COLLEGE OF HEALTH SCIENCE

SCHOOL OF PUBLIC HEALTH

REPRODUCTIVE AND FAMILY HEALTH DEPARTMENT

Survival Status of Infants With Congenital Anomalies in The Selected Hospitals, Addis Ababa, Ethiopia: A Retrospective Cohort Study

By Mahdere Tsegaye (GSR/7678/10)

A Thesis Submitted to the School of Graduate Studies Addis Ababa University School of Public health in Partial Fulfillment of the Requirements for the Degree of Master of Public Health in Reproductive Health

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Approved by the examining board:

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Abbreviations and acronyms

ANC	Antenatal Care
BINOCARs	British Isles Network of Congenital Anomaly Registers
CHD	Congenital Heart Diseases
CI	Confidence Interval
EA	Esophageal Atresia
ICD	International Classification of Disease
IPI	Inter Pregnancy Intervals
MACDP	Metropolitan Atlanta Congenital Defects Program
MMC	Myelomeningocele
NCBDMP	North Carolina Birth Defects Monitoring Program
NorCAS	Northern Congenital Abnormality Survey
NTD	Neural Tube Defects
ODK	Open Data Kit
TASH	Tikur Anbesa Specialized Hospital
TEF	Tracheoesophageal Fistula
ZMH	Zewditu Memorial Hospital
UK	United Kingdome
USA	United States of America
WHO	World Health Organization

Abstract

Background: Congenital malformations are a major health problem and highly contributed to neonatal and child mortality in all Sub-Saharan Africa. However, there are limited and inconsistent pieces of evidence on the survival status of congenital anomalies and their determinants in Ethiopia.

Objective: to assess the probability of survivorship and its predictors in the first year of life among babies with congenital anomalies.

Methods: A retrospective cohort study design was used among infants with congenital anomalies in Black Lion Specialized Hospital and Zewditu Memorial Hospital in Addis Ababa, registered from 2014 to 2017 which are referred from Addis Ababa region health facilities. Data were collected by reviewing the registration book and interviewing parents by visiting their homes using an electronic data collection tool. Data were analyzed using STATA version 14. The actuarial life table and Kaplan Meier survival curve were analyzed to estimate time to death with a log-rank test to compare survival time between groups. To identify independent predictors Cox-proportional model was carried out and crude and adjusted hazard ratios with 95% Confidence Interval (CI) were used to determine statistical significance.

Results: The overall survival probability of infants with congenital anomalies to 7 days, 28 days, and 1-year was 70.3%, 50.0%, and 46.5%. Infant 1-year survival probability with nervous system congenital anomalies had (40.9%), digestive system (42.5%), circulatory system anomalies (43.3%), chromosomal system anomalies (60.0%), musculoskeletal system anomalies (50.0%), respiratory system anomalies (75.0%), and urogenital system (93.3%). The median survival time for those cases that died was 6 days. Survival of male infants and low birth weight infants was significantly poorer survival and those infants who had surgical intervention were significantly better survival.

Conclusion: Survival of infants with congenital anomalies to one year is low. Effective interventions are required to focus on nutritional counseling, birth weight, and early surgical intervention to improve the survival probability of infants with congenital anomalies.

Key Words: Congenital anomalies, Survival Status, Infant, Addis Ababa

1. Introduction

1.1 Background

Congenital anomalies are structural or functional abnormalities, including metabolic disorders present from birth and a diverse group of disorders, caused by single gene defects, chromosomal disorders, multifactorial inheritance, environmental teratogens, and micronutrient malnutrition (1).

Congenital anomalies are a major health problem and highly contributed to neonatal mortality (2). According to Lancet (2015), 0.512 million children did not celebrate their 5^{th} birthday of this 0.3 million are neonates and the risk of dying in the first 5 years is estimated as 3.664 per 1000 live birth mortality rate (3).

Neonatal mortality rate among congenital anomalies in South-East Asia Region from 2013 to 2017 is to 21% in Thailand, 19% in Indonesia, and 10% in other member states of neonatal deaths (4). According to the March of Dimes report, Under-five children with major congenital anomalies 3.3 million children died each year, and leading to 3.2 million of those who survived children will develop congenital anomalies disabilities (5).

The morbidity, psychosocial effects, and mortality among infants with congenital anomalies are high. Chronic illness, long-term disabilities, and overall poor quality of life are the major consequences of congenital anomalies. Parents, caregivers, the child, and the health care team are also challenged by congenital anomalies (6). Delayed diagnosis of congenital anomalies, poor transport facilities, and delayed referral, and lack of advanced neonatological setup are the reasons for increased morbidity and mortality related to congenital anomalies in developing countries (7, 8).

Due to its significant contribution to neonatal mortality, there is a need for accurate quantification of the survival status of congenital anomalies. This could be used for genetic counseling, clinical decision making in the antenatal and neonatal periods, and public health policymaking (9). Few Literatures reported different survival probability for different types of anomalies. For example, the survival status of Tracheoesophageal fistula (TEF) and Esophageal Atresia (EA) is 58.36% (8), 84% of infants with Myelomeningocele (MMC) survived the first year of life (10).

In resource-poor settings children with life-threatening congenital anomalies frequently die before reaching appropriate care facilities and those children with non-threatening congenital anomalies survive with their disease due to delays in access to surgical care (11, 12).

1.2 Statement of the problem

All Sub-Saharan Africa countries are with the highest under-five mortality rate. One of the causes for neonatal and 1 – 59 months of death is congenital anomalies, mortality rate accounted for 5.1% and 3.5% respectively (3).

In a study conducted in Addis Ababa and Amhara Region, the trend of congenital anomalies increased through time and the prevalence is 1.9 (13). The study was done in Northwest Ethiopia and South Wollo and Oromia zone of Amhara regional state prevalence of congenital anomalies from 2015 – 2017 are 1.61% and 1.43% respectively (14, 15).

The common predisposing factors in Ethiopia are high folate deficiency and high iodine deficiency among women of reproductive age and high prevalence of syphilis and toxoplasmosis among pregnant women, intake of drugs, consumption of alcohol during pregnancy (14, 16). The most frequent type of anomaly found in Addis Ababa, Northwest Ethiopia, South Wollo and Oromia zone of Amhara regional state and Southwestern Ethiopia is neural tube defect (14, 15, 17, 18). Some of the anomalies identified in the study are cleft lip and palate, congenital heart diseases (CHD), club-foot, and gastro-intestinal anomalies, orofacial, neural tube defects (NTD), unspecified congenital anomalies, abdominal wall, genitourinary system, head, face, and neck defects (13, 14, 16).

Congenital malformations are the major cause of neonatal mortality and a high risk of death occurred among neonates (17, 19, 20). The common types for causes of death are cardiac malformations, central nervous system malformations, and digestive tract malformations (20, 21). According to Muntha and his colleagues (2019), two-third of deaths occurred during the first year of life due to congenital cardiovascular anomalies among cases of Down syndrome (22). Survival of infants with congenital anomalies to the first week and 1-year survival probability was 94% and 89% (9). An infant with hypoplastic left heart syndrome was a 27% survival probability during the first year of life (23). First-year survival for infants with EA and TEF who received the surgical intervention was 48.1% (24).

