agreed with the statement, “Abortion should be generally available to any woman who wants one” Most participants indicated that they would opt to have a screening test for all congenital anomalies (95%–98%) and the majority also indicated that they would have amniocentesis. Inclinations regarding pregnancy termination varied much more substantially by condition (30).

A systematic review examining the factors that affect the decision-making process of parental couples regarding prenatal screening and diagnostic tests were conducted on June 2020. 46 studies were included using PubMed and PsycInfo databases. The review identifies advanced maternal age and higher educational attainment is associated with a greater use of both invasive and non-invasive prenatal testing, having other children and long-term marital relationship seems to favor prenatal testing uptake, non-Caucasian women seem to underestimate the importance and have negative attitude toward both invasive and non-invasive prenatal tests, presence of previous abortion and fertility treatment were associated with better prenatal screening uptake. In the decision-making process, women confer a great importance to the technical features of the test, in particular accuracy, safety, timing and easiness. Women choose to undergo prenatal testing in order to seek a good life for themselves and their children, in spite of possible detrimental effects on pregnancy. Higher level of knowledge is associated with less decisional conflict and decisional regret, higher levels of wellbeing and lower levels of anxiety. Studies from different countries affirm that, in general, women do not have enough knowledge to be able to make an informed decision concerning prenatal screening and diagnosis. Acceptance of prenatal screening methods among pregnant women ranges from 46 to 57% according to studies reviewed (31).

Knowledge and acceptability of prenatal diagnosis among pregnant women attending antenatal clinic in a tertiary health institution in Sokoto, Nigeria was studied using cross-sectional study between December 2016 and March, 2017; 417 women were recruited. Their ages ranged between 17 years and 45. Majority of the respondents were Hausa/Fulani (55.2%), Muslims (70%), multigravida (59.2%) and reside in the urban area (84.7%). Over 4/5 of them had some level of formal education. The general knowledge on prenatal diagnosis was poor, as up to 340 (81.5%) had little to no idea about the term prenatal diagnosis, women that should be screened and the various methods used. Only 18.5% women have good knowledge. Those group with tertiary level of education had some and good knowledge of prenatal diagnosis in about 28.8 and 6.1% respectively, compared to those with no formal education, primary and secondary level of education with a $p < 0.05$. There appears no statistical correlation between correspondent's occupation and that of their spouses with level of knowledge at $p = 0.23$ and 0.089 respectively. The acceptability of prenatal diagnosis was generally good, as those who were willing to accept when offered accounted for 353 (84.7%) while those who do not were 64 (15.3%). Of the total that will not accept, 10 (15.63%) believed was against their religion, 11 (17.19) fear the risk of abortion, 10 (15.63%) thought the result may not be reliable and 33 (51.56%) had no reason. There seems to be a correlation between the level of education and overall knowledge of prenatal diagnosis and its acceptability. However, parity and religion do not affect the correspondents' acceptability. US appear to be the most preferred method (94.05%) of prenatal diagnosis (32).

The result from a cross-sectional survey conducted on a total of 351 Egyptian women showed; 52.7% women were lacking knowledge about availability of accurate screening tests for congenital malformations prenatally. Among those who were aware of availability of the tests, only 81.33% state correctly one or more of their types and 69.28% of them knew that the majority of tests are free from any side effects. More than three quarters of women (77.5%) showed positive attitude towards prenatal screening, others were either refusing or not sure about their opinion 4.6% and 17.9% respectively. Mean age among women who had a positive attitude towards screening willing to undergo screening was significantly higher. Lower level of education, rural residency and being a house wife were associated with negative attitude (33).

Hospital based cross-sectional descriptive study carried out at Lagos university teaching hospital between February 2018 and October 2019 on 422 pregnant women; Overall, barely half of the respondents 209 (49.5%) had good knowledge scores (14-20) while 165 (39.1%) had fair knowledge scores (7-13). Respondents listed health personnel 149 (35.3%), the internet 125 (29.6%) and the media 101 (23.9%) as their major sources of knowledge of genetic diseases and congenital anomalies. Majority of the respondents (334/422, 79.1%) were willing to undergo testing. Education was found to be significantly associated with willingness to test, $p=0.03$ (34).

Patient preferences for prenatal testing and termination of pregnancy for congenital anomalies and genetic disease were studied at SPHMMC, Ethiopia. 101 participants were recruited from pregnant women awaiting their appointment in the antenatal clinic at SPHMMC. The patient survey contained questions with descriptions of 14 congenital anomalies and genetic disorders. Of the 101 surveyed patients, 89% reported wanting testing for all conditions while only 3% did not want testing for any of the inquired conditions. The only conditions for which respondents were unsure of wanting testing were those describing children with severe intellectual disability, short stature and behavioral and intellectual disability. No differences were seen for preferences for prenatal screening based on; the number of previous pregnancy, median gestational age of pregnancy and maternal age (35).

2. Objectives

2.1. General objective:

- ✓ To assess perceptions and acceptability of prenatal congenital anomalies screening among pregnant women having antenatal care follow up during July 01 to October 31 2022 G.C at a Tertiary Hospital in Addis Ababa, Ethiopia.

2.2. Specific objective:

- ✓ To determine the level of knowledge of mothers on prenatal screening of congenital anomalies
- ✓ To assess the pregnant women perceptions towards prenatal congenital anomalies screening
- ✓ To describe factors that affect acceptance of prenatal screening for congenital anomalies

3. Methodology

3.1 Study area & period:

The study was conducted in the 4 months period from July 01 2022 G.C to October 31 2022 G.C at SPHMMC, Addis Ababa, Ethiopia.

