Screening Practice of major congenital malformation and associated factors among health care professionals at three teaching hospitals in Addis Ababa, Ethiopia

Eden Belay (MD, pediatrics Surgery Resident)

Advisor: Dr. Fisseha Temesgen (MD, consultant General and Pediatrics Surgeon)

October 2023,

Addis Ababa, Ethiopia

Screening Practice of major congenital malformation and associated factors among health care professionals at three teaching hospitals in Addis Ababa, Ethiopia

Eden Belay (MD, pediatrics Surgery Resident)

Advisor: Dr. Fisseha Temesgen (MD, consultant General and Pediatrics Surgeon)

A research report submitted to the department of Surgery, Addis Ababa University College of Health sciences in partial fulfillment of the requirement for specialty certificate in Pediatrics Surgery.

October 2023,

Addis Ababa, Ethiopia

Acknowledgment

First, I thank almighty God for giving me the time and energy to take this endeavor. Next my gratitude goes to Addis Ababa University College of health sciences and the department of surgery for arranging the opportunity of a research program. I would also like to express my appreciation and respect to my advisor Dr. Fisseha Temesgen for his guidance. I am also grateful for Dr. Abraham, Dr. Netsanet and Dr. Adu for their help in the data collection. Finally I would like to thank Dr. Tigist who has helped me throughout my work.

Eden Belay (MD, Pediatrics surgery Resident)

Abstract

Background: Congenital anomalies are structural, functional, and metabolic abnormalities that occur during the formation of organs and appear at birth or later in life. Newborn screening an activity aimed at early identification of newborns affected with certain genetic and/or metabolic conditions. Early diagnosis and treatment of these conditions reduce morbidity and mortality.

Objectives: To evaluate the health care professionals' practice on screening of major congenital anomalies among newborn infants at three tertiary government hospitals in Addis Ababa, Ethiopia.

Methods and Materials: Cross-sectional study was conducted from November 2022 to September 2023 on 163 healthcare professionals working at labor and delivery ward and neonatal intensive care units of Tikur Anbessa Specialized hospital, St. Paul Hospital Millennium Medical College and Menilik II comprehensive specialized hospital on Knowledge, attitude and practice of screening of congenital malformations. Analysis was conducted using Statistical Package for Social Sciences (SPSS) version 26 and descriptive statistics were reported as frequency, median, mean ± standard deviation (SD). Binary logistic regression analysis was done. Tests with P-Value < 0.05 were considered statistically significant.

Results: The Average score of knowledge, Attitude and practice were 6.52 (±1.48), 3.62 (±.304) and 4.63(±1.79), respectively. Only 45(27.6%) of the health care professionals had adequate overall knowledge, 113(69.3%) have favorable attitude and 18(11%) of the respondents have good practice.

Conclusion: majority of HCPs have moderate to adequate knowledge (74.2%), favorable attitude (69.3%) and poor practice (89%) regarding screening of congenital malformations. Knowledge of congenital malformations had shown a positive significant association with screening practice.

Keywords: congenital malformation, practice, knowledge, attitude

Contents

LIST OF TABLES AND FIGURE

ACRONYMS AND ABBREVIATIONS

ARM: anorectal malformation

A.A: Addis Ababa

AAU: Addis Ababa University

AAHB: Addis Ababa health Bureau

CA: Congenital Anomalies

CDC: United States Centers for Disease Control and Prevention

CNS: central nervous system

EA/TEF: esophageal atresia/ tracheoesophageal fistula

HCP: health care professional

LMIC: low and middle income countries

NICU: neonatal intensive care unit

SPHMMC: Saint Paul hospital millennium medical college

WHO: world health organization

Introduction

1.1 Background

Congenital anomalies are structural, functional, and metabolic abnormalities that arise during the formation of organs and appear at birth or are discovered later in life. (‘WHO’, no date; Handbook, Selected and Anomalies, no date; Organization;, 2014; WHO, CDC and ICBDSR, 2020)

Although there is no single definite cause for 50% of all congenital disabilities, common causes include genetic mutation, environmental factors, and a variety of other risk factors(‘WHO’, no date). These include specific single gene mutations, chromosome imbalances, and the action of environmental factors like intrauterine infections, maternal infections; teratogenic agents like exposure to radiation, certain pollutants; maternal nutritional deficiencies, maternal illness like diabetes or certain drugs like alcohol and phenytoin(‘WHO’, no date; WHO, CDC and ICBDSR, 2020).

Congenital malformations are categorized into two(Organization;, 2014): major and minor malformations. Major malformations are structural changes that have serious medical, surgical, social, or cosmetic consequences and necessitate medical intervention. Major anomalies are responsible for the majority of congenital anomaly-related mortality, morbidity, and disability. They include Anomalies of the nervous system, cardiovascular system and digestive system; Orofacial clefts; Abdominal wall defects, Chromosomal anomalies and Others (limb anomalies, renal anomalies, and skeletal dysplasias and syndromes) (5,6).

Minor anomalies are more frequently encountered structural changes that pose little or no significant health risk and social or cosmetic impact; however, they can be useful to help clinicians recognize syndromes and chromosome abnormalities. (7,8) Examples of minor anomalies include Accessory tragus, Natal teeth, Tongue-tie, Single umbilical artery, Umbilical hernia ,Overlapping digits single palmar crease and clinodactyly and anterior anus (8,2).

Newborn screening is a public health activity aimed at early identification of newborns affected with certain genetic and/or metabolic conditions. Early diagnosis and treatment of these conditions has been shown in many cases to reduce morbidity, premature death, mental

retardation and other developmental disabilities. (2,9) Screening for congenital anomalies can be conducted during the 3 periods. Preconception and Peri- conceptional health care comprises standard reproductive health procedures as well as medical genetic testing and counseling (2,4).

Neonatal screening: Studies have suggested that the initial newborn examination must be conducted by a qualified professional within 24hours of the life since the majority of anatomic malformations in resource limited settings are detectable at birth and may necessitate urgent intervention to ameliorate adverse outcomes. (10,11). In addition, screening with examination is invaluable to make appropriate and timely referrals for further tests or treatment and to provide reassurance to the parents (Penchaszadeh, 2002) A second examination is performed at 6-8 weeks of age to identify abnormalities that develop or become apparent later.

A complete newborn examination entails complete history of the family and the new born as well as Pregnancy details, risk factors for neonatal infection and congenital malformation. Pertinent Newborn history includes Feeding pattern, change in the pattern of Urination, Passage of meconium and Parental concerns if there is any. (1,11,12)

Complete physical examination along is also necessary along with laboratory tests which are dictated by the finding from clinical examination. (1.4) Newborns should be screened for Hearing, Sight, major malformations on each system like neurologic, cardiac, gastrointestinal, genital and musculoskeletal and for certain metabolic, Hematologic and endocrine disorders. (1,3)

1.2 Statement of the Problem

Congenital anomalies affect 3% of live births, 20% of stillbirths and are estimated to cause 20 to 30 percent of infant mortalities globally. (Taye *et al.*, 2018) According to WHO, around 7.9 million infants are born with potentially fatal congenital abnormalities every year and 240 000 newborns die within the first 28 days of birth due to their impairments. An additional 170 000 children between the ages of 1 month and 5 years die each year as a result of congenital abnormalities. In addition to this, they can cause long-term disabilities, which have a profound impact on patients, families, healthcare systems, and societies.(1, 14)

Currently birth defects account for an increasing share of neonatal and under-5 mortality as other causes of neonatal and under-5 mortality like infectious causes continue to drop. (1,2)

The overall prevalence of congenital anomalies in developing countries is comparable to that observed in developed countries. However, the health impact of birth defects is higher because of a lack of adequate services for the care of affected infants and a higher rate of exposures to infections and malnutrition(Penchaszadeh, 2002). However recent WHO report states that nine of ten children born with a major birth defect are in low- and middle-income countries. (1,2). A more common exposure to environmental teratogens such as infectious agents and environmental chemicals may cause higher rates of malformations in developing countries compared to developed ones (Taye *et al.*, 2018)(Mekonnen *et al.*, 2020) What is more, some preventable anomalies with certain preventive measures such as immunization, sufficient folic acid or iodine intake through supplements or food fortification of staples, and adequate care before and throughout pregnancy might not be adequately addressed in developing countries. Reduced access to health care and screening is also a contributing factor for higher incidence of malformations in low income countries. ('WHO', no date)(WHO, CDC and ICBDSR, 2020)(*Birth Defects*, 2012) Due to deficiencies in diagnostic capabilities and a lack of reliable medical records and health statistics, the birth prevalence of congenital anomalies in the developing world is underestimated. (Penchaszadeh, 2002)

The prevalence of birth defects was 66.2/10,000 births according to a hospital-based surveillance project carried out in Uganda. (Mumpe-Mwanja *et al.*, 2019). In Ethiopia, the current understanding of the prevalence of congenital malformations and the etiologies of these defects is quite limited. One study has shown that there is a high incidence of congenital anomaly affecting 199 out of every 10,000 hospitalized children in central and northwest Ethiopia (Taye *et al.*, 2018) (Mekonnen *et al.*, 2020)

1.3 Significance of the study

Even though a thorough newborn examination may reliably identify the majority of major congenital malformation at birth, a sizable proportion of patients continue to present later in infancy or childhood, which complicates diagnosis and treatment and is associated with a poor prognosis.

The problem is more pronounced in resource-limited settings, where home deliveries, illiteracy, lack of awareness, and poverty are prevalent, however, lack of standardized tool for newborn examination, screening protocol and proper documentation further complicates the problem. Since previous Studies on similar topic are lacking in our country this study assesses the practice of health care providers who are directly involved in newborn care regarding examination and screening of newborns for the common major anatomic malformations. In addition it tries to identify the practice gap and forward recommendations for health facilities and other concerned authorities to review and improve the quality of newborn care provision and use standardized newborn screening protocols. Additionally, it will inspire future researchers to carry out further research in this field, and this study will serve as a baseline study.