Major congenital anomalies increased risk of mortality in children with low birth weight, prematurity, parity, sex, maternal age greater than 30 are highly affected by (25-28). According to few pieces of literature gestational age, birth weight, maternal age, day of admission, number

of prenatal follow up, parental education, number of pregnancies identified as predictors for the survival of children with congenital anomalies (10, 11, 29, 30)

Lack or inadequacy of vital registration systems in developing countries, and inaccurate records of the causes of death, are major barriers to estimating the size of public health problems attributable to birth defects.

Globally, only a few and inconsistent reports are available on the survival probability of congenital anomalies and the effect of low birth weight, sex, maternal age, plurality, and gestational age on the survival status of congenital anomalies. Similarly, in Ethiopia, there is limited evidence on the survival status of congenital anomalies. Thus, this study investigated the survival status of congenital anomalies and the effect of determinants on survival among infants in Tikur Anbesa Specialized Hospital (TASH) and Zewditu Memorial Hospital (ZMH), Addis Ababa, Ethiopia.

1.3 Significance of the study

A limited piece of evidence is available on the survival status of infants with congenital anomalies in Ethiopia. This study identify factors that affect survival status of infants with congenital anomalies, this helpful information for policymakers, local leaders, and healthcare providers to consider interventions for factors that affect the survival of infants with congenital anomalies.

The study provides useful information for local leaders and health care providers to assess the outcome of congenital anomalies for affected families and; design effective newborn care and infant survival strategies. Future research implications were forwarded to the scientific community.

2. Literature review

2.1 Epidemiology of congenital anomalies

Despite significant numbers of children are affected by congenital anomalies, most congenital anomalies types are preventable (31). Annually worldwide 7.9 million births or 6% of total births deliver with congenital anomalies out of this 94 % of births occurred in the middle and low-income countries and 7 % of deaths are neonates (5).

According to 2010 WHO report congenital anomalies are 7% of all neonatal deaths and 260,000 deaths worldwide and 25% are from the European region in 2004 (32). The European network of population-based registries for the epidemiological surveillance of congenital anomalies study report shows that 17%–43% of infant mortality was attributed to congenital anomaly, with higher attributable rates recorded in Malta (43%) and Ireland (42%). The average infant mortality with congenital anomaly was 1.1 per 1000 births (33).

A review conducted in 11 European countries reported that the average total prevalence was 26.9 congenital anomaly cases per 1000 births. Of these, 77.0% were live births surviving infancy (33). Worldwide the prevalence of congenital heart defects is one-third of all major anomalies(34). According to the World Health Organization (WHO) report, the most common congenital anomalies are NTD, CHD, and Down syndrome (32).

Congenital anomalies have contributed significantly to perinatal mortality and the "under 5 mortality," and to morbidity both in developed and developing countries (35). According to the 2015 fact sheet, congenital anomalies accounted for 303, 000 newborns deaths worldwide, 1% of all deaths (36).

In Africa, around 1.5 million newborns were affected by birth defects, which was the highest frequency when compared to other continents (3). CHD is major congenital anomalies for mortality and morbidity of children in Africa because of low socioeconomic status, high fertility rate, and inadequate technical platform and human resources (37, 38).

Under-five mortality in Africa due to congenital anomalies accounts in 263,000, this accounts for 4.6% of under-five deaths. 54 countries with a low under -5 mortality rate (10 – 25 per 1000livebirth) and very low (< 10 per 1000 live birth) contribute 9% and 2% of the world's under-5 deaths respectively (3). The incidence of congenital anomalies of the kidney and urinary

tract in Taiwan was 4.2 per 10,000 live births (27). The trend of major congenital anomalies prevalence was increased from 1993 to 2012 (39).

In Ethiopia the trend of congenital anomalies was increasing during the past years, the trend increases from 1.14% in 2010 to 2.83% in 2014 (13). Central nervous system anomalies are higher prevalence among neonates in Ethiopia (17). Asefa and his colleagues (2020) conducted a systematic review and meta-analysis reported that the higher prevalence of NTD in Ethiopia; the pooled prevalence is 82 per 10,000 (40). Tigray region in Ethiopia overall incidence of NTD is 131 per 10, 000 births and in southwestern Ethiopia 4.05cases per 1000 (17, 41).

2.2 Determinants of congenital anomalies

Congenital anomalies are associated with maternal and neonatal factors. According to different pieces of literature low birth weight, prematurity, multiparty, consanguinity, socioeconomic status is a major risk factor for congenital anomalies

The risks of congenital anomalies that are more common among neonatal factors are low birth weight, prematurity, increasing birth order, being male are the highest risk for congenital anomalies (2, 25-27, 42-44).

Maternal age at conception, multiparty, drug use in the first trimester, lack of antenatal care (ANC), exposure to pollutants, maternal education, maternal cigarette smoking, maternal consumption of alcohol and drug, maternal gestational diabetes, thalassemia, polyhydramnios or oligohydramnios, mode of delivery are maternal related factors contribute to congenital anomalies (26, 27, 45-47).

Maternal age found that determinant for different types of congenital anomalies (45, 48) but a study done on advancing maternal age found that maternal age greater than 35 years can decrease the risk of congenital anomalies (49).

The incidence of Down syndrome and other chromosomal anomalies increased with maternal age than paternal age but for musculoskeletal, genital, and urinary anomalies there is an association between very young mothers aged 12-19 and aged 35 and older fathers (50).

Sarkar and his colleges (2013) reported that Multiparas is 3.3% more risk for congenital anomalies than primiparas (1.8%) (48). Mode of delivery also factor delivery by caesarian section can increase the risk of congenital anomalies (46, 48).

Consanguinity is as a couple share one or more common ancestors; according to medical genetics a couple related as second cousins or closer (51). Different articles found that consanguinity is a determinant for congenital anomalies (42, 46, 48, 51). North and Sub-Saharan Africa is the highest countries that practice this kind of trend (51). In Egypt and North Central Nigeria, Saudi, Bangladesh, south India consanguineous marriage among patients with congenital anomalies is 45.8%, 22%, 54.5%, 10%, and 20% respectively (4, 42, 47, 52).

Short (0-5 months) and long (24-35 months) interpregnancy intervals (IPI) (between childbirth to the conception of the next child) also a risk factor for congenital anomalies. Short IPI is associated with folate deficiency and neural tube defects because of breastfeeding and related to delivery, physiological changes that occur after delivery will change maternal condition (53-55).

Maternal weight both underweight and obese is a risk factor for congenital anomalies. Obesity 1.56 times increased risk of developing ventricular septal defect under weigh are 2.86 times more likely increased risks of the atrial septal defect (56). A systemic review was done on maternal overweight and obesity the risk of congenital anomalies is increased with maternal obesity (57). There is also a relationship between maternal obesity and congenital abnormalities of the kidney and urinary tract in offspring (58).

Low socio-economic levels are related to congenital malformation because these peoples are associated with a higher number of parental siblings, younger maternal age, increased frequency of pregnancy, and a low number of antenatal these factors contributed to developing the child with major congenital anomalies (6, 59).