The St. Paul's hospital millennium medical college in Addis Ababa is one of the largest hospitals in Ethiopia. It was built by Emperor Haile Selassie in 1969 with the help of the German evangelical church. It aimed to serve the poor. A medical college was formed in 2007. The hospital has more than 350 beds, cases seen as annual average of 200,000. The hospital has 1200 clinical and non-clinical staff. Department of obstetrics and gynecology is one the thirteen departments. Currently it has 58 full time obstetricians and gynecologists of whom consisted of 8 fetomaternal, 5 oncology, 1 urogynecology & 6 family planning fellows. There are 110 residents in the department.

It has well established fetomaternal unit consisting of 7 fetomaternal subspecialists and 8 fellows. It provides prenatal care for about 160 mothers on each working day at regular antenatal care and high risk clinic. The department has also created strong relationship in the form of catchment health centres where by the health centres refer pregnant mothers who are beyond their capacity so as to provide a better care which has reduced the number of mothers who suffer due to lack of bed and they provide postpartum care including family planning service. Currently there are around 19 catchment health centres who work in close proximity with the department.

3.2 Study design

- ✓ Hospital based descriptive cross sectional study was used to assess the perception and acceptability of prenatal congenital anomalies screening among pregnant mothers

3.3. Populations:

3.3.1 Source population

All pregnant women who attended antenatal care services at SPHMMC were the source population

3.3.2 Study population

The study population consisted of selected/sampled members of pregnant women who attended antenatal care services at SPHMMC from July 01 to October 31 2022 G.C and who satisfied the inclusion and exclusion criteria

3.4. Inclusion and exclusion criteria

Inclusion criteria:

- ✓ All pregnant women who had antenatal care follow up from July 01 to October 31 2022G.C at SPHMMC were included in the study

Exclusion criteria:

- ✓ Women who are younger than 15 years
- ✓ Critically ill women
- ✓ Intrauterine fetal death

3.5 Sample size determination and sampling procedure

3.5.1 Sample size determination

The sample size was determined by using single population proportion formula by considering

d= Acceptable margin of error (precision of measurement) = 5%

z= 95% confidence level =1.96

p= 29% prenatal screening acceptability rate from a study conducted at Nigeria (36)

Thus, the sample size was, $n = 314$ and using the formula $N - f = No / 1 - \% \text{ lost to follow up}$. Then the final sample size was 348.

3.5.2. Sampling procedure

Systematic random sampling was employed to select the study participants. First, we estimated the number of ANC service users for previous four consecutive months which was 12000. Then we calculated the K^{th} interval and which is 34. Then, we interviewed the study participants every 34 ANC service users.

3.6 Data collection:

Data was collected by trained nurses, midwives, interns and Obgyn residents. The research assistants or staffs explained the study procedures, conducted eligibility screening and obtained informed verbal and written consent. A well structured questionnaire written in English developed based on literature search of similar studies and customized for this study was used. The questionnaire had 4 parts; the 1st part consisted of sociodemographic and clinical characteristics of the participants, the 2nd part assessed the knowledge of the participant on prenatal screening. After completing this part, mothers were given information about prenatal testing for congenital anomalies, types of tests, their importance and their possible side effects. Then they were asked to fill the 3rd and 4th part of the questionnaire which includes questions to assess their perceptions towards prenatal testing and acceptance of these tests. The items used in the questionnaire were adapted from two previous studies Rostant et al (37) and Pruksanusak et al (38) that have been validated in Australia and Thailand.

3.7. Variables

Dependent variables:

- Level of knowledge of prenatal screening
- Perceptions toward prenatal screening
- Factors affecting uptake of prenatal screening

Independent variables

- Age
- Marital status
- Religion
- Occupation
- Monthly income
- Place of residence
- Educational Status
- Gravidity
- Parity

3.8. Operational Definitions:

- ✓ **Knowledge:** Understanding of the respondents about prenatal congenital anomalies screening with the respect to the questionnaire on risk factors, pregnancy outcome, safety & different methods of prenatal screening. Knowledge was measured by a scale consisting of 15 items. The scale was based on answers of “TRUE”, “FALSE” and “Don’t Know” about these tests. An answer showing accurate knowledge received 1 point and an answer showing the lack of knowledge or “Don’t Know” was scored with 0 points. The women with a total score of equal or less than 5 were classified as having a low level of knowledge, the women with a score between 6 and 10 were classified as having an average level and the women with a score between 11 and 15 were classified as having a high level of knowledge. We have taken into account the fact that in order to make an informed choice, it is necessary to have a level of knowledge above average.
- ✓ **Perception:** Belief and feeling of respondents about prenatal congenital anomalies screening and issues related to it. Measured by standard tool of Likert Scale System. Likert items use respondents’ attitudes to a particular question or statement and responses are coded. Maximum point is 5 and given to strongly agree, minimum point is 1 and given to strongly disagree. Total score obtained for individuals, then mean score of all respondents was calculated
Score equal to or more than mean: positive attitude
Score < mean: negative attitude
- ✓ **Acceptability:** willingness to have specific methods of prenatal screening during pregnancy
- ✓ **Parity:** delivery experience of a mother after 28 completed weeks of gestation irrespective of the outcome.
- ✓ **Gravidity:** number of pregnancies irrespective of the outcome and gestational age

3.9. Data quality assurance and management

The questionnaire was designed in English language and pre-tested on 30 mothers similar to the study population (10% of the sample size) in the study hospital which were not included in the study. The finding of the pre-test was incorporated into the final instrument for the study. To maintain data quality, data collectors were trained and they were selected based on educational level, the work experience and knowledge on antenatal care and prenatal congenital anomalies screening. The collected data were reviewed and checked for omissions, legibility of handwriting, completeness and consistency by principal investigator on daily bases during data collection time. After the data were collected, it were cleared for inconsistency and completeness by using Epi-info version 7.2.5 software and further it was checked by the investigator.