2. Literature review

In many western nations, newborn infants are routinely screened for certain congenital abnormalities, but this practice is almost nonexistent or, at best, rudimentary in many developing countries. In many low-middle income countries (LMIC), where guidelines for newborn screening are relatively unavailable; delay in recognition, delayed presentation to the hospital, delivery outside recognized obstetric care settings and socioeconomic challenges contribute to a higher rate of neonatal mortality(Lawal, Yusuf and Fatiregun, 2015). Parental responsibility for identifying newborns with birth abnormalities is disproportionately increased in the absence of precise recommendations for newborn screening. (Lawal, Yusuf and Fatiregun, 2015)

Regarding the timing of newborn examination; it was recommended by several studies and the English National Board (ENB N96) that infants be inspected within 24 hours of birth, again at hospital release, or at 10 days of age.(Rogers *et al.*, 2015)

A five years retrospective study done by Mekonnen et.al in Ethiopia found only 0.35%(543) birth defect report at 37 delivery service providing institutions in Addis Ababa which is a clear underestimate of the problem. The contributing factors for the underestimation of birth defects in these regions were: constrained diagnostic capability, poor health related statistics, lack of birth defect surveillance and registries and reliance on hospital-based rather than population-based studies.(Eshete *et al.*, 2021)

Numerous researches conducted in low- and middle-income countries (LMIC) countries have shown that greater newborn morbidity and mortality is related to delayed diagnosis and referral. It has been demonstrated that a delayed diagnosis of esophageal atresia with or without tracheoesophageal fistula (EA/ TEF) represents a separate negative prognostic risk in LMIC. There is room for improvement given that EA mortality in LMIC is still estimated to vary from 30 to 80% and delay in diagnosis and/or referral of individuals with EA are some of the challenges mentioned in LMIC documented literature. Since aspiration pneumonia has been linked to babies who were referred from outside hospitals, contrast studies, and/or trial of oral feeding, raising pediatricians' knowledge of EA, cautioning them against performing contrast studies, and developing early referral guidelines (Alslaim *et al.*, 2020).

A Cross-Sectional Study, conducted in Pakistan showed majority of patients with ARM (52.7% Vs 47.3 %) were diagnosed by a non-medical person despite the babies being delivered mostly at the hospital, and the median age at ARM identification is 48 hours reflecting the need for meticulous neonatal examination(Perveen *et al.*, 2022). Similar to this, a research done in Malawi found that the median age of presentation was 24 days, and only 8 (17.39%) of 46 patients with ARM appeared during the first week after birth. (Beudeker *et al.*, 2013)In contrast, Statovci S. et al. examined 76 patients with ARM; of these, 18 (23.68%) patients had neonatal presentations. (Statovci *et al.*, 2015)

Another study, prospective observational one done India on Anorectal malformations comparing the timing of diagnosis with the outcome has found that nearly half (48%) of all neonates presenting with ARM had a delayed diagnosis (> 48 h after birth(Reddy *et al.*, 2021)which was found to be higher compared to reports from developed countries like by Lindley et al. (42%), Wilson et al. (32%)(Wilson *et al.*, 2010), and Turowski et al. (21.2%) (Turowski, Dingemann and Gillick, 2010)

According to the same study, delayed diagnosis which has been defined differently by different authors and includes presentation after 24 hours, 48 hours, or 7 days after delivery, after hospital discharge, or after 3 months in females with low ARM was linked to higher morbidity and mortality. (Reddy *et al.*, 2098)

A thorough clinical examination of the perineum of all babies within 24 hours of birth by a suitably qualified clinician or health worker, paying particular attention to the presence, position, patency, and appearance of an anal orifice, is the best way to quickly diagnose ARM(Reddy *et al.*, 2098)

A prospective randomized controlled trial was done in UK in 2004 comparing routine newborn examination in a healthy baby between physicians and Midwives and showed that there is no statistical difference between physicians and midwife examination in terms of appropriate referral but midwives were found to have carried out the assessment more appropriately and maternal satisfaction was superior in the midwife group. (Bloomfield and Rogers, 2003). So the study concluded that increasing the participation of midwives in newborn assessment is likely to lead to better examination quality, increased parental satisfaction, and cost savings. (Rogers *et al.*, 2015)

Several studies have identified that there is a knowledge and practice gap among healthcare professionals regarding newborn screening for various abnormalities. Around 50% of family physicians in Kingdom of Saudi Arabia did not screen any child for hearing loss during their last five years of experience.(Alqudah *et al.*, 2021) 54.45% nurses in a Neurosurgery Department in egypt had incompetent total score of practice regarding Congenital anomalies of CNS(A.H., S.S. and H.R, 2022)

Conceptual framework

The relationship between patient-related factors and factors affecting the healthcare practitioner is demonstrated below.

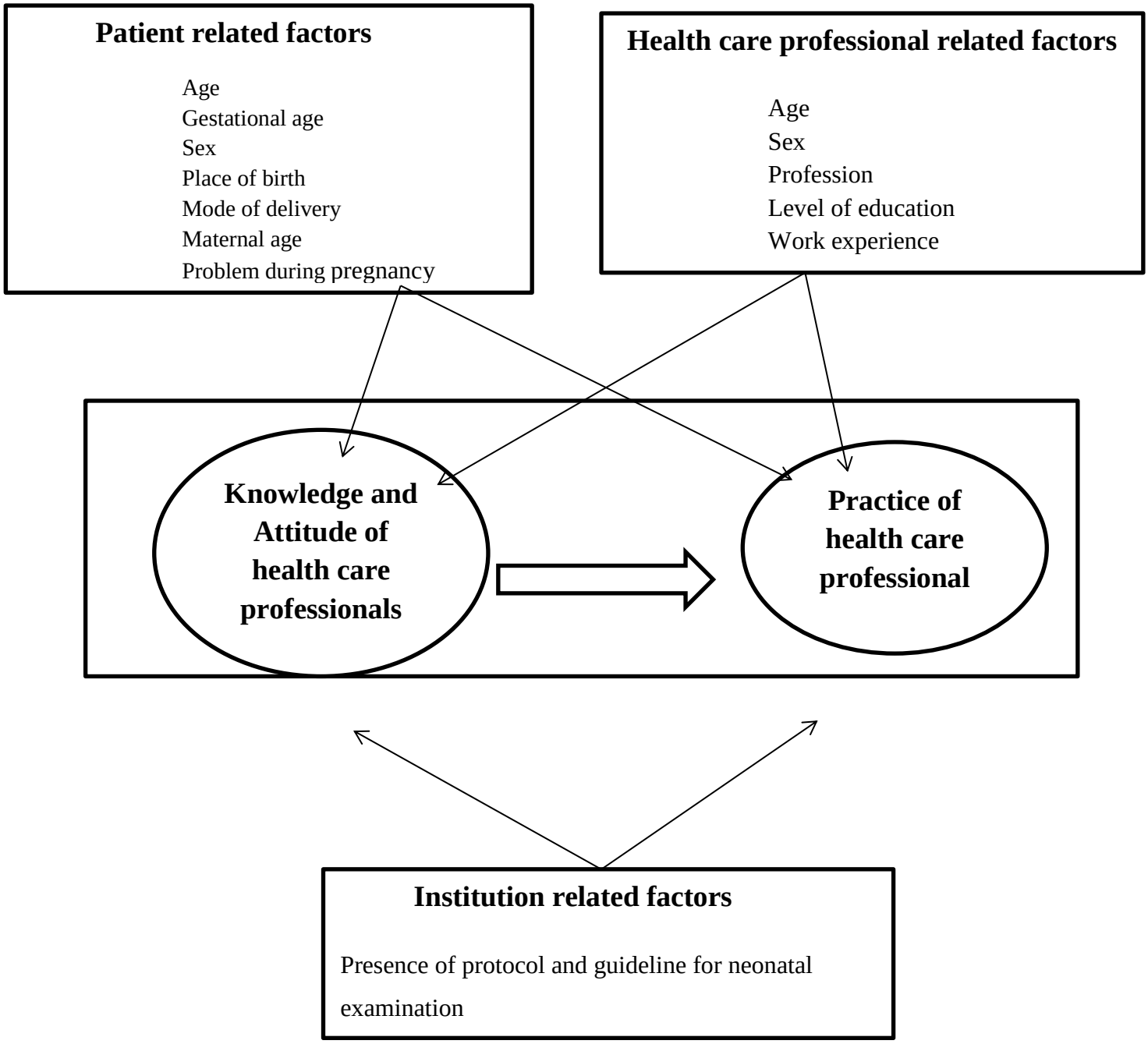

Figure 1: conceptual frame work (4)(29)(30)

3. Objectives of the study

3.1 General objective

- To evaluate the health care professionals' practice on screening of major congenital anomalies among newborn infants.

3.2 Specific objectives

- To determine health care professionals' level of practice on screening of congenital malformations among newborn infants
- To identify factors associated with health care professionals' level of practice on screening of congenital malformations among newborn infants

4. Methodology

4.1 Study area and period

This study is a multicenter study conducted in the hospital's that provide neonatal intensive care and pediatric surgical service providing centers in Addis Ababa, the Capital City of Ethiopia. Addis Ababa was deliberately chosen since it has more hospitals that offer pediatric surgical care. The study was conducted from November 2022 to September 2023.

The city has 16 government hospitals. Seven of the hospitals have pediatric surgical service and three of them were selected purposefully based on the load of pediatrics surgical service to be included in this study. Tikur Anbessa Specialized Hospital, St. Paul's Hospital Millennium Medical College, and Menilik II Hospital were the hospitals selected to be included in the study.