2.3 Survival of children with congenital anomalies

A study done at the University of North Carolina Hospitals less than one day was median age at death and 75% of infants died before 10 days and 90% died before 4 months of life (60). Most deaths occurred within the first week of life (61). The median survival time for congenital anomalies is 11 days. from this urogenital tract and kidney anomalies have the shortest median survival time (1 day) and children with Down's syndrome have the longest median survival time (100 days). chromosomal anomalies have a poorest survival status than other types of congenital anomalies (9).

Survival among congenital heart defect is 96.7% and with critical CHD the survival was 85.3% (62). A one-year survival among non-isolated CHD is higher than isolated CHD at 97.1% and 75.2% respectively (11). A systematic review and meta-analysis study shows a one-year survival among CHD was 87.0% (63). In a population-based study in Hong Kong, 6 months and one-year survival among Down syndrome was 95.8% and 94.4% respectively (64).

In a study done in northern India tertiary hospital survival of EA and TEF was 60.37% and early surgical intervention is an important factor to increase the survival of infants (8). The survival of esophageal atresia is 78% and EA with associated anomalies 49% but the cases of EA with CHD is 33% (7). Due to EA and TEF, 62% of deaths occurred among cases postoperatively (65).

2.4 Possible factors affecting survival status of children with congenital anomalies

According to different literature, low birth weight and preterm birth were major predictors for infants with congenital anomalies (23, 61).

A population-based study on congenital heart disease low birth weight and preterm birth are independent predictors for the survival of children with congenital anomalies (29) and in Down syndrome cases low birth weight is 2.38 more likely to decrease survival compared to normal weight (64). Among critical congenital heart defects low birth weight, maternal age greater than 30, and diagnosis greater than 1-day decrease one-year infant survival (8, 11). Children diagnosed with greater than one day and low birth weight is a poor prognosis with a survival of 71.7% and 78.8% respectively compared to diagnosed less than one day (82.5%) and normal birth weight (97.9%) (11, 29).

Prematurity, associated congenital anomalies, the gap between esophageal ends, and preoperative respiratory status are factors for EA and TEF (66).

Aggressive interventions are a factor of infant death with lethal congenital anomalies and it's better to continue with medical interventions to prevent neonatal death related to intrapartum and postoperative complications (60). Sepsis is a cause of infant mortality after surgical intervention (24, 66).

Most socio-demographic factors are predictors for the survival of infants such as maternal education, plurality, marital status but, paternal age less than 35 years are decreases survival than

age greater than 35 years (67). Low socioeconomic status is a factor for poor survival (66). An uninsured infant is 3 times more likely to die because of congenital heart disease (62).

2.5 Conceptual framework

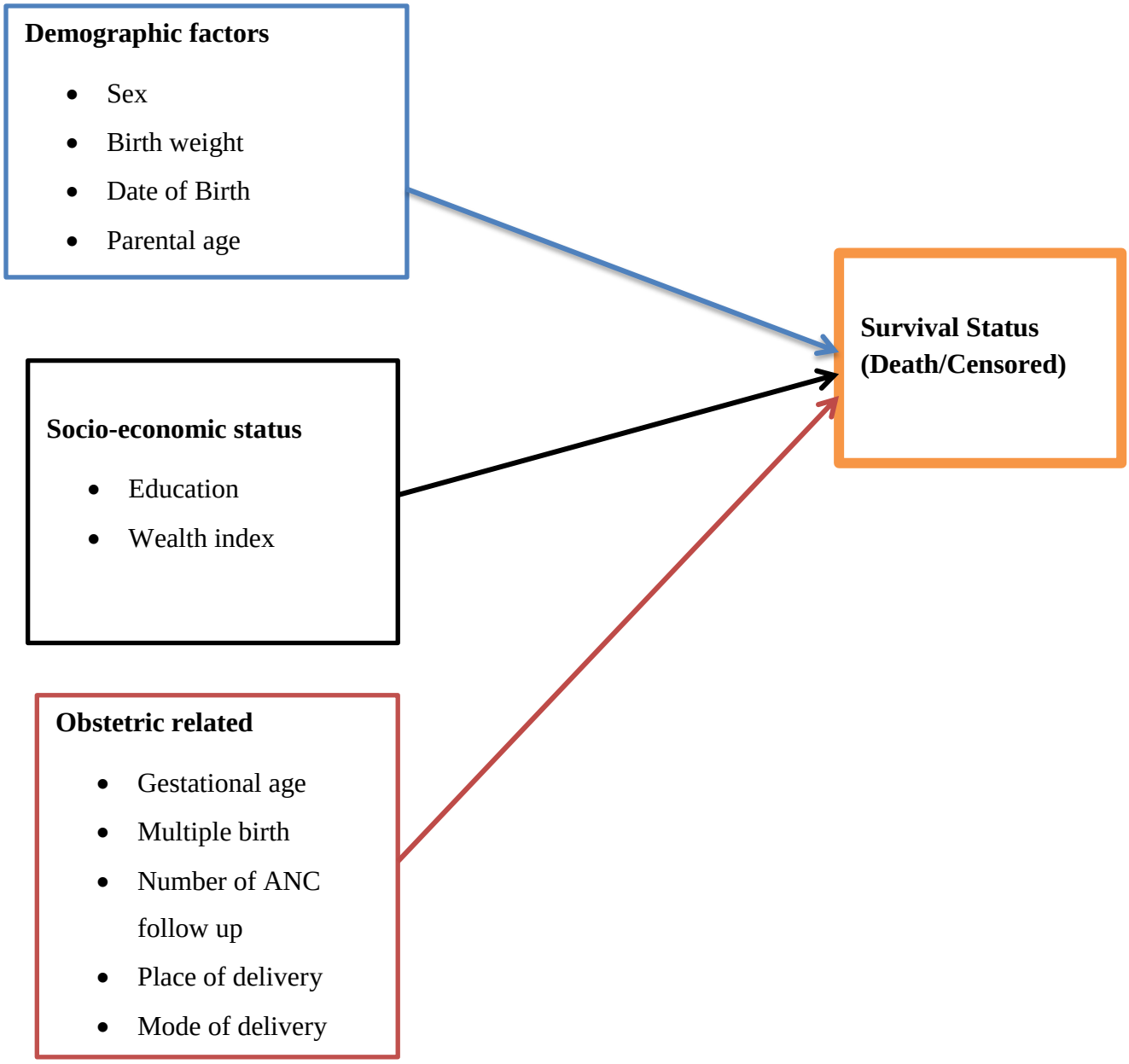


Figure 1: Conceptual framework to identify factors affecting the survival status of infants with congenital anomalies develops from literature

3. Objectives

3.1 General objective

To assess the probability of survivorship and its predictors in the first year of life among babies with congenital anomalies who have been admitted in TASH and ZMH, Addis Ababa, Ethiopia.

3.2 Specific objectives

- To measure the probability of survival in the first year of life among babies with congenital anomalies who have been admitted in TASH and ZMH.
- To identify factors affecting survival in the first year of life among babies with congenital anomalies who have been admitted in TASH and ZMH.