3.10. Data processing and analysis

Coding of individual questionnaires was checked and data was entered into latest version of SPSS and analyzed. Descriptive analysis was used to characterize the dependent and independent variables. Bivariate and multivariate logistic regression analysis was used to determine independent variables for acceptability of prenatal congenital anomalies screening methods.

3.11. Ethical considerations

Ethical clearance was obtained from Departmental Research and Ethics Review Committee of SPMMC, Department and Institutional Review Board (IRB) of St. Paul Hospital Millennium Medical College. The study participants were informed about the study objective and written consent form was obtained prior to data collection. Every patient's identity is not to be mentioned.

3.12. Disseminations of the result

The results of the study will be presented during thesis defense and submitted to the SPHMMC department of obstetrics and gynecology. Finally, effort will be made to present the result in various workshops and for publication on relevant national and international journals.

4. Results

4.1. Socio demographic and reproductive characteristics

A total of 348 pregnant women were included in the study; complete data was obtained from 308 participants yielding a response rate of 89%. The age range of study participants were from 18 to 40 with mean age of 30.2 years. More than half of the participants were orthodox 164 (53.2%) and housewives 162(52.6%). Most of them were from urban areas (98%) and multigravidas (63.3%). The distribution of educational & marital status indicated that 51.3% of study participants were educated above high school level and 77% were married. (Table 1)

Table 1: Socio demographic and reproductive characteristics of participants, Addis Abeba, Ethiopia, 2023 GC

Characteristics		Frequency	Percentage (%)
Age (Mean, SD)		30.2, 4.2	
Religion	Orthodox	164	53.2
	Muslim	118	38.3
	Protestant	26	8.5
Residence	Urban	302	98.1
	Rural	6	1.9
Educational Status	No Formal education	6	1.9
	Elementary	144	46.8
	High school	91	29.5
	college and above	67	21.8
Occupation	House wife	162	52.6
	Merchant/self employed	95	30.8
	Government employment	48	15.6
	Others	3	1.0
Gravidity	Primigravida	86	27.9
	Multigravida	195	63.3

	Grandmultipara	27	8.8
Marital Status	Married	237	77
	Single	58	18.8
	Divorced	13	4.2

4.2. Knowledge of participants about prenatal congenital anomalies screening

Knowledge of participants regarding prenatal congenital anomalies screening were assessed by using questions like; Have you heard about any of the prenatal screening tests? Does fetus with congenital anomalies have a higher chance of abortion than normal ones? Is advancing maternal age a risk factor for having a fetus with congenital anomalies? Can we perform tests to identify pregnancies at risk of congenital malformations as early as 11-13 weeks/3 months?

Out of the 308 surveyed participants, most pregnant women 257(83.4%) were able to indicated the correct answer that advancing maternal age increases the risk of having a fetus with congenital anomalies while only 11(3.6%) have knowledge that both ultrasound and maternal blood tests are used for first trimester screening. More than 2/3rd of participants provide correct answer about the safety of prenatal congenital anomalies screening to both the mother and fetus

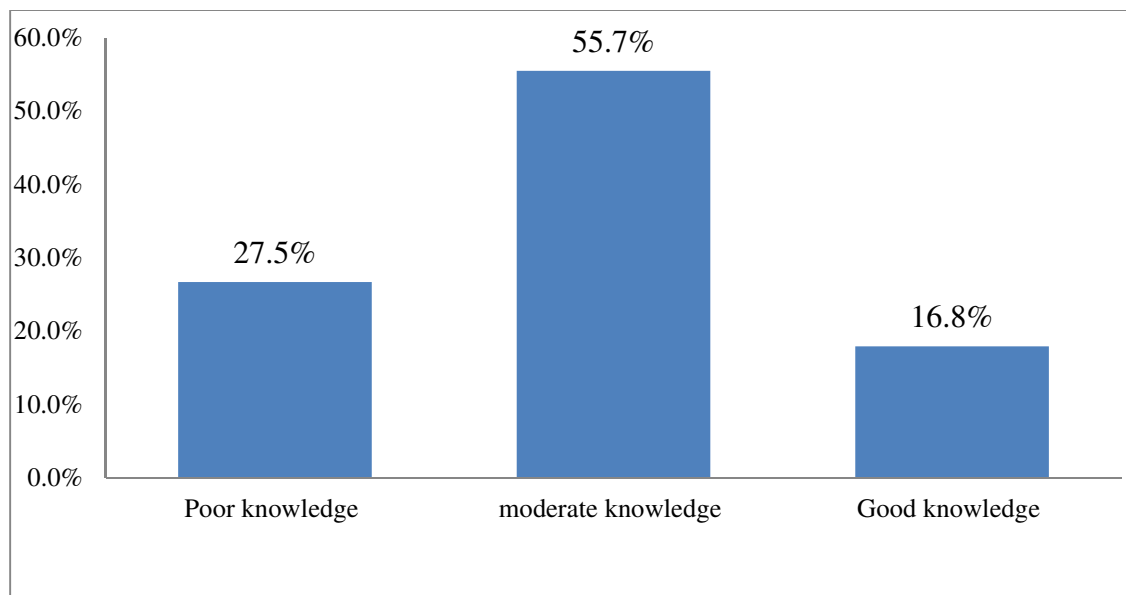
Table 2: Variables used to assess prenatal congenital anomalies screening knowledge of participants Addis Abeba, Ethiopia, 2023 GC

Questions	Response	
	Correct n (%)	Incorrect n (%)
Have you heard about any of the prenatal screening tests?	274(89%)	34(11%)
Congenital malformations are a defect that occurs at the conception of the baby	264(85.7%)	44(14.3%)
Fetuses with congenital anomalies have a higher chance of abortion than normal ones.	222(72.1%)	86(27.9%)