Tikur Anbessa Specialized Hospital was established in 1966 and located in Lideta Sub City. It is the largest referral hospital in country. TASH provides several tertiary level health care services, including obstetrics, Neonatal and pediatrics surgical services.

St. Paul's Hospital Millennium Medical College: It is situated in the Gulelle Sub-city and was established in 1969. It is Ethiopia's second-largest referral hospital. It has several departments where the specialty services are offered. And also has neonatal intensive care unit which has

been functional for over 14 years.(Alifia, 2021) It also started pediatrics surgical service about 6 years ago. Currently the numbers of nursing staffs in this NICU and delivery room are about 115.

Menilik II Referral Hospital: It is the first hospital in Ethiopia which was established in 1909 in collaboration with Russian health personnel. Currently it provides specialty services including neonatal intensive care unit.

4.2 Study design

Hospital based Analytic Cross-Sectional Study was conducted. Simple random sampling technique was used to select the study participants from health care providers involved in neonatal care at the study areas.

4.3 Population

4.3.1 Source population

All healthcare professionals involved in the care of newborns in the aforementioned medical facilities in the OB/GYN and Pediatrics & Child Health departments during the study period.

4.3.2 Study population

All selected healthcare professionals involved in the care of newborns in the aforementioned medical facilities in the labor ward and Neonatal ICU during the study period and who fulfill the eligibility criteria.

4.4 Inclusion criteria and Exclusion Criteria

All health care professionals who are directly involved newborn care services at the selected health facilities during the study period were included

Health care professionals who are assigned to this service area but are not around during the study period were excluded.

4.5 Sample size

The required sample size for is calculated using single population proportion formula with the following assumptions.

$$n = \frac{(Z\alpha/2)^2 \, p \, (1-p)}{d^2}$$

Where,

n= sample size to be calculated

P = is the (estimated) proportion of the population which is taken to be 50% due to lack of previous comparable studies

CI=95%

Z= 1.96 at 5% level of significance

d= margin of error taken to be degree of freedom of 0.05

With the above the calculated sample size will be

n= 384

Since the total population (health care professionals working in the delivery room and neonatal intensive care unit of the selected Hospitals is 242 n, which is less than 10,000, the adjustment formula is used:

$$nf = \frac{ni}{1 + \frac{ni}{N}}$$

Where nf=final sample size

ni=initial sample size

N= total population

The sample size after adjustment will be 148.46≈148

After considering a 10% non-response rate, the final sample size is 163

The number of study units to be sampled from each hospital is determined using proportional to site allocation formula from the selected four hospitals:

Where: ni =number of HCP in each of the selected hospitals

nf = the final sample size

N= the total number of HCP working in the selected hospitals.

- Tikur Anbessa Specialized Hospital = 163*80/242 = 53.88≈ 54
- Saint Paul's Hospital Millennium Medical College = 163*115/242 = 77.45≈ 77
- Menilik II hospital=163*47/242 =31.65≈32

4.6 Sampling technique

A simple random sampling technique was used to select study participants.

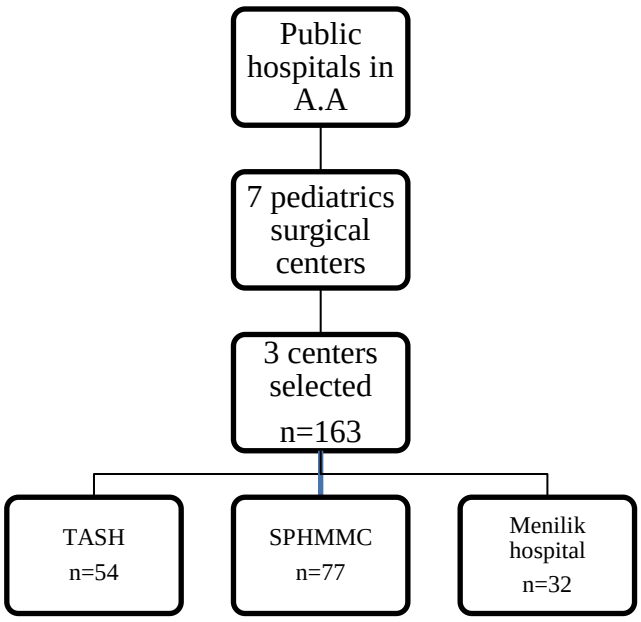

Figure 2: Sampling and procedure: The sample was drawn from health care professionals involved in newborn care and those who practice at pediatrics surgical centers

4.7 Data collection tools and techniques

Data was collected through a structured self-administered questionnaire distributed through hard copy and google form and direct observation by the principal investigator and trained data collectors for assessment of screening practice of HCPs. Data was pretested on 5% of randomly selected health care professionals at the 3 hospitals and the necessary amendment on the data collection tool was made.

4.8 Study variables

- **Outcome variables**
  - ✓ Practice
- **Exposure variables**
  - ✓ Patient related factors
    - Sex
    - Gestational age
    - Place of birth
    - Mode of delivery

- Maternal age
- Problem during pregnancy

✓ Health care provider related factors

- Age
- Sex
- Profession
- Level of education
- Work experience
- Acquisition of on job training
- Knowledge
- Attitude

✓ Institution related factors

- Presence of protocol and guideline
- Presence of standardized checklist for neonatal examination

4.9 Operational definition

Neonate/ newborn: an infant under 28 days of age

Major Congenital malformation: structural changes that have serious medical, surgical, social, or cosmetic consequences and need surgical correction (3,4)

- ✓ Spina bifida
- ✓ Cleft lip and palate
- ✓ Intestinal atresia
- ✓ Anorectal malformation
- ✓ Tracheoesophageal fistula
- ✓ Abdominal wall defects
- ✓ Hypospadia
- ✓ Inguinal hernia
- ✓ Undescended testes
- ✓ DDH, club foot
- ✓ Jaundice: Biliary atresia

Newborn surveillance/examination: public health activity aimed at early identification of newborns affected with certain anatomic, genetic and/or metabolic conditions

Knowledge: Knowledge of major congenital abnormalities among medical professionals, including their definition, risk factors, causes, types, symptoms, complications, potential treatments, and prognosis of the condition. Questions were formulated based on WHO and CDC guidelines. The incorrect response will have zero points, while the correct response will have one point. These scores will be summed up and translated to a percent score, and then divided into three categories according to modified Bloom's cutoff values:.

Adequate knowledge: when score is ≥80%

Moderate knowledge: when score is 60-80%

Inadequate knowledge: when score is < 60%

Attitude: The attitude of Health care professionals' regarding the care of infants with congenital anomalies. Questions were formulated based on WHO and CDC guidelines and their responses were measured by Likert scale. The average score for the part will be calculated by adding up the item scores and dividing the result by the number of items. These results will be translated to a percent score, which will then be categorized as follows according to modified Bloom's cutoff values:

Favorable attitude: when score is ≥ 80%.

Unfavorable attitude: when score is <80%

Practice questions were adopted from newborn Screening tool created by WHO, UNICEF, CDC and the guidelines used at national and institutional level as well as our expert's clinical practice to evaluate the HCP's practices regarding to care of infants who have congenital anomalies, including assessment, preoperative care, and postoperative care, as well as, explains rationale and guidelines for caring of infants, educates parents about caring procedure, and demonstrates caring to parents. The step that is completed correctly received one mark, whereas the step that is skipped or completed erroneously will receive zero mark. The results were added up, translated to a percent score, and then divided into two levels according to modified Bloom's cutoff value as follows:

Good Practice: when the score is ≥80%

Poor practice: when the score is <80%

4.10 Data management and Data analysis

Before entering the data, the study population's records were checked for completeness and cleaned for incorrect entries and outliers. The IBM SPSS statistics version 26 for Microsoft Windows was used to analyze the data. Mean ± SD and median with interquartile range were calculated for continuous variables. Frequency and percentage were calculated for categorical variables. Binary logistic regression model was used to assess the association between independent variables and practice of health care professionals an outcome variable.

Univariate analysis was performed to calculate an unadjusted odds ratio (OR) and to screen out potentially significant independent variables with *p*-value <0.25 which will be included in a multivariable binary logistic regression model. A p-value <0.05 with 95% CI was considered statistically significant to identify factors associated with screening practice of congenital anomalies. Hosmer-Lemeshow goodness-of-fit test was used to assess the fitness of the model. The results are presented by use of graphs, charts, tables and texts.

4.11 Ethical consideration

Ethical approval was obtained from a research review committee of Addis Ababa University. IRB clearance will be obtained from the SPHMMC and AARHB. Written informed consent was obtained from each study participant. All information obtained from each study participant was kept confidential throughout the study.

5. Results

5.1 Sociodemographic characteristics of Participants

The study comprised of a total of one hundred sixty three (163) healthcare professionals in three hospitals (Tikur Anbessa Specialized Hospital, St. Paul's Hospital Millennium Medical College and Menilik II comprehensive specialized Hospital participated making a response rate of 100%. Among the total participant 55.2 % (90) were male. Majority (71.16%) was aged below 30 years and the median age of the participants was 28 years with interquartile range of 26-30years.

Majority of the participants were residents (46%) and have an average work experience of 3.26 years (SD± 1.98). significant number, 125(76.7%) of the participants had a less than 5-yearwork experience. Only 9 (5.5%) of the HCPs attended an on- job training in newborn evaluation for congenital malformations, and all of them indicated that the training was beneficial in their clinical practice.