4. Methods

4.1 Study area and period

This study selected two hospitals: Tikur Anbesa Specialized Hospital (TASH) and Zewditu Memorial Hospital (ZMH) and included patients referred from Addis Ababa city hospitals and health centers to these hospitals.

TASH is the largest general public hospital in Addis Ababa and the largest tertiary level referral hospital in Ethiopia. It is also where specialized clinical services provide to the whole nation that is not available in other public or private institutions and opens 24 hours for emergency services. TASH offers diagnosis and treatment for approximately 370,000 – 400,000 patients a year. ZMH also found in Addis Ababa established in 1976 the hospital was named after Empress Zewditu. It is a large teaching and referral hospital under Addis Ababa health biro. Majorly most neural defects are surgically repaired in this site.

The study was done from January 2014 to December 2017 by retrieving information from the charts of admitted neonates with congenital anomalies and interviews the parents in the community.

4.2 Study design

A retrospective cohort study design was used among infants with congenital anomalies who were admitted at TASH and ZMH.

4.3 Source population

The source populations were infants diagnosed with congenital anomalies admitted in the TASH and ZMH and referred from health facilities located at Addis Ababa from 2014 to 2017.

4.4 Study population

Infants diagnosed with congenital anomalies were admitted in TASH and ZMH, who were referred from Addis Ababa city health facilities from 2014 to 2017.

4.5 Study unit

Randomly selected infants were diagnosed with congenital anomalies admitted in TASH and ZMH, who were fulfilled inclusion criteria.

4.6 Inclusion criteria

- Infants born with congenital anomalies
- Infants referred from health facilities in Addis Ababa city or directly admitted in the hospital and the resident is Addis Ababa from January 1, 2014, to December 31, 2017
- Mothers or guardians of the babies who currently reside in Addis Ababa city

4.7 Exclusion criteria

- Infants with congenital anomalies with incomplete living address, who changed their address and who were out of reach

4.8 Sample size determination

The sample size was computed using single population proportion formula with the assumption of 95% CI, 5% margin of error, p=0.5 (as far as the researcher's knowledge no previous study data available regarding proportion on the survival of infants with congenital anomalies).

$$n = Z^2_{\frac{\propto}{2}} * \frac{P(1-P)}{d^2}$$

$$n = 1.96^2 * \frac{0.5(0.5)}{0.05^2} = 384$$

After adding 10% for the non-response rate, the total sample size was 422.

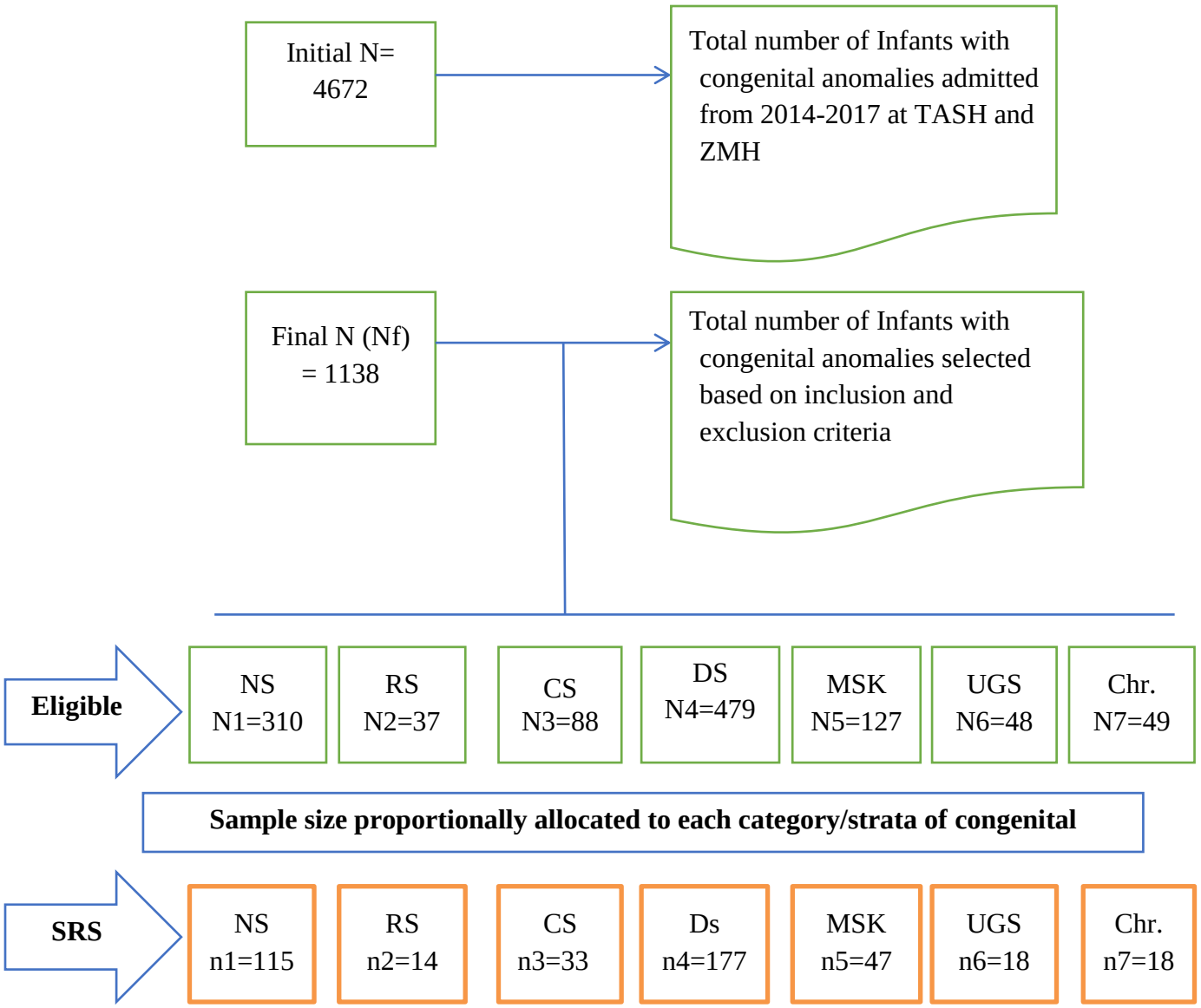
To check the adequacy of sample size for the second objective, the sample size was computed again using a double population formula with the assumptions of 95% CI, 5% margin of error, power of 80%, and 1:1 Ratio. Despite lack of local evidence, the proportion of survival among infants with congenital anomalies based on their gestational age exposed infants gestational age < 37 weeks (78.7%) and proportion of survival among non-exposed infants gestational age ≥ 37 weeks (64.2%) were taken from the previous study conducted in a developed country (67). The estimated sample size with a 10% non -response rate was 363. Thus, from the sample sizes calculated the largest sample size was taken which were 422.