All pregnant women have a chance of having a fetus with congenital anomalies	51(16.6%)	257(83.4%)
Risk of having a fetus with congenital anomalies is higher with advancing maternal age	227(73.7%)	81(26.3%)
First trimester screening involves ultrasound and maternal blood tests	11(3.6%)	297(96.4%)
The prenatal screening tests only tell us that the fetus has more or less chance of having congenital anomalies	32(10.4%)	276(89.6%)
Tests can be done as early as 11-13 weeks/approximately 3 months to identify pregnancies at risk of congenital malformation	18(5.8%)	290(94.2%)
Second trimester maternal serum screening can be done at 15-20 weeks/approximately 5 months to identify pregnancies at risk of congenital anomalies	15(4.9%)	293(95.1%)
Ultrasound can detect all cases of congenital anomalies	204(66.2%)	104(33.8%)
Prenatal congenital screening methods are safe for both the mother and fetus	220(71.5%)	88(28.5%)
If the screening test shows at increased risk for congenital anomalies, further tests can be done to clarify a diagnosis	241(78%)	67(22%)
Prenatal screening should be offered to all pregnant women	265(86%)	43(14%)

Most of the participants 274(89%) have received some information about prenatal congenital anomalies screening methods. When asked about the type of screening methods they have heard about 91% answered US. The mean knowledge score of the study participants was 7.2 (range 0 to 15, SD= 3.85) with none of the respondents obtained maximum score. The classification by levels of knowledge showed that majority of the respondents 171(55.7%) had an average knowledge level, 85(27.5%) had low knowledge level whereas the remaining 52(16.8%) women had a high level of knowledge. (Figure 1)

Figure 1: Participants knowledge level of prenatal congenital anomalies screening



4.3 Perceptions of participants regarding prenatal congenital anomalies screening

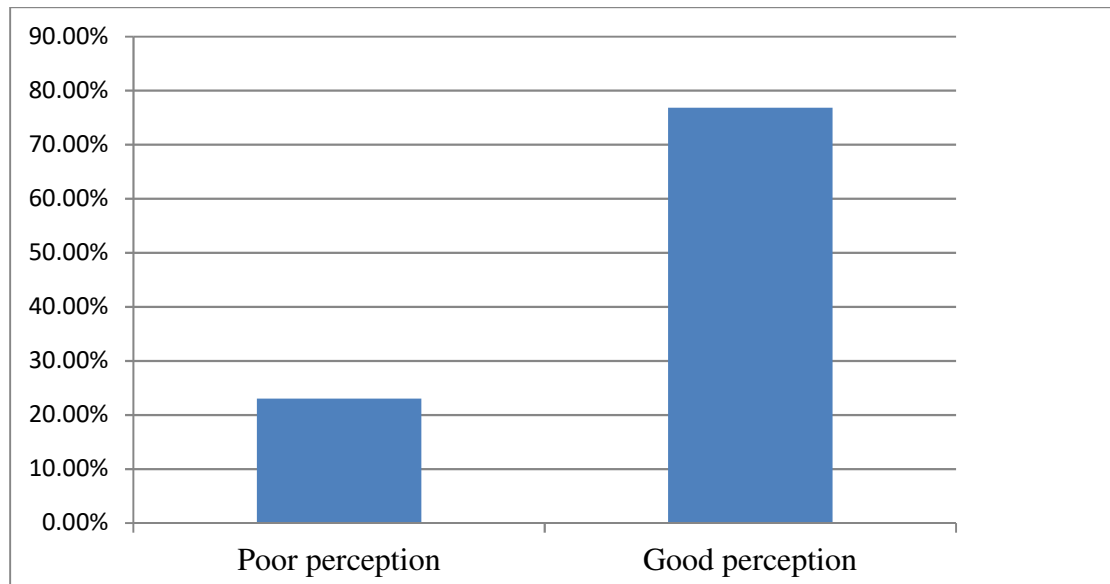
168(54.5%) of the participants strongly agreed prenatal congenital anomalies screening tests can help reduce anxiety of the pregnant women and 199(64.6%) respondents agreed that it would be very difficult for the couple if they had a child with Down Syndrome. Around 3/4th of the study participants agreed they have been provided with enough information about prenatal screening tests during pregnancy and 95(30.8%) of them disagreed that the cost of prenatal screening tests should not influence whether they are done or not. (Table 3)

Table 3: Variables used to assess participants perception of prenatal congenital anomalies screening, Addis Ababa, Ethiopia, 2023 G.C

Question	Response n (%)				
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Prenatal screening tests are valuable	3(1%)	3(1%)	6(2%)	236(76.5%)	57(18.5%)
The cost of prenatal screening tests should not influence whether they are done or not	6(1.9%)	95(30.8%)	98(31.8%)	91(29.5%)	18(5.8%)
During my pregnancy I was worried about my baby health	5(1.6%)	6(1.9%)	12(3.9%)	199(64.6%)	86(27.9%)
Prenatal screening tests help reduce anxiety during pregnancy	4(1.3%)	7(2.3%)	3(1%)	126(40.9%)	168(54.5%)
It would be very difficult for me if I had a child with Down Syndrome	10(3.2%)	6(1.9%)	55(17.9%)	199(64.6%)	38(12.3%)
I was provided with enough information about prenatal screening tests	9(2.9%)	24(7.8%)	21(6.8%)	227(73.7%)	27(8.8%)

Over all, Among 308 pregnant women participated in this study 237 (76.9%) had a good perception regarding prenatal congenital anomalies screening while 71(23.1%) had poor perception. (Figure 2)

Figure 2: Perceptions of participants regarding prenatal congenital anomalies screening



4.4. Acceptability of prenatal congenital anomalies screening

The acceptability of prenatal screening among the study participants was generally good. Among all pregnant women participated in the study, 273(88.6%) were willing to accept prenatal congenital anomalies screening when offered. The most common reasons mentioned for not accepting the prenatal screening test were; limited information is provided about these tests 15(42%), non affordability of the cost screening tests 9(26%), believed it is against their religion 6(17%), fear of abortion 3(9%) & no reason 2(6%).US appear to be the most preferred method of prenatal screening by the respondent. This accounted for 251 (92.2%) out of those that accepted to have prenatal congenital anomalies screening. Among the remaining participants; 16 preferred serum biochemical markers & NIPT, 6 of them selected amniocentesis.