The socio-demographic characteristic of the study population is shown in table -1

Table 1: Socio-demographic characteristics of HCPs

Characteristic		**Number (%)**
Age group (years)	<30	115(70.6)
	≥30	48(29.4)
Sex	Male	90(55.2)
	Female	73(44.8)
Profession	Clinical Nurse	16(9.8)
	Midwife	19(11.7)
	General Practitioner	15(9.2)
	OBGYN resident	20(12.3)
	Pediatrics resident	54(32.5)
	Obstetrician and gynecologist	5(3.1)
	Pediatrician	8(4.9)
	Others*	26(16)
Level of education	Diploma	7(4.3)
	BSc Degree	30(18.4)
	MD	38(23.3)
	Resident	75(46)
	Specialist	12(7.4)
	Sub-Specialist	1(0.6)
Work experience(years)	<5	125(76.7)
	≥5	38(23.3)
On-job Training on evaluation	No	154(94.5)

of congenital anomalies	Yes	9(5.5)
Others*-Interns		

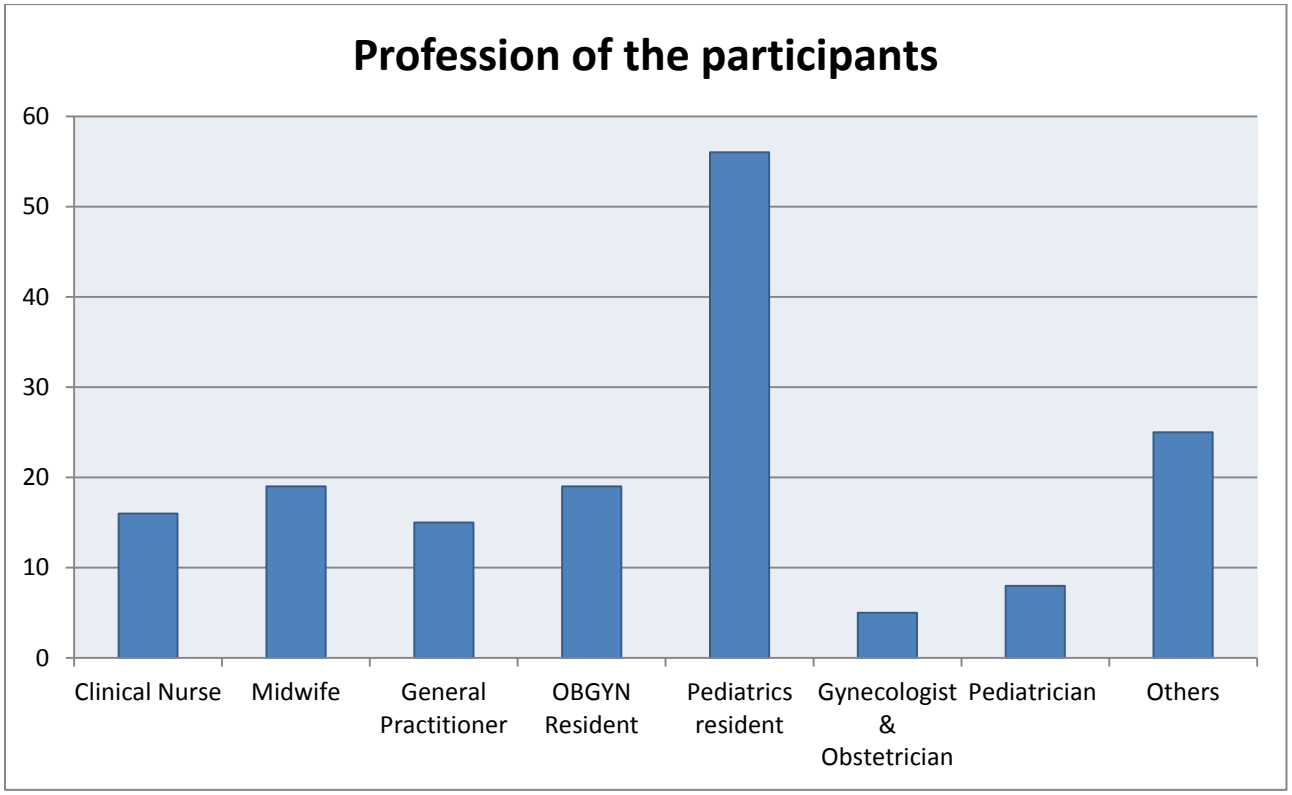

Figure 3 Profession of participants

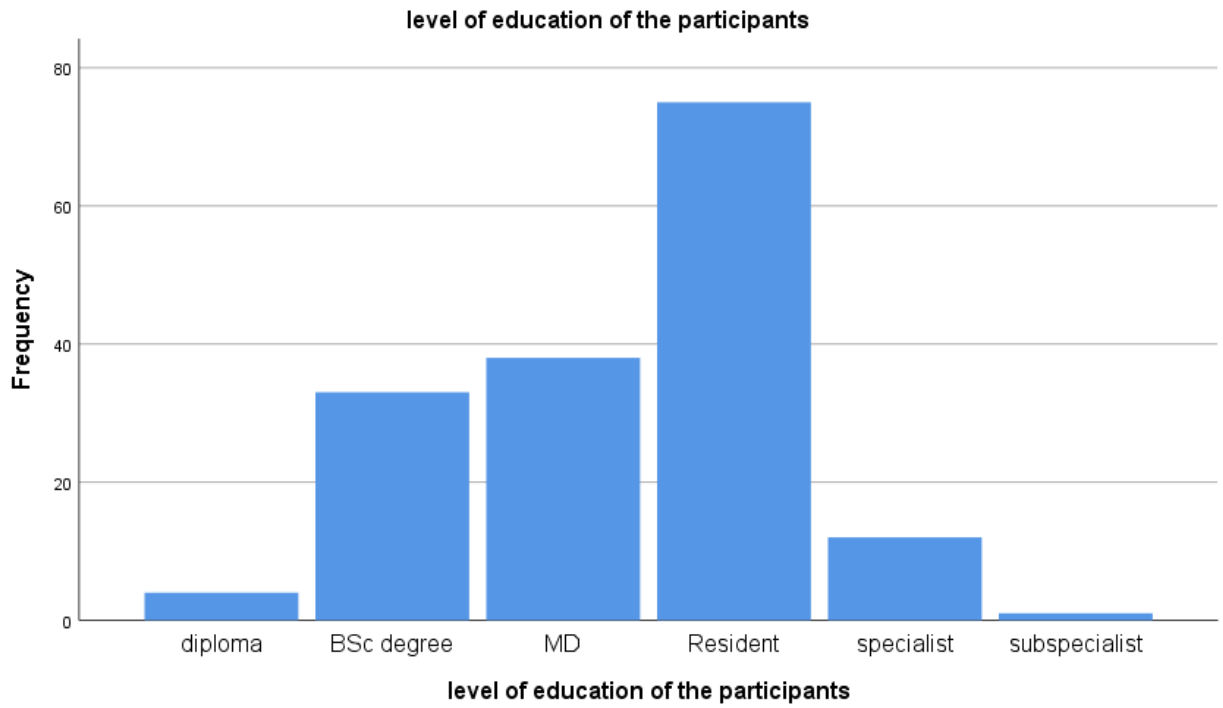

Figure 4: Level of education of the participants

5.2. Knowledge, attitude, and practice of the respondents

The Average score of knowledge, Attitude and practice were 6.52 (±1.48), 3.62 (±.304) and 4.63(±1.79), respectively. Only 45(27.6%) of the health care professionals had adequate overall knowledge while 76(46.6%) had moderate knowledge and the rest had inadequate knowledge.

Majority of the respondents 113(69.3%) have favorable attitude while the rest have unfavorable attitude. However, only nearly one tenth 18(11%) of the respondents have good practice.

Knowledge of HCPs about congenital malformations

More than 90% of the participants were aware of the importance of screening of congenital malformations and the responsible HCP to conduct newborn examination.

Table 1: Knowledge of HCPs about congenital malformations

Knowledge about congenital malformation		Number (%)
What is the importance of surveillance of congenital malformations?	Incorrect Answer	14(8.6)
	Correct answer	149(91.4)

What is the best time to do screening for congenital malformation?	Incorrect Answer	67(41.1)
	Correct answer	96(58.9)
Can Major congenital Anomalies be easily identified at birth?	Incorrect Answer	18(11.0)
	Correct answer	145(89.0)
Which of the following congenital malformations do you think is not classified as major?	Incorrect Answer	86(52.8)
	Correct answer	77(47.2)
Which of the following members of the healthcare team should conduct newborn examination for surveillance of congenital malformations?	Incorrect Answer	16(9.8)
	Correct answer	147(90.2)
What do you do for a newborn presented at 4 hours of birth with excessive oral secretion and respiratory distress?	Incorrect Answer	56(34.4)
	Correct answer	107(65.6)
What is the management of a boy found to have absent testis at birth?	Incorrect Answer	89(54.6)
	Correct answer	74(45.4)
Which one is true about a neonate who didn't pass meconium after 24 hours of life?	Incorrect Answer	40(24.5)
	Correct answer	123(75.5)
Which statement is true about the management of a newborn with congenital abdominal wall defect?	Incorrect Answer	108(66.3)
	Correct answer	55(33.7)
What do you do if you encounter a newborn who failed to pass urine after 24 hours of life?	Incorrect Answer	86(52.8)
	Correct answer	77(47.2)