4.9 Sampling procedure

The study classified types of congenital anomalies according to the International classification of disease (ICD-10) classification of disease only for cases of congenital anomalies available in TASH and ZMH. That means, the congenital anomalies classifications were divided into 7 strata, which are Nervous, respiratory, circulatory, digestive, musculoskeletal, urogenital system, and chromosomal abnormalities. A sampling frame was constructed for each stratum by reviewing a 4 years hospital registry book records of infants with congenital anomalies admitted at TASH and ZHM. Then, the sample size was allocated proportionally to each classification category of congenital anomalies (stratum) computed based on the following formula:

$$\boldsymbol{nj} = \frac{\boldsymbol{n}}{\boldsymbol{N}} * \boldsymbol{Nj}$$

Finally, the study participants were selected using simple random sampling techniques from each category of congenital anomalies or strata (Figure 2).



NS=Nervous System; RS= Respiratory System; CS= Circulatory System; DS= Digestive System; MSK=Musculoskeletal System; UGS= Urogenital System and Chr. =Chromosomal Abnormalities

Figure 2: Sampling procedure of participants

4.10 Variables

4.10.1 Dependent variable

- Survival status (Death/Censored)

4.10.2 Explanatory variables

- Birth weight
- Gestational age
- Sex of Infant
- Multiple births
- Maternal and paternal age
- Maternal and paternal education
- Number of antenatal follow-ups
- Place and mode of delivery
- Consanguinity
- Wealth

4.11 Data collection technique and instrument

An interviewer-administered questionnaire was developed by reviewing relevant literature and EDHS-2016 for an urban setting that was used to collect data at the community level. The tool consists of 52 numbers of items categorized into four sections including socioeconomic status, parental, child-related questions, and risk factors of congenital anomalies. Additionally, a structured checklist was developed to extract data from the hospital register book and charts including child-related questions.

The Instrument prepared in the English language was then translated to Amharic and administered in the Amharic language. Both the English and Amharic versions were used to design an electronic data collection tool using open source software called Open Data Kit (ODK) software. Data were collected electronically using a tablet on ODK software and the collected data were stored in the cloud storage server of the KoBoCollect humanitarian response website, which provided free data storage spaces for the researcher.

Data were collected by four urban health extension workers, recruited from four different sub-city of Addis Ababa, and 2 days of training was provided for data collectors on the instrument

and electronic data collection software (ODK) by the principal investigator and ODK designer. The training content includes getting informed consent and maintains ethical consideration, data collection and interview technique, dealing with emotional parents, and how to use ODK software.

After contacting each mother/guardian of infants, the data collectors and the principal investigator were provided detailed information about the research and informed consent was sought from each participant. After, getting the informed consent, the address of the study participants was recorded, and an appointment was scheduled. The data collectors have contacted the study participants based on the agreed appointment schedule.

4.12 Quality control

The overall activity was controlled by the principal investigator of the study. Internal validity was maintained by designing the proper data collection tool and by adjusting confounding variables. The questionnaire was translated from English to Amharic. Before data collection, a pre-test was conducted done on 25 individuals from different settings to check the reliability of the tool. The training was provided both for data collectors and supervisors. To ensure data completeness and accuracy, an electronic data collection tool (ODK) was used for data collection and the collected data was back up and the data security was always maintained.

4.13 Operational definition

- **Survival status:** is an event that measures time to death in days from birth to less than one year as a result of congenital anomalies.
- **Types of congenital anomalies:** classified based on ICD 10 disease classification (68).
  Congenital malformation of nervous System: a type of congenital anomalies includes MMC, encephalocele, hydrocephalus, and spinal bifid; congenital malformation of the respiratory system: a type of congenital anomalies includes choanal atresia; digestive system: a type of congenital anomalies includes EA, TEF, imperforate anus, congenital atresia and stenosis of intestinal; congenital malformation of circulatory system: a type of congenital anomalies includes CHD; congenital malformation of urogenital: a type of congenital anomalies includes hypospadias and bladder exstrophy; chromosomal abnormality: Down syndrome
- **Birth weight:** a newborn birth weight measured < 2500gm referred to as low birth weight and ≥2500gm as normal birth weight.

- **Gestational age:** an infant delivered with gestational age ≤ 36 weeks referred to as preterm and ≥37 weeks as term baby.
- **Wealth Index:** the score constructed by principal component analysis for each household by weighting a response concerning each item (household characteristics and assets) and divide the scores into three quantiles as poor, middle, and rich.

4.14 Data Analysis

Data were collected by electronic data collection software (ODK) and stored on the KoBoCollect humanitarian response website. The collected data was downloaded in Ms. Excel (Xls) format and was exported to STATA version 14 for data analysis after data cleanness was checked before analysis. Continuous variables with missed values were substituted with mean values and ignore variables with the system missing.

Participant's characteristics were described in terms of mean/median value for continuous data and percentage for categorical data. The wealth index score was constructed by using the principal component analysis to generate a weight for each household item. First categorical variables generate dichotomous variables 0 and 1, for each category and recode to 1 and 0 for yes or no original variables. Put all socio economic indicator variables into PCA and those variables with zero variance were dropped. The wealth index scores are divided into three quantiles as poor, middle, and rich.

The actuarial life table was constructed to calculate the chance of survival after being diagnosed with congenital anomalies and used to generate a survival curve. Seven days were used as the length of a time interval.

Kaplan Meier Survival Curve was computed to estimate survivorship of infants with congenital anomalies with the log-rank test to compare survival time between groups like birth weight, sex, gestational age, and maternal and paternal age, maternal and paternal education, child age at admission, intervention performed, multiple pregnancies, number of ANC visit, type of anomalies and wealth index score.

Variance inflation factor (VIF) is used to check multicollinearity after regression if there is a linear relationship between the predictors. To identify independent predictors of the probability of survival bivariate and multivariate Cox-proportional adjusted model was carried out. The

assumptions checked for observations are independent and hazards are proportional. Proportional hazard assumption checked by examining Log (-Log) S (t) plots. Those variables with parallel plots or linear associations met the proportional hazard assumptions. Efron method used adjustment to ties. The model gives crude and adjusted hazard ratios with their 95% Confidence Interval (CI) and P-Value. Predictors at P-value < 0.2 in bivariate analysis were exported to a multivariable cox proportional hazard model. A P-Value of less than 0.05 was used to declare the presence of a significant association between predictors and outcomes.

4.15 Ethical consideration

Ethical approval was obtained from Addis Ababa University, College of Health Science Institutional Review Board (IRB). Additionally, ethical consideration was obtained from AARHB, Addis Ababa Public Health Research, and Emergency Management Directorate; and permission letter was sought from each hospital and respective departments

Information was provided regarding the purpose of the study and how they will be benefited indirectly from the study result. The results will initiate public health professionals and policymakers for designing appropriate interventions for affected populations. Participants were informed the participation is voluntary and the right to quit their participation at any time was respected. Written informed consent was sought from all selected participants. Confidentiality of data was maintained; participants name was not written in the questionnaire only their address was provided to the data collectors to keep their privacy. There might be possible harm for deceased parents asking about their dead child might cause emotional disturbance. To minimize the risk, the data collectors were taken training on emotional support. The recorded data was not accessed by a third person except the principal investigator. All the information was explained in the local language.

4.16 Dissemination of results

Upon defense, the findings of the study will be disseminated to the School of Public Health, Addis Ababa University; TASH and ZMH; AARHB, other relevant stakeholders. An effort will be also made to publish the findings in national/international reputable journals and to be communicated in different scientific conferences.