Binary logistic regression was done to see the association of each independent variable with the acceptability of prenatal congenital anomalies screening. Knowledge level of participants and Gravidity were found to have significant association with acceptability of prenatal congenital anomalies screening with P values of 0.025 and 0.03 respectively. On further analysis with multivariable logistic regression to assess the strength of association; Multigravida respondents were 2.92 times more likely to accept prenatal congenital anomalies screening than Primigravida mothers (AOR=2.92,95%CI(1.61,5.30)). Participants with high level of knowledge were 1.7 times more likely to accept prenatal screening than those with low level of knowledge (AOR=1.7, 95%CI (1.11, 3.75)).

5. Discussion

This institutional based cross sectional study was conducted to assess the perceptions and acceptability of prenatal congenital anomalies screening among pregnant women having antenatal care follow up during July 01 to October 31 2022 at SPHMMC, Addis Ababa, Ethiopia. The study also assessed the knowledge level of study subjects about prenatal screening and factors associated with acceptability of prenatal tests. Currently prenatal screening tests and procedures are being incorporated in the antenatal care packages of pregnant women only in a few health institutions of Ethiopia and the available data were mostly from the studies conducted at developed nations of the world

The study showed general knowledge of the study participants was relatively good with a majority 55.7% of them had average knowledge level, 27.5% had low knowledge level and remaining 16.8% of women had a high level of knowledge. The level of knowledge among studied women is considered high compared to what was reported from studies conducted at Alexandria, Egypt with 52.7% participants lacking knowledge about availability of accurate prenatal screening tests and from Sokoto, Nigeria with 81.5% had little to no knowledge. This could be due to differences from the variable used and cut of point to classify level of knowledge and as a result of better educational status attained by respondent in our study. On the other hand, these findings are consistent with other studies conducted at Lagos, Nigeria where 49.5% had good knowledge scores & 39.1% had fair knowledge scores and from Romania 57.1% had an average level of knowledge, 30.9% low level & 12% high level. This similarity might be due to the fact that these studies were health facility based and done in the urban areas. Higher knowledge levels were reported from studies carried out in Hong Kong (78.1%) and USA (98%) which may be due to difference in the characteristics of participants and availability of prenatal screening programs.

More than half (54.5%) of the participants strongly agreed prenatal congenital anomalies screening tests can help reduce anxiety of the pregnant women. Similar finding was reported from survey carried out at university of California from September 2010 to May 2012; where 81% of the participants strongly agreed with the same statement.

Regarding participants' prenatal congenital anomalies screening perceptions, 76.9% had a good perception while 23.1% had a poor perception. This result lines with a study from Alexandria,

Egypt which revealed more than three quarters of women (77.5%) showed good perception towards prenatal screening if recommended by the physician however others were either have poor perception or not sure about their opinion (4.6% & 17.9% respectively). Similarly cross sectional study from Romania stated 78.95% respondents had a positive attitude to prenatal congenital anomalies screening, almost a quarter (20.4%) were neutral & only 0.7% had a negative attitude. The high percentage of participants with good prenatal screening perceptions can be due to; most of respondents are from urban area or may be related to maternal responsibility and the wish to fulfill it by accepting the investigations proposed.

88.6% of study participants were willing to accept prenatal congenital anomalies screening when offered. The acceptability of prenatal screening from studies carried out at Nigeria was Sokoto (84.7%) & Lagos (79.1%). Similarly the acceptability of prenatal congenital anomalies screening from other studies were good; Romania (77%), Norway (78%), Netherland (90%), California USA (95%). Study of 101 participants about patient preferences for prenatal testing & termination of pregnancy for congenital anomalies and genetic disease was conducted at SPHMMC, Ethiopia; 89% wanted testing for all 14 congenital anomalies and genetic disorders while only 3% did not want testing for any of the inquired conditions. This result was consistent with the findings of our study respondents.

The reasons mentioned for not accepting prenatal screening in our study were similar to those reported from study at Nigeria; limited information is provided about prenatal tests, non affordability of the cost screening tests, believed it is against their religion, fear of abortion & no reason. Gravidity and knowledge level were associated with acceptability of prenatal screening. A systematic review examining the factors that affect the decision making process regarding prenatal screening and diagnostic tests conducted on June 2020 identifies advanced maternal age, higher educational attainment, having other children & long-term marital relationship associated with greater prenatal testing uptake.

Limitations of the study:

This study was undertaken in a public tertiary hospital; with well established maternal fetal medicine unit and varied model of care to both high and low risks pregnancies. Adherence to recommendations in prenatal screening guidelines should be examined in other antenatal care settings and with larger samples, to examine potential individual provider and site level variations in quality of care. The limited options of prenatal congenital anomalies screening methods available in Ethiopia may have an impact on the knowledge and perceptions of pregnant women.

Strengths of the study

This is one of the few studies that assess the perceptions, knowledge and acceptability of prenatal congenital anomalies screening in these part of the world. Therefore it can be used as a basis to conduct further studies.

Conclusion:

Over all there was a mediocre level of knowledge among most study participants about prenatal congenital anomalies screening which is insufficient regarding to informed choice. Most of the women have a good perception of prenatal screening tests. The vast majority of pregnant women would accept prenatal screening tests if they were to be offered. Due to availability, affordability and safety of US, almost the entire respondent will accept it as a diagnostic tool for prenatal investigation.