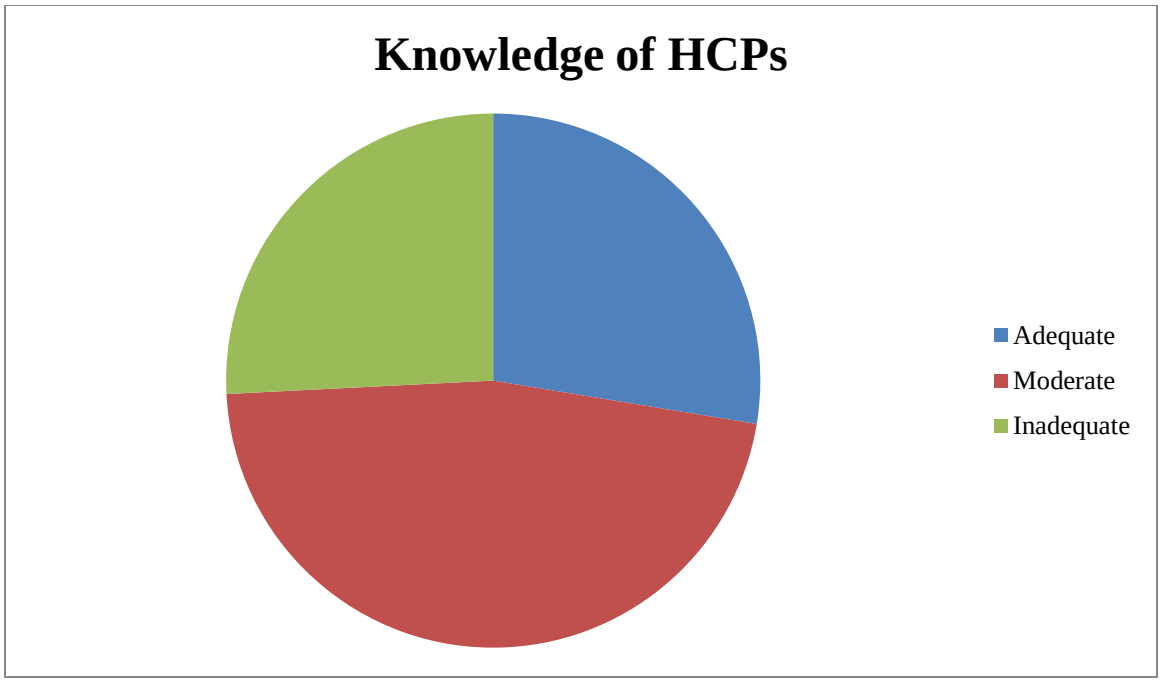

Figure 5: Knowledge of HCPs about congenital malformations

Attitudes of HCPs towards congenital malformations

Among the total 163 HCPs 90(55.3%) believe that there is a practice gap regarding newborn screening for congenital malformations. Most of the professionals indicated that lack of neonatal screening and management guideline in their institution (77.3%), inadequate staff training regarding newborn examination and congenital malformations (85.3) and work overload and lack of time (68.1) can be potential causes for the practice gap.

Some HCPs (15.2%) believe that the screening practice is suboptimal and staff resistance to change practice can be one of the barriers.

Table 2: Attitude of HCPs about congenital malformations

Attitude of HCPs about congenital malformations	Number (%)				
	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
There is a practice gap regarding screening of birth defects among health care professionals in my hospital	53(32.5)	7(4.3)	13(8.0)	78(47.9)	12(7.4)
Lack of neonatal screening and management guideline in my institution is a barrier that prevents the optimal newborn screening for	0(0.0)	14(8.6)	23(14.1)	114(69.9)	12(7.4)

birth defects					
Screening for congenital malformations is not routine practice in my institution due to inadequate staff training regarding newborn examination and congenital malformations	0(0.0)	10(6.1)	14(8.6)	113(69.3)	26(16.0)
Staff resistance to change practice is the main reason for delayed diagnosis of major congenital malformations	21(12.9)	63(38.7)	54(33.1)	23(14.1)	2(1.2)
Work overload and lack of time can be one of the reasons for lack of proper newborn examination.	1(.6)	21(12.9)	30(18.4)	99(60.7)	12(7.4)
I always follow Guidelines in my clinical practice regarding screening of newborns for anatomic malformations	7(4.3)	25(15.3)	48(29.4)	76(46.6)	7(4.3)
A health care provider should be empathic towards the patient and family and begin the conversation by saying “I’m sorry” during breaking the bad news.	1(.6)	37(22.7)	13(8.0)	88(54.0)	24(14.7)
The family should be counselled about the risk of malformation on subsequent pregnancies as soon as their baby is diagnosed with a birth defect	1(.6)	10(6.1)	3(1.8)	104(63.8)	45(27.6)
Evaluation of the family’s level of understanding and perception about the problem should be made for counselling about birth defect	1(.6)	2(1.2)	1(.6)	111(68.1)	48(29.4)
It is mandatory to allow the families to express their concerns about the physical condition of their child and provide clear information about the malformation.	0(0.0)	1(.6)	6(3.7)	75(46.0)	81(49.7)

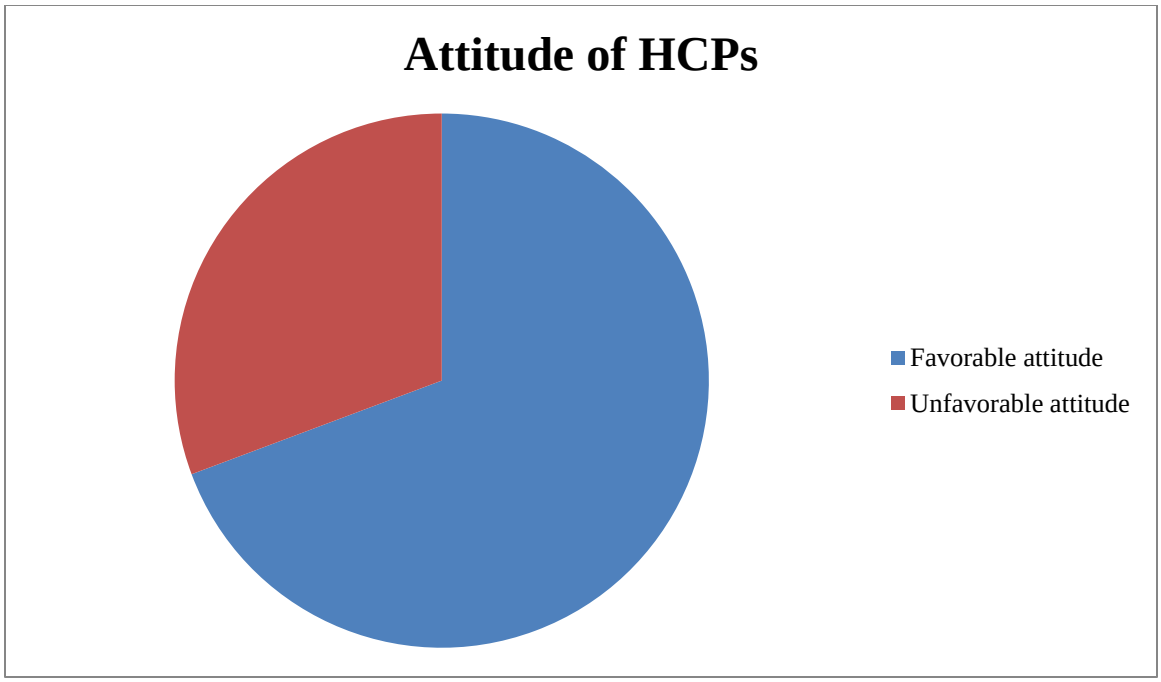

Figure 6: Attitude of HCPs about care of congenital malformations

Practice on screening of congenital malformation

Table 3: Practice on screening of congenital malformation

Practice on screening of congenital malformation		Number (%)
Does the HCP use any surveillance tool for congenital malformation?	No	161(98.8)
	Yes	2(1.2)
Does the HCP routinely measure saturation the newborn baby with puloxymeter?	No	38(23.3)
	Yes	125(76.7)
Does the HCP take maternal history about the details of pregnancy?	No	19(11.7)
	Yes	144(88.3)
Does the HCP evaluate the baby for any chocking after feeding is initiated?	No	77(47.2)
	Yes	86(52.8)
Does the HCP examine the umbilicus for the any abnormality?	No	102(62.6)
	Yes	61(37.4)
Does the HCP inspect the perineum of a newborn and check for patency of anal canal?	No	76(46.6)
	Yes	87(53.4)

Does the HCP routinely examine the genitalia of a newborn baby and presence of testes in boys?	No	84(51.5)
	Yes	79(48.5)
Does the HCP examine the back of a newborn for the presence of MMC?	No	130(79.8)
	Yes	32(19.6)
Does the HCP routinely examine the hips for abnormal mobility in newborn babies?	No	161(98.8)
	Yes	2(1.2)
Does the HCP provide parents of a baby with up-to-date information regarding the management and prognosis of the defect of their baby	No	52(31.9)
	Yes	111(68.1)