5. Result

A total of 422 participants were included in the study. Of the participants, 394 were interviewed, resulting in a response rate of 93.4%. The mother of the child means age was 29.29±3.76 years and the paternal mean age was 33.35±4.39 years. Regarding the literacy status of the mother 358(90.86%) were could write and read and 36(16.75%) were could not write or read.

Mothers attended higher education were 207 (52.5%), secondary education were 86(21.8%) and, 65 (16.5%) were primary education and 36(9.1%) were not attended any formal education. Fathers attended higher education were 223(56.6%), 71(18%) were secondary education, 79(20.1%) were primary education and 21(5.3%) were not attended formal education. Of this 391(99.24%) were could write and read and 3(0.76) were could not write and read. The household wealth index quantiles 132(33.5%) were poor, 131(33.3%) were middle, and 131(33.3%) were rich. The participants had less than two children were 274(69.5%) and 120(30.5%) were had greater than three children. 393(99.7%) were deliver singleton and only one deliver was a twin. Most of the mothers attended ANC visits greater than or equal to 4 visits were 261(66.2%) and 133(33.8%) were attended less than or equal to three ANC visits.

Table 1: Parental - related characteristics, Addis Ababa, Ethiopia, 2020

Question	Response	Number	Percent
Maternal age	< 35 years	368	93.4
	≥ 35 years	26	6.6
Paternal age	< 35 years	229	58.1
	≥ 35 years	165	41.9
Maternal education	No education	36	9.1
	Primary education	65	16.5
	Secondary education	86	21.8
	Higher education	207	52.5
Paternal education	No education	21	5.3

	Primary education	79	20.1
	Secondary education	71	18.0
	Higher education	223	56.6
Wealth index quantile	Poor	132	33.5
	Middle	131	33.3
	Rich	131	33.3
Number of children	≤ 2 children	274	69.5
	≥ 3 children	120	30.5
Number of babies delivered	Singleton	393	99.8
	Multiple	1	0.3
Mother antenatal visits	≤ 3 ANC visits	133	34.2
	≥ 4 ANC visits	261	66.2

Among the children with congenital anomalies, 228(57.9%) were male and 166 (42.1%) were female. 138(35%) were childbirth weight less than 2500gm and 256(65%) were children birth weight greater than or equal to 2500gm. The mean birth weight was 2681.73(±545.87) gm. Gestational age less than 36 weeks were 57(14.5%) of the child and 337(85.5%) were age gestational age greater than or equal to 37 weeks with a mean of 38.49(±1.70) weeks. The child admitted in hospital at less than 24 hours of their age were 207 (52.5%)urs of their age and 187 (47.5%) were greater than or equal to 24 hours of age. 364 (92.4%) were performed surgery, 30 (7.6%) took the medication as an intervention during hospital admission. Most of the children were dead in hospital 195(49.5%) and 16 (4.1%) were dead in their home. 211(53.6%) were dead and 183(46.4%) were alive. Among types of congenital anomalies, 174 (44.2%) were digestive system, 110 (27.9%) were nervous system, 38(9.6%) were musculoskeletal system, 30 (7.6%) were circulatory system, both urogenital and chromosomal system were 15 (3.8%) and respiratory system were 12 (3.1%). Most deliveries were attended in institution 385 (97.7%) and

9 (2.3%) were at home. 330(83.8%) were delivered through spontaneous vaginal delivery, 50(12.7%) were cesarean section and 14 (3.5%) were assisted in instrumental delivery.

Table 2: Child-related characteristics, Addis Ababa, Ethiopia, 2020

Question	Response	Number	Percent
Sex of the child	Male	228	57.9
	Female	166	42.1
Birth weight	<2500 gm	138	35.0
	≥2500 gm	256	64.9
Gestational age	≤36 weeks	57	14.5
	≥37 weeks	337	85.5
Age of admission	< 24 hours	207	52.5
	≥24 hours	187	47.5
Interventions performed during admission	Surgery	364	92.4
	Medical	30	7.61
Child status	Alive	183	46.5
	Dead	211	53.6
Place of death	Hospital	195	92.4
	Home	16	7.6
Type of Congenital anomaly	Nervous system	110	27.9
	Respiratory system	12	3.1
	Circulatory system	30	7.6
	Digestive system	174	44.2
	Muskuloskeletal	38	9.6

	system		
	Urogenital system	15	3.8
	Chromosomal system	15	3.8
Place of delivery	Home delivery	9	2.3
	Institutional delivery	385	97.7
Mode of delivery	Spontaneous vaginal delivery	330	83.8
	Caesarean section	50	12.7
	Instrumental delivery	14	3.5

Incidence of death during the follow-up period

A total of 394 births with congenital anomalies were followed retrospectively for a median (IQR) duration of 28.5 days (5-365). The total analysis time at risk and under observation was 69257 person-days of follow-up and 211 incident deaths occurred during the overall follow-up period. The overall death rate among infants with congenital anomalies was 3.05(95% CI: 2.66-3.49) per 1000 person-days of follow-up. The death rate was 3.53(95% CI: 2.97-4.19) per 1000 person-days of follow-up among males and 2.49(95% CI: 2.0-3.10) per 1000 person-days of follow-up among females.

Survival of infants with congenital anomalies

The median survival time for the entire ascertained cases that died was 6 days (95% CI: 5 to 7). The median survival time for those who died was ranged from 2 days for cases with urogenital system anomaly to 10 days for cases with respiratory system anomalies. The median survival time for those who died from the nervous system, circulatory system, and chromosomal system congenital anomalies was 6 days. Whereas, the median survival time for those who died from digestive system and musculoskeletal system congenital anomalies was 5 days (Table 3).

Table 3: Median survival time of infants with congenital anomalies among cases who died from birth to 1 year of age, Addis Ababa, Ethiopia, 2020

Congenital anomalies	Number of live births followed	Number of deaths from birth to age 1year	Median survival time for those who died (days)	95% CI for median survival (days)
Nervous system	110	65	6	5-8
Respiratory system	12	3	10	-
Circulatory system	30	17	6	3-11
Digestive system	174	100	5	4-7
Musculo- skeletal system	38	19	5	2-7
Urogenital system	15	1	2	-
Chromosomal system	15	6	6	-
Total congenital anomalies	394	211	6	5-7

The life table presents the live-born infants with congenital anomalies surviving from birth to one year. The overall 7 days, 28days and 1-year survival probability was 70.3%, 50.0%, and 46.5%, respectively (Table 4) and (Figure 2). Infants with Nervous system congenital anomalies had the lowest 1-year survival probability 40.9% followed by the digestive system (42.5%) and circulatory system anomalies (43.3%).While, infants with urogenital system anomalies had the highest 1-year survival probability (93.3%), followed by respiratory system anomalies (75.0%), chromosomal system anomalies (60.0%), and musculoskeletal system anomalies (50.0%) (Table 5) and (Figure 4).