Recommendations:

Congenital malformations are considered as a major cause of infant morbidity and mortality globally. The marked advances in prenatal screening for congenital malformations offer a good opportunity for early diagnosis and decision making in early management of the condition. There is an obvious need for creating more awareness on the importance of prenatal diagnosis. This can be done during ANC, through media houses and channels and during community outreach. All stakeholders should work to improve accessibility of prenatal screening to pregnant women and it should be a component of package of medical care provided to pregnant women.

References

1. Francine R, Psascale S, Aline H. Congenital anomalies: prevalence and risk factors. *Universal J Public Health*. 2014;2(2):58–63
2. De Silva J, Amarasena S, Jayaratne K, Perera B. Correlates of knowledge on birth defects and associated factors among antenatal mothers in Galle, Sri Lanka: a cross-sectional analytical study. *BMC Pregnancy Childbirth*. 2019 Jan 17;19(1): 35
3. Ajao AE, Adeoye IA. Prevalence, risk factors and outcome of congenital anomalies among neonatal admissions in OGBOMOSO, Nigeria. *BMC Pediatr*. 2019;19(1): 88
4. Page RL, Murphey C, Aras Y, Chen L-S, Loftin R. Pregnant Hispanic women's views and knowledge of prenatal genetic testing. *J Genet Couns*. 2021;30:838–848
5. Ahmed AM, el Kader SA, El Hamid A, Gaafar M. Assessment of risk factors for fetal congenital anomalies among pregnant women at Cairo University hospitals. *J Am Sci*. 2011;7(12):899–907.
6. Mohammed AR, Mohammed SA-R, AbdulFetah AMH. Congenital anomalies among children: knowledge and attitude of Egyptian and Saudi mothers. *JBiol Agric Healthc*. 2013;3(20):18–29.
7. Brent RL. Environmental causes of human congenital malformations: the pediatrician's role in dealing with these complex clinical problems caused by a multiplicity of environmental and genetic factors. *J Am Acad Pediatr*. 2004;113(4):957–68
8. Serra-Juhe C, Rodriguez-Santiago B, Cusco I, Vendrell T, Camats N, Toran N, Perez-Jurado LA. Contribution of rare copy number variants to isolated human malformations. *PLoS One*. 2012;7(10):1–8
9. Akinyanju OO, Otaigbe AI, Ibidapo MOO. Outcome of holistic care in Nigerian patients with sickle cell anaemia. *Clinical Laboratory Hematology*. 2005;27:195-199
10. Congenital Malformations Worldwide. A Report from the International Clearinghouse for Birth Defects Monitoring Systems. Amsterdam: Elsevier; 1991
11. Ojofeitimi EO, Elegbe I. Mothers' beliefs as to causation and prevention of birth defects in IleIfe, Nigeria. *J R Soc Health*. 1984 Jun;104(3): 116-8
12. Fransen MP, Essink-Bot M-L, Oenema A, Mackenbach JP, Steegers EAP, Wildschut HIJ. Ethnic differences in determinants of participation and non-

- participation in prenatal screening for Down syndrome: a theoretical framework. *Prenat Diagn.* 2007 Oct;27(10): 938-50.
13. Seven, M., Akyüz, A., Eroglu, K., Daack-Hirsch, S., & Skirton, H. (2017). Women's knowledge and use of prenatal screening tests. *Journal of Clinical Nursing*, 26(13–14), 1869–1877.
 14. Society for Maternal-Fetal Medicine (SMFM), Hughes, B. L., & GyamfiBannermann, C. (2016). Diagnosis and antenatal management of congenital cytomegalovirus infection. *American Journal of Obstetrics and Gynecology*, 214(6), B5–B11
 15. American College of Obstetricians Gynecologists Committee on Practice Bulletins (2007). ACOG Practice Bulletin No. 77: Screening for fetal chromosomal abnormalities. *Obstetrics and Gynecology*, 109, 217–227
 16. Li, L., Fu, F., Li, R., Liu, Z., & Liao, C. (2018). Prenatal diagnosis and pregnancy outcome analysis of thickened nuchal fold in the second trimester. *Medicine*, 97(46), e13334.
 17. Bryant, A. S., Norton, M. E., Nakagawa, S., Bishop, J., Pena, S., Gregorich, S., & Kupperman, M. (2015). Variation in women's understanding of prenatal testing. *Obstetrics and Gynecology*, 125, 1306–1312
 18. Adetiloye VA, Dare FO, Olayemi OA. A ten-year review encephalocele in a teaching hospital. *International Journal of Gynecology & Obstetrics*. 1993;41(3):241-249
 19. Adeleye AO, Dairo MD, Olowookere KG. Central nervous system congenital malformation in a developing country: Issues and challenges against their prevention. *Childs Nervous System*. 2010;26(7):914-924
 20. Taye M, Afework M, Fantaye W, Diro E, Worku A. Magnitude of birth defects in central and northwest Ethiopia from 2010-2014: a descriptive retrospective study. *PLoS One*. 2016; 11(10):1-12.
 21. Adane F, Seyoum G. Prevalence and associated factors of birth defects among newborns at referral hospitals in Northwest Ethiopia. *Ethiop J Health Dev*. 2018;32 (3)
 22. The Federal Democratic Republic of Ethiopia, ministry of health. National Newborn and Child Survival Strategy Document Brief Summary 2015/16-2019/20. 2015
 23. World Health Organization. Community Genetics Services: Report of a WHO Consultation on Community Genetics in Low-and Middle-Income Countries. 2011.