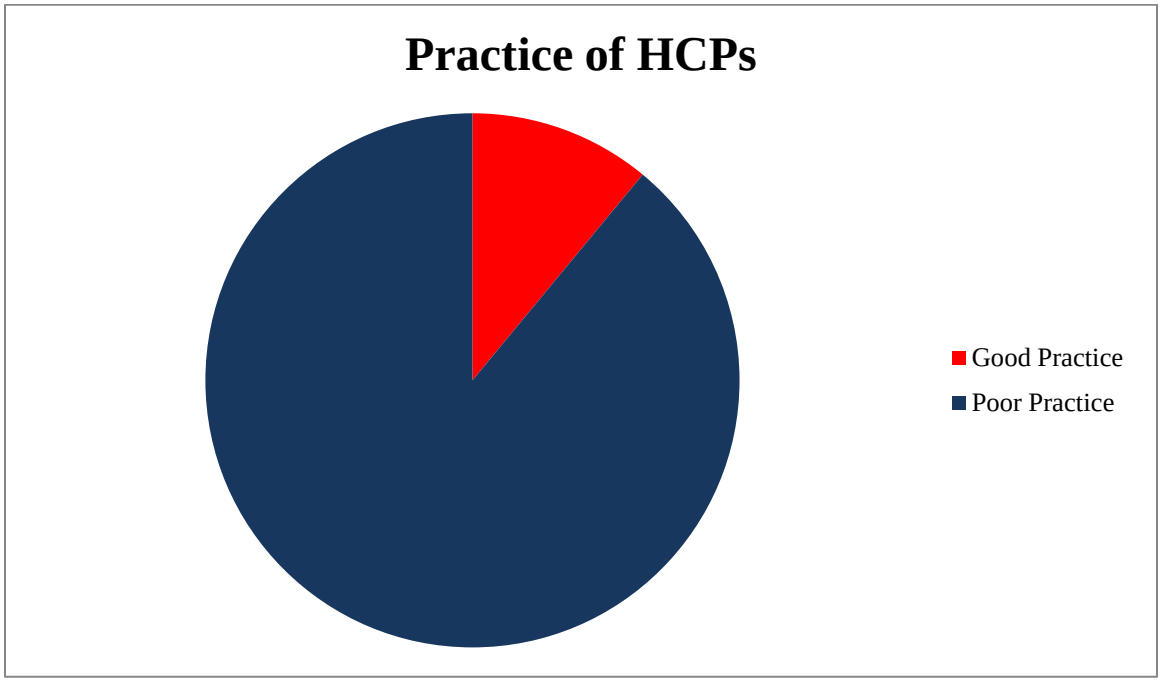

Figure 7: Practice on screening of congenital malformation

5.3 Patient factors

Table 4: sociodemographic Characteristic of patients

Characteristic		**Number (%)**
Sex	Male	90(55.2)
	Female	73(44.8)
Gestational Age	Preterm	76(46.6)
	Term	81(49.7)
	Post-term	6(3.7)
Place of Birth	The same hospital	62(38.0)
	Other hospital	51(31.3)
	Health center	47(28.8)
	Home	3(1.8)
Mode of delivery	SVD	102 (62.6)
	C/S	60(36.8)
	Forceps/Vacuum	1(.6)
Maternal age(years)	<35	148(90.8)
	≥35	15(9.2)
Problem during pregnancy	No	126(77.3)
	Yes	37(22.7)

5.4 Facility related Factors

Only 9 (5.5%) of the HCPs had received formal training in congenital malformation screening while on the job. 78 (47.9%) of the respondents revealed that there was no guideline for the screening practice of congenital malformation, while 75 (46%) were unaware of the existence of a guideline in their facility and only 10 (6.1%) claimed that there was a guideline in their service area.

Table 5: Facility related Factors

Facility related Factors		Number (%)
on job training on examination of newborns for congenital anomalies	No	154(93.9)
	Yes	10(6.1)
Is there any guideline for screening and management of congenital malformation in your institution?	No	78(47.9)
	Yes	10(6.1)
	I don't know	75(46.0)

5.5 Factors associated with Practice of HCPs on screening of congenital malformations

Binary logistic regression was performed to determine how sociodemographic characteristics of the HCPs, their knowledge and attitude and sociodemographic characteristics of the newborn affect the level of practice among HCPS regarding screening of newborns for congenital malformation.

From the univariate analysis Knowledge, attitude, problem during pregnancy and gender of the newborn were significantly associated with the level of practice on screening of congenital malformations among HCPs at 25% level of significance. However, only knowledge, problem during pregnancy and gender of the newborn were significantly associated with the level of practice on screening of congenital malformations among HCPs in the binary logistic regression model at 5% level of significance.

Accordingly after adjusting for the other covariates analysis revealed that knowledge is the independent determinant of practice. The study revealed that knowledge is the independent determinant of practice. The odds of having good practice was about thirty times higher in participants with adequate knowledge compared to those who have inadequate knowledge. [AOR= 30.841, p=0.00; 95% CI: 0.15 – 0.95].

There is also significant association between the presence of the presence of complication during pregnancy and the screening practice of HCPs. Infants born after eventful pregnancy have eighteen times higher chance of being evaluated for congenital malformation. (p=0.01, 95% CI). The other significantly associated factor with screening practice of HCPs for congenital malformations was sex of the newborn. The likelihood of male infants being screened for congenital malformation almost 80% higher compared to their female counterparts.

There was no statistically significant difference in screening practice of congenital malformations among different age groups of HCPs (p=0.760) or based on their work experience (p=0.817). Similarly sex, profession and level of education of the participants didn't show significant association with the screening practice, (p=0.067), (p=0.466) and (p=0.186) respectively**. (Table 7)**

Table 6: Binomial Logistic Regression analysis results of factors associated with Practice

Variables	Categories	Practice		Crude Odds Ratio (COR) (95%CI)	Adjusted Odds Ratio (AOR) (95%CI)	p-value
		Poor	Good			
Age group (years)	<30	103	11	1	1	
	≥30	42	7	1.561	1.438	0.715
Sex	Male	81	9	1	1	
	Female	64	9	1.266	1.780	0.429
Work experience(years)	<5	112	13	1	1	
	≥5	33	5	0.766	0.700	0.722
On-job Training	No	137	16	1	1	
	Yes	8	2	2.141	1.056	0.965
Knowledge	Inadequate	114	4	1	1	
	Adequate	31	14	12.871	30.841	**0.000***
Attitude	Unfavorable	49	1	1	1	0.058
	Favorable	96	17	8.677	12.738	
Patient's Gender	Male	75	15	1	1	**0.043***
	Female	70	3	0.214	0.205	
Maternal age(years)	<35	131	15	1	1	
	≥35	14	3	1.871	0.674	0.711
Problem during pregnancy	No	118	8	1	1	
	Yes	27	10	5.463	19.096	**0.001***

6. Discussion

This study assessed KAP among 163 HCPs and identified factors associated with screening practice of congenital malformations in three tertiary hospitals in Addis Ababa, Ethiopia. Accordingly, the proportion of adequate knowledge, favorable attitude and good screening

practice towards congenital malformations among HCPs was 27.6%, 69.3%, and 11%, respectively.

A good practice of screening was observed only in 11% of the studied population. This is a very low practice compared to the 100% standard set by WHO.

The multivariate analysis revealed that knowledge is the independent determinant of practice. The odd of having good practice was about thirty times higher in participants with adequate knowledge compared to those who have inadequate knowledge. There is also significant association between the presence of problem during pregnancy and the screening practice of HCPs and infants born after eventful pregnancy have eighteen times higher chance of being screened for congenital malformation. This might be due to the HCPs perception that there is higher risk of congenital abnormalities in babies born from complicated pregnancy.

The newborn's gender has also demonstrated a substantial relationship with the screening practices of HCPs, with males having a higher likelihood of being assessed. Though it is difficult to draw conclusions from this study, it may be the case that male newborns have a higher tendency to have genital examinations.

The poor practice of HCPs in newborn screening for congenital malformation is in line with previous studies. Several studies done on stated this practice is almost nonexistent or, at best, rudimentary in many developing countries.

In our study only 9 (5.5%) respondents stated that there is a guideline in their practice area for screening of congenital malformation which is supported by literatures from many low-middle income countries (LMIC), where guidelines for newborn screening are relatively unavailable; delay in recognition, delayed presentation to the hospital, delivery outside recognized obstetric care settings and socioeconomic challenges contribute to a higher rate of neonatal mortality(Lawal, Yusuf and Fatiregun, 2015). Parental responsibility for identifying newborns with birth abnormalities is disproportionately increased in the absence of precise recommendations for newborn screening. (Lawal, Yusuf and Fatiregun, 2015)

Regarding the timing of newborn examination; it was recommended by several studies and the English National Board (ENB N96) that infants be inspected within 24 hours of birth, again at

hospital release, or at 10 days of age (Rogers *et al.*, 2015). However, only 58.9% of the respondents in this study have correct knowledge regarding the timing of screening.

A metanalysis of 19 studies (n = 436,758), found that Pulxoxymetry for detection of Cyanotic CHDs had a sensitivity of 76.3% (95% confidence interval [CI] 69.5 to 82.0%) and a specificity of 99.9% (95% CI 99.7 to 99.9%) with a false-positive rate of 0.14% (95% CI 0.07 to 0.22) and recommends routine screening of newborns with Pulseoxymeter. (Jullien, 2021) It was shown in our study that the screening practice of measuring oxygen saturation is good with 125(76.7) of the study participants measure oxygen saturation.

There is knowledge and practice gap regarding the diagnosis esophageal atresia with or without tracheoesophageal fistula (EA/ TEF) as only 65.6% correctly answered the knowledge question and only 58.2% of HCPs properly assess the newborns for possible chocking episode after initiation of feeding. This finding is consistent with a study done on EA mortality in LMIC is still estimated to vary from 30 to 80% and delay in diagnosis and/or referral of individuals with EA are some of the challenges mentioned in LMIC documented literature. Since aspiration pneumonia has been linked to babies who were referred from outside hospitals, contrast studies, and/or trial of oral feeding, raising pediatricians' knowledge of EA, cautioning them against performing contrast studies, and developing early referral guidelines (Alslaim *et al.*, 2020).

A Cross-Sectional Study conducted in Pakistan showed majority of patients with ARM (52.7% vs. 47.3 %) were diagnosed by a non-medical person despite the babies being delivered mostly at the hospital, and the median age at ARM identification was 48 h, reflecting the need for meticulous neonatal examination(Perveen *et al.*, 2022). Similarly, a study conducted in Malawi found that the median age at presentation was 24 days, and only eight (17.39%) of 46 patients with ARM appeared during the first week after birth.(Beudeker *et al.*, 2013). Similar to this, Statovci S. et al. examined 76 patients with ARM; of these, 18 (23.68%) patients had neonatal presentations. (Statovci *et al.*, 2015)

Another study, prospective observational one done India on Anorectal malformations comparing the timing of diagnosis with the outcome has found that nearly half (48%) of all neonates presenting with ARM had a delayed diagnosis (> 48 h after birth(Reddy *et al.*, 2021) which was found to be higher compared to reports from developed countries like by Lindley et al. (42%),

Wilson et al. (32%)(Wilson *et al.*, 2010), and Turowski et al. (21.2%) (Turowski, Dingemann and Gillick, 2010)

According to the same study, delayed diagnosis which has been defined differently by different authors and includes presentation after 24 hours, 48 hours, or 7 days after delivery, after hospital discharge, or after 3 months in females with low ARM was linked to higher morbidity and mortality. (Reddy *et al.*, 2098)

Our study showed better outcomes in anorectal malformation screening. Around 53.4% of HCPs conduct perineal examination for anal canal patency. This could be explained by the fact that the research area only included tertiary hospitals that offer pediatric surgical care and it might not be representative of other facilities.