Table 4: Survival probability of infants with congenital anomalies birth to 1year, Addis Ababa, Ethiopia, 2020

Time interval	Beginning total	Number of deaths	Survival Probability (95% CI)
0 - 7	394	117	70.3(65.5-74.6)
7 - 14	277	55	56.4(51.3-61.1)
14 - 21	222	20	51.3(46.2-56.1)
21 - 28	202	5	50.0(44.9-54.8)
28 – 35	197	3	49.2(44.2-54.1)
35 - 42	194	4	48.2(43.2-53.1)
42 – 49	190	2	47.7(42.7-52.6)
49 – 56	188	1	47.5(42.5-52.3)
70 - 77	187	1	47.2(42.2-52.0)
175 – 182	186	1	46.9(41.9-51.8)
210 – 217	185	1	46.7(41.7-51.5)
266 – 273	184	1	46.5(41.5-51.3)
364 – 371	183	0	46.5(41.5-51.3)

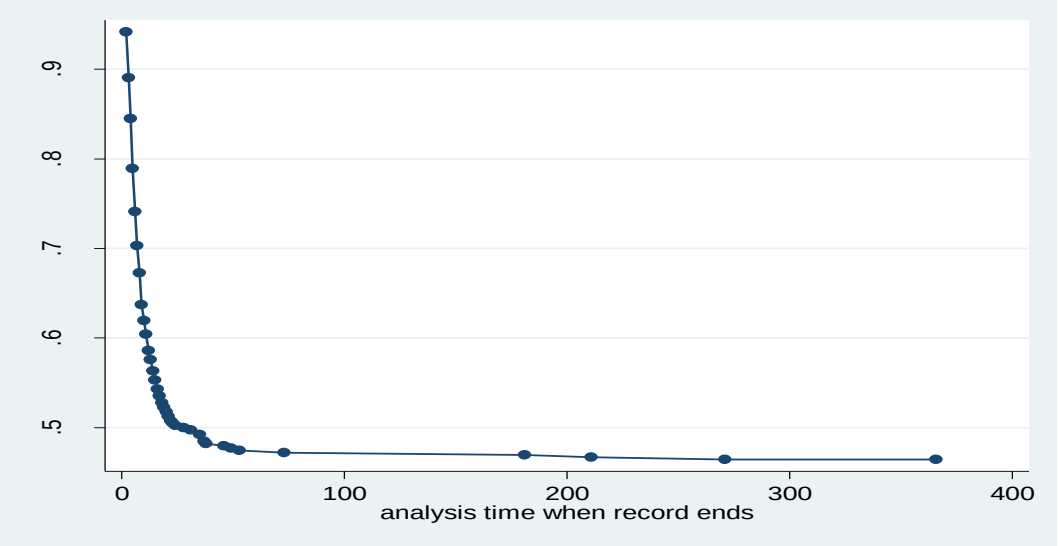


Figure 3: Overall survival probability of infants with congenital anomalies birth to 1 year, Addis Ababa, Ethiopia, 2020

Table 5: Survival probability of infants with congenital anomalies at 7 days and 1year based on the type of anomalies, Addis Ababa, Ethiopia, 2020

Congenital anomalies	Births	Deaths	Survival probability (95% CI)	
			7 day	1 year
All congenital anomalies	394	211	70.3(65.5- 74.6)	46.5(41.5-51.3)
Nervous system	110	65	69.1(59.5- 76.8)	40.9(31.7-49.9)
Respiratory system	12	3	91.7(53.9-98.8)	75.0(40.8-91.2)
Circulatory system	30	17	66.7(46.9-80.5)	43.3(25.6-59.9)
Digestive system	174	100	68.4(60.9-74.7)	42.5(35.1-49.7)
Musculo- skeletal system	38	19	65.8(48.5-78.5)	50.0(33.4-64.5)
Urogenital system	15	1	93.3(61.3-99.0)	93.3(61.3-99.0)
Chromosomal system	15	6	80.0(49.9-93.1)	60.0(31.8-79.7)

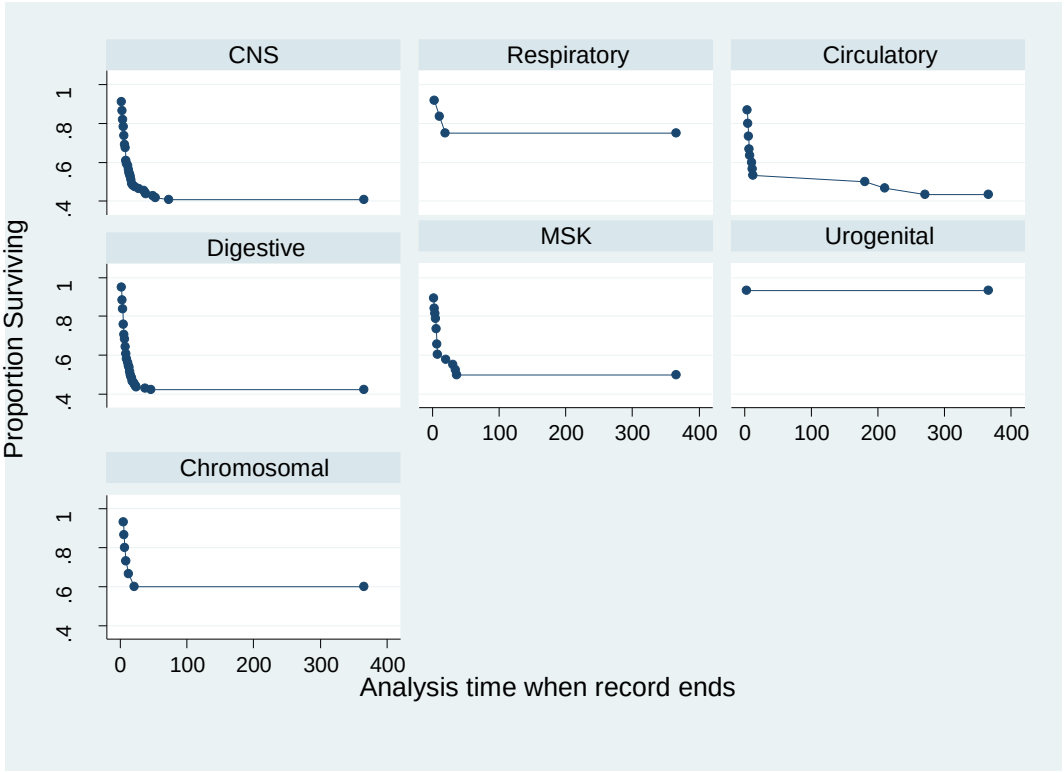


Figure 4: Survival probability of infants with congenital anomalies by type of anomalies from birth to 1 year, Addis Ababa, Ethiopia, 2020