24. Robin L. Page, Christina Murphey, Yahyahan Aras, Lei-Shih Chen, Ryan Loftin.
Pregnant Hispanic women's views and knowledge of prenatal genetic testing J Genet
Couns. 2021;30:838–84
25. Mehmet D, Mehmet S. K. Aysecan T, Mahmut T. O. Asli S. Factors influencing the
acceptance of prenatal testing by pregnant women, Kuwait Medical Journal 2020; 52 (2):
138 – 142
26. Melania Elena Pop-Tudose, Dana Popescu-Spineni, Petru Armean and Ioan Victor Pop;
Attitude, knowledge and informed choice towards prenatal screening: a cross-sectional
study, Pop-Tudose et al. BMC Pregnancy and Childbirth (2018) 18:439
27. Sitras V, Ulriksen M, Benth JS. Pregnant women's attitudes to prenatal screening in
Norway, Tidsskr Nor Laegeforen. Norwegian. 2020 doi: 10.4045
28. K.T.G.Kanchana, P.Youhasan. Knowledge and Attitudes on Fetal Anomalies among
Pregnant Women in Teaching Hospital Mahamodara, Galle, International Journal of
Public Health Science (IJPHS) Vol. 7, No. 4, December 2018, pp. 231~235 ISSN: 2252-
8806, doi:10.11591
29. Mary E. Norton, Sanae Nakagawa, Miriam Kuppermann; Women's Attitudes Regarding
Prenatal Testing for a Range of Congenital Disorders of Varying Severity. Journal of
Clinical Medicine 2014, 3, 144-152; doi:10.3390/jcm3010144
30. Janneke T Gitsels - van der Wal, Pieterneel S Verhoeven, Judith Manniën, Linda Martin,
Hans S Reinders, Evelien Spelten, Eileen K Hutton; Factors affecting the uptake of
prenatal screening tests for congenital anomalies; a multicentre prospective cohort study,
. BMC Pregnancy and Childbirth 2014, 14:264
31. Valentina Di Mattei, Federica Ferrari, Gaia Perego, Valentina Tobia¹, Fabio Mauro,
Massimo Candiani, Decision-making factors in prenatal testing: A systematic review
Health Psychology Open January-June 2021: 1 –20
<https://doi.org/10.1177/2055102920987>
32. Yakubu Ahmed, Abubakar A. Panti, Amina G. Umar, Anas R. Funtua, Nafisa Abdullahi,
Jamila A. Garba; Knowledge and acceptability of prenatal diagnosis among pregnant
women attending antenatal clinic in a tertiary health institution in Sokoto, Nigeria. Int J
Reprod Contracept Obstet Gynecol. 2021 Oct;10(10):3678-3683

33. Rehab Elsaid Nour Eldin Youssef, Heba Taha El-Weshahi, Mona Hamdy Ashry; Knowledge, attitudes and beliefs of women in the reproductive age towards prenatal screening for congenital malformations, Alexandria-Egypt. *Int J Reprod Contracept Obstet Gynecol.* 2017 May;6(5):1707-1712
34. Chibuzor Franklin Ogamba et al. Correlates of knowledge of genetic diseases and congenital anomalies among pregnant women attending antenatal clinics in Lagos, South-West Nigeria. *Pan African Medical Journal.*2021;38(310).
10.11604/pamj.2021.38.310.26636
35. Daniel Brooks, Katharine Asta, Julie Sturza, Birhanu Kebede, Delayehu Bekele, Balkachew Nigatu, Jenny Hewison, Shane C. Quinonez; Patient Preferences for Prenatal Testing and Termination of Pregnancy for Congenital Anomalies and Genetic Diseases in Ethiopia.doi:10.1002/pd.5472
36. Adekanbi AOA, Olayemi OO, Fawole AO. The knowledge base and acceptability of prenatal diagnosis by pregnant women in Ibadan. *Afr J Reprod Health.* 2014 Mar;18(1): 127-32
37. Rostant K, Steed L, O’Leary P. Survey of the knowledge, attitudes and experiences of Western Australian women in relation to prenatal screening and diagnostic procedures. *Aust N Z J Obstet Gynaecol.* 2003;43(2):134–8.<https://doi.org/10.1046/j.0004-8666.2003.00041>
38. Pruksanusak N, Suwanrath C, Kor-Anantakul O, Prasartwanakit V, Leetanaporn R, Suntharasaj T, et al. A survey of the knowledge and attitudes of pregnant Thai women towards Down syndrome screening. *J Obstet Gynaecol Res.* 2009;35(5):876–81.<https://doi.org/10.1111/j.1447-0756.2009.01035>

Annexes

Annex 1: Consent form

Patient's information document

Dear participants!

My name is -----, I am currently a member of data collectors for a research which is conducted by Dr. Anteneh Mersha on the study intended to assess Perceptions and acceptability of prenatal congenital anomalies screening at SPHMMC which is expected to forward recommendations and suggestions on Factors associated with acceptance of prenatal congenital anomalies screening. You are invited to participate on this project. If you are willing to participate on this project, you need to understand and sign the agreement form. You do not need to write your name or to tell your name to the data collector and all your response and the results obtained will be kept confidentially by using coding system.

Procedure:

We invite you to participate in this project. If you are willing to participate in this project, you need to understand and sign the agreement form. Then after, you will be interviewed by data collectors. You do not need to write your name or to tell your name to the data collector and all your responses and the results obtained will be kept confidentially by using coding system whereby no one will have access to your response.

Risk/Discomfort:

By participating in this research project, you may feel that it has some discomfort especially on wasting time about 10 minutes. We hope you will participate in the study for the sake of the benefit of the research result. There is no risk in participating in this research project.

Benefits:

If you participate in this research project, there may not be direct benefit to you but your participation is likely help us to meet the research objective.

Incentives:

You will not be provided any incentives or payment to take part in this project.

Confidentiality

The information collected from this research project will be kept confidential. Information will be stored in a file, without your name, only code number is used. It will not be revealed to anyone except the principal investigator and it will be kept locked with key.