A study done Egypt on Assessment of Nurses' Competency Level Regarding the Care of Infants with Congenital Anomalies of Central Nervous System showed only slightly more than half of them had good total knowledge, slightly more than half of them had incompetent total practice and slightly less than two thirds of them had positive attitude toward infants with CA of CNS.(A.H., S.S. and H.R, 2022). In contrary, our study has revealed that only 32(19.6%) of the HCPs have practiced examination for screening of spinal dysraphism.

A prospective randomized controlled trial was done in UK in 2004 comparing routine newborn examination in a healthy baby between physicians and Midwives and showed that there is no statistical difference between physicians and midwife examination in terms of appropriate referral but midwives were found to have carried out the assessment more appropriately and maternal satisfaction was superior in the midwife group. (Bloomfield and Rogers, 2003). So the study concluded that increasing the participation of midwives in newborn assessment is likely to lead to better examination quality, increased parental satisfaction, and cost savings. (Rogers *et al.*, 2015). Likewise the current study has revealed that there is no significant difference in the practice of HCPs across different professionals.

Several studies have identified that there is a knowledge and practice gap among healthcare professionals regarding newborn screening for various abnormalities. Around 50% of family physicians in Kingdom of Saudi Arabia did not screen any child for hearing loss during their last

five years of experience.(Alqudah *et al.*, 2021) 54.45% nurses in a Neurosurgery Department in egypt had incompetent total score of practice regarding Congenital anomalies of CNS(A.H., S.S. and H.R, 2022)

7. Strength and Limitations of the study

To the best of our knowledge this is the first study in Ethiopian to assess the health care professionals' knowledge attitude and practice towards newborn screening for congenital malformations. Moreover the study was a multicenter study conducted in three referral and teaching hospitals and tried to include all health care professionals who practice at labor and delivery ward and neonatal intensive care units. The practice of health care professionals was directly assessed through observation by the principal investigator and trained data collectors which increases validity of the data. To minimize observation bias, observation was made at random days by unknown observer but it might still have some extent of observation bias.

The study had some limitations however. Firstly, no standardized tool for assessing KAPs on screening of congenital malformations has been validated previously. We have however organized the questions from WHO and CDC guidelines and reports on congenital malformations. But, the questions used to measure the knowledge, attitude and practice of HCPs on screening of congenital malformations may not sufficiently assess the scenario. Secondly, only HCPs in tertiary governmental health facilities where patients are already referred with certain diagnosis were participated in the survey and the results of this study may not reflect the KAPs of HCPs in other institutions. Thirdly the study didn't assess newborns with congenital malformations and those without separately.

8. Conclusion and Recommendation

Prevalence of screening practice of HCPS for congenital malformations working at the three tertiary hospitals with pediatric surgical service is significantly lower than the WHO recommendation implying that early diagnosis and appropriate management of congenital malformation practice is inadequate to prevent the mortality, morbidity and disability associated with them.

Knowledge about congenital malformations, gender of the newborn and presence of complication during pregnancy had shown a positive significant association with screening practices while other factors didn’t demonstrate significant correlation.

Therefore, given the results obtained in this study, expanding HCPs' professional knowledge through staff training and experience sharing, adopting appropriate protocols and guidelines and preparation for their applicability appear necessary for improvement of congenital malformation screening practice.

References

1.2 Congenital Anomalies | Birth Defects Surveillance Toolkit | CDC (no date). Available at: https://www.cdc.gov/ncbddd/birthdefects/surveillancemanual/facilitators-guide/module-1/mod1-2.html (Accessed: 22 September 2022).

A.H., K., S.S., A.-S. and H.R, T. (2022) 'Assessment of Nurses' Competency Level Regarding the Care of Infants with Congenital Anomalies of Central Nervous System', *Egyptian Journal of Health Care*, 13(3), pp. 592–604. Available at: https://doi.org/10.21608/ejhc.2022.253725.

Alifia, M. (2021) 'No 主観的健康感を中心とした在宅高齢者における 健康関連指標に関する共分散構造分析Title', 7, p. 6.

Alqudah, O.I. *et al.* (2021) 'Knowledge, attitude and management of hearing screening in children among family physicians in the Kingdom of Saudi Arabia'. Available at: https://doi.org/10.1371/journal.pone.0256647.

Alslaim, H.S. *et al.* (2020) 'Tracheoesophageal fistula in the developing world: are we ready for thoracoscopic repair?', 36, pp. 649–654. Available at: https://doi.org/10.1007/s00383-020-04639-7.

Beudeker, N. *et al.* (2013) 'The hidden mortality of imperforate anus', *African Journal of Paediatric Surgery*, 10(4), pp. 302–306. Available at: https://doi.org/10.4103/0189-6725.125417.

Birth Defects (2012) *SpringerReference*. Available at: https://doi.org/10.1007/springerreference_301094.

Bloomfield, L. and Rogers, C. (2003) 'A qualitative study exploring junior paediatricians ', midwives ', GPs ' and mothers ' experiences and views of the examination of the newborn baby', (August 2002), pp. 37–45. Available at: https://doi.org/10.1054/midw.2002.0323.

Eshete, M. *et al.* (2021) 'Assessing the Practice of Birth Defect Registration at Addis Ababa Health Facilities', *Ethiopian Journal of Health Sciences*, 31(3), p. 683. Available at: https://doi.org/10.4314/ejhs.v31i3.

Glinianaia, S. V. *et al.* (2020) 'Long-term survival of children born with congenital anomalies: A

systematic review and meta-analysis of population-based studies', *PLOS Medicine*, 17(9), p. e1003356. Available at: https://doi.org/10.1371/JOURNAL.PMED.1003356.

Handbook, Q.R., Selected, O.F. and Anomalies, C. (no date) *BIRTH DEFECTS SURVEILLANCE QUICK REFERENCE HANDBOOK OF SELECTED CONGENITAL ANOMALIES*.

Health, M.O.F. (2018) 'MINISTRY OF HEALTH NEONATAL CARE CLINICAL GUIDELINES'.

Jullien, S. (2021) 'Newborn pulse oximetry screening for critical congenital heart defects', *BMC Pediatrics*, 21. Available at: https://doi.org/10.1186/S12887-021-02520-7.

Kanungo, S. *et al.* (2010) 'Newborn Screening', *The Clinical Biochemist Reviews*, 31(2), p. 57. Available at: https://doi.org/10.1891/0739-6686.29.113.

Lawal, T.A., Yusuf, O.B. and Fatiregun, A.A. (2015) 'Knowledge of birth defects among nursing mothers in a developing country', *African Health Sciences*, 15(1), pp. 180–187. Available at: https://doi.org/10.4314/ahs.v15i1.24.

Mekonnen, A.G. *et al.* (2020) 'Modifiable risk factors of congenital malformations in bale zone hospitals, Southeast Ethiopia: An unmatched case-control study', *BMC Pregnancy and Childbirth*, 20(1), pp. 1–9. Available at: https://doi.org/10.1186/S12884-020-2827-0/TABLES/5.

Mumpe-Mwanja, D. *et al.* (2019) 'A hospital-based birth defects surveillance system in Kampala, Uganda', *BMC Pregnancy and Childbirth*, 19(1). Available at: https://doi.org/10.1186/s12884-019-2542-x.

'Newborn Screening Practitioner's Manual Overview 1-2 List of Disorders Included in Illinois Screening Panel 3 Newborn Screening Program Contact Information 4' (2011).

Organization;, W.H. (2014) 'Organization WH, (U.S.) C for DC and P, Systems IC for BDM. Birth defects surveillance: a manual for programme managers', *Geneva: World Health Organization*, p. 126. Available at: http://www.who.int/iris/handle/10665/110223.

Penchaszadeh, V.B. (2002) 'Preventing Congenital Anomalies in Developing Countries', *Public*

Health Genomics, 5(1), pp. 61–69. Available at: https://doi.org/10.1159/000064632.

Perveen, S. *et al.* (2022) 'Place & Person involved in delivery: Factors leading to delay in diagnosis of Anorectal Malformation in Newborns', *Pakistan Journal of Medical Sciences*, 38(1), p. 297. Available at: https://doi.org/10.12669/PJMS.38.1.4156.

Rasmussen, S.A. *et al.* (2014) 'Assessment of congenital anomalies in infants born to pregnant women enrolled in clinical trials', *Clinical Infectious Diseases*, 59(Suppl 7), pp. S428–S436. Available at: https://doi.org/10.1093/cid/ciu738.

Reddy, M. *et al.* (2098) 'Anorectal Malformations: The Earlier the Diagnosis, the Better the Outcome', *Indian Journal of Pediatrics* [Preprint]. Available at: https://doi.org/10.1007/s12098-021-03887-2.

Rogers, C. *et al.* (2015) 'National survey of current practice standards for the newborn and infant physical examination', *British Journal of Midwifery*, 23(12), pp. 862–873. Available at: https://doi.org/10.12968/BJOM.2015.23.12.862.

Statovci, S. *et al.* (2015) 'Late Diagnosis of Anorectal Malformations in Children', *Surgical Science*, 6(3), pp. 143–148. Available at: https://doi.org/10.4236/SS.2015.63023.