Right to refuse or withdraw:

You have full right to refuse from participating in this research. You can choose not to respond to some or all question if you do not want to give your response. You have also full right to withdraw from this study at any time you wish without losing any of your right.

Person to contact:

This research project will be reviewed and approved by the IRB Saint Paul's hospital millennium medical college. If you have any question you can contact any of the following individuals and you may ask any time you want.

Contact address of principal investigator: -

1. Anteneh Mersha (MD)-investigator

Tell: 0913379461 Email: Mershaanteneh81@gmail.com

2. Dilayehu Bekele (MD, Associate professor of Obstetricis and Gynecology, MFM subspecialist, MPH)-Adviser
3. Abdulfetah Abdosh (MD, Assistant professor of Obstetricis and Gynecology, MFM subspecialist)-Adviser

Annex 2: Questionnaire

Hello! My name is _____ and I am collecting data for a study on the perceptions and acceptability of prenatal congenital anomalies screening among pregnant women attending antenatal care services at SPHMMC. The interview would take about 25 minutes. Your participation in the study is very critical to know the perceptions and acceptability of prenatal congenital anomalies screening. Your participation is fully voluntary. The data you provided will be kept in highly confidential manner and none of your **personal identifiers will be on the questionnaire**.

Verbal consent obtained Yes ☐ No ☐

Date of data collection ____ / ____ / ____

(Ethiopian calendar: Day Month Year)

Part I Socio-demographic characteristics		
101	Age	_____
102	Religion	1. Orthodox 4. Catholic 2. Muslim 5. Others _____ 3. Protestant
103	Parity	1. Primigravida 2. Multigravida 3. Grandmultipara
104	Place of residence	1. Urban 2. Rural
105	Woman's educational status	1. No formal education 2. Elementary 3. Grade 9-12 4. University or higher
106	Profession	1. Government employee 2. Merchant/Self employed 3. Housewife 4. Farmer 5. Others _____
107	Monthly Income	
108	Marital Status	1. Married 2. Single 3. Divorced
109	Who follow up your pregnancy?	1. Midwives 2. Obstetrician and gynaecologist 3. General practitioner 2. Others

Part II Knowledge of women about prenatal congenital anomalies screening		
201	Have you heard about any of the prenatal screening tests?	1. Yes 2. No
202	If your answer for question 201 is Yes, which of the following tests have you heard?	1. Ultrasound and blood test before 11-13weeks/aprox. 3 month of pregnancy 2. Second trimester maternal serum screening (MSS) 3. Second trimester morphology ultrasound 4. Non-Invasive (Cell free DNA) Testing
203	Congenital malformations are a defect that occurs at the conception of the baby	1. True 2. False 3. Don't Know
204	Fetuses with congenital anomalies have a higher chance of abortion than normal ones.	1. True 2. False 3. Don't Know
205	All pregnant women have a chance of having a fetus with congenital anomalies	1. True 2. False 3. Don't Know
206	Risk of having a fetus with congenital anomalies is higher with advancing maternal age	1. True 2. False 3. Don't Know
207	First trimester screening involves ultrasound and maternal blood tests	1. True 2. False 3. Don't Know
208	The prenatal screening tests only tell us that the fetus has more or less chance of having congenital anomalies	1. True 2. False 3. Don't Know
209	Tests can be done as early as 11-13 weeks/approximately 3 months to	1. True 2. False

	identify pregnancies at risk of congenital malformations	3. Don't Know
210	Second trimester maternal serum screening can be done at 15-20 weeks/approximately 5 months to identify pregnancies at risk of congenital anomalies	1. True 2. False 3. Don't Know
211	Ultrasound can detect all cases of congenital anomalies	1. True 2. False 3. Don't Know
212	If a positive or at increased risk result is given this mean the fetus definitely has congenital malformations	1. True 2. False 3. Don't Know
213	Prenatal congenital screening methods are safe for both the mother and fetus	1. True 2. False 3. Don't Know
214	If the screening test shows at increased risk for congenital anomalies, further tests can be done to clarify a diagnosis	1. True 2. False 3. Don't Know
215	Prenatal screening should be offered to all pregnant women	1. True 2. False 3. Don't Know

Part III Perceptions of women towards prenatal congenital anomalies screening

301	Prenatal screening tests are valuable	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
302	Prenatal screening tests benefit all pregnant women	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
303	The cost of prenatal screening tests should not influence whether they are done or not	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
304	If I were to have another pregnancy I would have prenatal screening tests	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
305	During my pregnancy I was worried about my baby health	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
306	Prenatal screening tests help reduce anxiety during pregnancy	1. Strongly disagree 2. Disagree 3. Neutral

		4. Agree 5. Strongly agree
307	It would be very difficult for me if I had a child with Down Syndrome	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
308	I was provided with enough information about prenatal screening tests	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
309	My doctor/midwife knew enough about the tests that were available	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree
310	Having a fetus with congenital malformations has serious impact on the mother	1. Strongly disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly agree

Part IV Acceptability of prenatal congenital anomalies screening

401	Do you accept if you are offered prenatal screening for congenital anomalies?	1. Yes 2. No
402	If the answer for question 401 is Yes ; Which of the following prenatal screening tests do you prefer?	1. Ultrasound 2. Serum biochemical markers 3. Non-Invasive prenatal testing 4. Amniocentesis 5. Chorionic villous sampling
403	If the answer for question 401 is No ; What is the reason for not accepting prenatal screening test?	1. Limited information is provided about these tests 2. Non affordability of the cost of conducting the test 3. Non-availability of prenatal screen centers 4. It is against their religion 5. Fear of the risk of abortion 6. Tests may not be safe 7. Tests result may not be reliable 8. No reason