Taye, M. *et al.* (2018) 'Factors associated with congenital anomalies in Addis Ababa and the Amhara Region, Ethiopia: a case-control study', *BMC pediatrics*, 18(1). Available at: https://doi.org/10.1186/S12887-018-1096-9.

Turowski, C., Dingemann, J. and Gillick, J. (2010) 'Delayed diagnosis of imperforate anus: An unacceptable morbidity', *Pediatric Surgery International*, 26(11), pp. 1083–1086. Available at: https://doi.org/10.1007/s00383-010-2691-5.

'WHO' (no date). Available at: https://www.cdc.gov/ncbddd/birthdefects/surveillancemanual/chapters/chapter-3/chapter3-9.html.

WHO, CDC and ICBDSR (2020) *Birth defects surveillance: a manual for programme managers, second edition*, *Who*.

Wilson, B.E. *et al.* (2010) ‘Delayed diagnosis of anorectal malformations: are current guidelines sufficient?’, *Journal of paediatrics and child health*, 46(5), pp. 268–272. Available at: https://doi.org/10.1111/j.1440-1754.2009.01683.x.

9. ANNEXES

ANNEX I: INFORMATION SHEET and CONSENT FORM

Research title: screening practice of major congenital malformation among health care professionals and associated factors at hospitals that provide neonatal intensive care and pediatrics surgical service in Addis Ababa, Ethiopia

Principal Investigator (PI): Eden Belay (MD, Pediatrics Surgery Resident)

Advisor: Dr. Fisseha Temesgen (MD, Consultant General and pediatrics surgeon)

Sponsor: Addis Ababa University College of Health sciences

Dear respondent, my name is Dr. Eden Belay a pediatrics surgery resident at AAU College of health sciences. I am here to collect data for a study which is entitled Screening Practice of major congenital malformation among health care professionals and associated factors at Hospitals that provide Neonatal intensive care and pediatrics surgical service in Addis Ababa, Ethiopia

The research consists of health care professional's interview which takes a maximum of 10 minutes and direct observation of newborn examination being performed by the professionals. To achieve goals of the study, your honest and genuine participation by responding to the question prepared is very important and highly appreciated. You have also a right to continue or to discontinue as a participant and there is no any influence that insists you to participate unless you are volunteer.

We will proceed to the interview after you understand the following points

Objective of the study: To assess health care professionals' practice on screening of major congenital anomalies among newborn infants and associated factors

Benefit: You will not be receiving any payment or compensation for participating in this study but the information generated from the study will help the hospital, policy makers and health

care professionals implement programs that can improve the outcome of patients with congenital anomalies through early detection and management.

Harm: The study will not cause any harm on you and refusal to participate will not affect you in anyway

Alternatives to participation: participation is voluntary and you have the right to choose to leave the study for any reason, related to the study or personal.

Confidentiality: We would like to assure you that the privacy will strictly be maintained throughout. Your responses to any of the questions will not be given to anyone else and no reports of the study will ever identify you. To ensure this your name will not be included in the study and a separate code will be used. If a report of the results will be published, only Information about the total group will appear.

Person to contact: If you have any question you can contact the investigator at the following address at any time you want.

Dr. Eden Belay

Tel: +251925652944

E-mail: edenbelay2014@gmail.com

CONSENT FORM

I am aware that taking part in the study is completely voluntary. My responses to the questions won't be shared with anyone else, and my identity won't be mentioned in any of the study's findings. I am therefore prepared and willing to take part in this investigation.

And I confirm by signature _____

Date of interview_____

Thank you for willingness to participate

ANNEX II: Data collection check list

Sociodemographic data of participants

Item	Response	Remark
Age		
Gender	○ Male ○ Female	
Profession	○ Clinical Nurse ○ Midwife ○ General practitioner ○ Obstetrics and Gynecology resident ○ Pediatrics and child health resident ○ Gynecologist ○ Pediatrician ○ Other(specify)	
Level of education	○ Diploma ○ BSc Degree ○ Resident ○ Specialist ○ Subspecialist	
Work Experience in years		
Have you ever taken on Job trainings related to congenital malformation?	○ Yes ○ No	
If you said Yes to the previous question was it helpful in your clinical practice for identifying congenital malformations	○ Yes ○ No ○ Maybe ○ I'm not sure	

Knowledge assessment questions

1. Why is surveillance for congenital malformations important? (More than one option can be selected)
   - All congenital anomalies can easily be identified at birth
   - They have significant public health impact
   - For some congenital anomalies, there is the potential for primary prevention.
   - Other(specify)
2. Which of the following is a good time to do screening for congenital malformation?
   - The first 24 hours of life
   - The first week of life
   - The first 28 days of life
   - I don’t know
3. Major congenital Anomalies can be easily identified at birth
   - Yes

- No
- I don't have the right knowledge to answer

4. Which of the following congenital malformations do you think is not classified as major?
   - Hypospadias
   - Anorectal malformation
   - Umbilical Hernia
   - Undescended testes
5. Which of the following members of the healthcare team are important to conduct newborn examination for surveillance of congenital malformations?
   - Physicians
   - Nurses
   - Midwives
   - All of the above
6. A newborn who is drooling and has abnormal respiratory sounds after 2 hours of birth (more than one answer is possible)
   - Should continue breast feeding
   - NG tube should be inserted for Feeding
   - May have abnormal communication of trachea and esophagus
   - May need surgical treatment
7. What would you do if you find a newborn boy with empty scrotum due to undescended testes?
   - Orchiopexy at neonatal age
   - Orchiopexy after the age of 6 months
   - Wait for spontaneous descent of the testes until 3 years of age
8. Which statement is true about a neonate who didn't pass meconium after 24 hours of birth?
   - Plain abdominal X-ray is the next first stage of management
   - Female with normal perineum should have 3 openings in the vestibule
   - Perineum should be checked for the patency of anal canal in all patients
9. Which of the following is true about the management of congenital abdominal wall defect?
   - Wrap the baby with plastic bag to prevent hypothermia and immediate referral to surgical center
   - Dress the bowel with wet gauze and referral
   - Try to reduce the bowel to peritoneal cavity
10. What would you do first if you find a newborn boy who failed to pass urine after 24 hours of birth?
    - Immediate consultation for surgical management
    - Catheterize him
    - Reassure the parents and discharge for most neonates will pass urine after 48 hours
    - Do abdominal Ultrasound and serum creatinine

Attitude Questions

1. There is a practice gap regarding screening of birth defects among health care professionals in my hospital
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree
2. Lack of neonatal screening and management guideline in my institution is a barrier that prevents the optimal newborn screening for birth defects
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree

3. Screening for congenital malformations is not routine practice in my institution due to inadequate staff training regarding newborn examination and congenital malformations
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree
4. Staff resistance to change practice is the main reason for delayed diagnosis of major congenital malformations
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree
5. Work overload and lack of time can be one of the reasons for lack of proper newborn examination.
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree
6. I always follow Guidelines in my clinical practice regarding screening of newborns for anatomic malformations
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly agree
7. A health care provider should be empathic towards the patient and family and begin the conversation by saying "I'm sorry" during breaking the bad news.
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly Agree

8. The family should be counselled about the risk of malformation on subsequent pregnancies as soon as their baby is diagnosed with a birth defect.
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly Agree
9. Evaluation of the family's level of understanding and perception about the problem should be made for counselling about birth defect
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly Agree
10. It is mandatory to allow the families to express their concerns about the physical condition of their child and provide clear information about the malformation.
    - Strongly disagree
    - Disagree
    - Not sure
    - Agree
    - Strongly Agree

Practice Questions

Item	Response	Remark
1. Does the HCP use any surveillance tool for congenital malformation?	○ Yes ○ No	
2. Does the HCP routinely measure saturation the newborn baby with puloxymeter?	○ Yes ○ No	
3. Does the HCP take maternal history about the details of pregnancy?	○ Yes ○ No	
4. Does the HCP evaluate the baby for any chocking after feeding is initiated?	○ Yes ○ No	
5. Does the HCP examine the umbilicus for the any abnormality?	○ Yes ○ No	
6. Does the HCP inspect the perineum of a newborn and check for patency of anal canal?	○ Yes ○ No	
7. Does the HCP routinely examine the genitalia of a newborn baby and presence of testes in boys?	○ Yes ○ No	

8. Does the HCP examine the back of a newborn for the presence of MMC?	○ Yes ○ No	
9. Does the HCP routinely examine the hips for abnormal mobility in newborn babies?	○ Yes ○ No	
10. Does the HCP provide parents of a baby with up-to-date information regarding the management and prognosis of the defect of their baby	○ Yes ○ No	

Institution related questions

1. Is there any guideline for screening and management of congenital malformation in your institution?
    - Yes
    - No
    - I don't know
2. Is there a standardized checklist you use to examine newborns in your institution?
    - Yes
    - No
    - I don't know

Patient related questions

1. Gender
    - Male
    - Female
2. Gestational age
    - Preterm
    - Term
    - Post term
3. Place of birth
    - The same hospital

- Other hospital
- Health center
- Home

4. Mode of delivery
    - SVD
    - C/S
    - Forceps/Vacuum
5. Maternal age
6. Problem during pregnancy
    - Yes
    - No
7. If yes, what was the problem?

ANNEX III: ASSURANCE OF INVESTIGATOR

I the undersigned resident declare that this thesis is my original work, in partial fulfillment of the requirement for certificate of specialty in pediatrics surgery. I also declare that it has never been presented in this or any other higher institution and all the resources and materials used in the research have been duly acknowledged.

Name of the Resident: _____

Signature: _____

Date: _____

Approval of Advisors

Name of the Advisor: _____

Signature: _____

Date: _____