First-year survival of infants with congenital anomalies by different groups

Kaplan-Meier survival curve showed that the first-year survival of infants with congenital anomalies was not significantly different from sex, place of delivery, time of diagnosis, maternal and paternal age and education, wealth index, or number of children. Male infants had lower first-year survival (42.5%, 95%CI: 36.1%-48.9%) compared to female infants (51.8%, 95%CI: 43.9%-59.1%). Home delivery had lower first-year survival (22.2%, 95%CI: 3.4%-51.3%) compared to infants delivered in the institution (47.0%, 95%CI: 41.9%-51.9%). Infants admitted less than 24 hours had higher first-year survival (47.0%, 95% CI: 40.0%-53.7%) compared to infants admitted after 24 hours of age (45.8%, 95%CI: 38.8%-52.7%). Maternal age less than 35 years had lower first-year survival (45.9%, 95%CI: 40.8%-50.9%) compared to maternal age greater than 35 years (53.9%, 95% CI: 33.3%-70.1%). paternal age less than 35 years had higher first-year survival (48.0%, 95%CI: 41.4%-54.3%) compared to maternal age greater than 35 years (44.2%, 95% CI: 36.6%-51.6%). Illiterate mothers had lower first-year survival (38.9%, 95% CI: 23.3%-54.2%) compared to educated mothers (47.2%, 95% CI: 41.9%-52.3%).

uneducated father had higher first-year survival of infants with congenital anomalies (61.9%, 95% CI: 39.1%-78.8%) compared to educated father (45.6%, 95% CI: 40.5%-50.5%). Poor socioeconomic status had lower first-year survival of infants with congenital anomalies (43.9%, 95% CI: 35.5%-52.2%) compared to higher socioeconomic status (49.6%, 95% CI: 40.8%-57.8%). The number of children less than two children had higher first-year survival (47.8%, 95% CI: 41.8%-53.6%) compared to greater than three children (43.3%, 95% CI: 34.4%-51.9%).

The first-year survival of infants with congenital anomalies was significantly different from birth weight, gestational age, intervention types, mother ANC visits, and type of congenital anomalies. Low birth weight infants (<2500 grams) had significantly lower first-year survival (32.6%, 95%CI: 24.9%-40.5%) compared to infants with birth weight ≥2500 grams (53.9%, 95%CI: 47.6%-59.8%); P-value= 0.0001. Infants born before 37 weeks of gestational age had significantly lower first-year survival (29.8%, 95%CI: 18.6%-41.9%) compared with Infants born at gestational age of 37 weeks and above (49.3%, 95%CI: 43.8%-54.5%); P-value= 0.001. The first-year survival of infants with congenital anomalies was also significantly different by types of interventions received (P-value =0.001). First-year survival for infants who received the surgical intervention was 48.1%, 95%CI: 42.9%-53.1%) and for those who received the medical intervention was 26.7%, 95%CI: 12.2%-43.0%); P-value=0.001..

First-year survival of infants was also significantly different from types of congenital anomalies diagnosed; ranged from 40.9%, 95%CI: 31.7%-49.9% for infants with nervous system anomalies to 93.3%, 95%CI: 61.3%-99.0% for infants with Urogenital system anomaly; (P-value =0.01). Infants whose mother had at least four antenatal care visits had significantly higher first-year survival (50.6%, 95%CI: 44.4%-56.5%) than infants whose mother had lower than four ANC visits (38.4%, 95%CI: 30.1%-46.5%); P-value= 0.01 (Table 6).

Table 6: First-year survival of infants with congenital anomalies by different groups, Addis Ababa, Ethiopia, 2020

Characteristics		Cases	Deaths	Survival(95%CI)	P-value
Sex of the child	Male	228	131	42.5(36.1-48.9)	0.0572
	Female	166	80	51.8(43.9-59.1)	
Birth weight	<2500 gm	138	93	32.6(24.9-40.5)	**0.0001**
	≥2500 gm	256	118	53.9(47.6-59.8)	
Gestational age	≤36 weeks	57	40	29.8(18.6-41.9)	**0.0013**
	≥37 weeks	337	171	49.3(43.8-54.5)	
Place of delivery	Home delivery	9	7	22.2(3.4-51.3)	0.2161
	Institutional delivery	385	204	47.0(41.9-51.9)	
Age at admission	<24 hours	202	107	47.0(40.0-53.7)	0.4574
	≥24 hours	192	104	45.8(38.8-52.7)	
Interventions	Surgery	364	189	48.1(42.9-53.1)	**0.0012**
	Medication	30	22	26.7(12.5-43.0)	
Maternal age	<35 years	368	199	45.9(40.8-50.9)	0.5923
	≥35 years	26	12	53.9(33.3-70.1)	
Paternal age	<35 years	229	119	48.0(41.4-54.3)	0.6326
	≥35 years	165	92	44.2(36.6-51.6)	
Maternal education	No education	36	22	38.9(23.3-54.2)	0.1763
	Primary & above	358	189	47.2(41.9-52.3)	
Paternal education	No education	21	8	61.9(39.1-78.8)	0.1545
	Primary & above	373	203	45.6(40.5-50.5)	

Wealth index	Poor	132	74	43.9(35.5-52.2)	0.6327
	Middle	131	71	45.8(37.1-54.1)	
	Rich	131	66	49.6(40.8-57.8)	
Number of children	≤2 children	274	143	47.8(41.8-53.6)	0.5140
	≥ 3 children	120	68	43.3(34.4-51.9)	
Mother ANC Visits	≤3 Visits	133	82	38.4(30.1-46.5)	**0.008**
	≥4 Visits	261	129	50.8(44.5-56.7)	
Type of Congenital anomalies	Nervous system	110	65	40.9(31.7-49.9)	**0.0133**
	Respiratory system	12	3	75.0(40.8-91.2)	
	Circulatory system	30	17	43.3(25.7-59.9)	
	Digestive system	174	100	42.5(35.1-49.7)	
	Musculo- skeletal system	38	19	50.0(33.4-64.5)	
	Urogenital system	15	1	93.3(61.3-99.0)	
	Chromosomal system	15	6	60.0(31.8-79.7)	

Predictors of time to death of infants with congenital anomalies

To identify independent predictors of time to death, the Cox proportional hazards model was used. Before fitting the covariate into the model proportional hazards assumption was checked by examining Log (-Log S (t)) plots. Those variables full filled the assumption were selected for analysis using the Cox proportional hazards model. Low birth weight [CHR: 1.8 (95% CI: 1.4-2.4], gestational age ≤36 weeks [CHR: 1.8 (95% CI: 1.2-2.5], surgical intervention [CHR: 0.5 (95% CI: 0.3-0.7)], and mother had lower than four ANC Visits [CHR: 1.5 (95% CI: 1.1-1.9], were found to be significantly associated with time to death.

In the final Cox proportional hazards model gestational age, maternal and paternal education, and mother ANC visits were no significant association with survival of infants with congenital anomalies. The hazard of died from congenital anomalies among preterm infants was 1.2 times

higher compared to infants with normal gestational age [AHR: 1.2(95%CI: 0.8-1.8)]. The hazard of infant death from congenital anomalies among uneducated mothers was 1.4 times higher compared to educated mothers [AHR: 1.4(95%CI: 0.9-2.1)]. The hazard of infant death from congenital anomalies among uneducated father was 0.7 times lower compared to educated father [AHR: 0.7(95%CI: 0.3-1.5)]. The hazard of died from congenital anomalies among mothers who had less than three visits was 1.2 times higher compared to mothers who had greater than four visits [AHR: 1.2(95%CI: 0.9-1.6)].

Male infants, low birth weight, and surgical intervention were found to be significantly associated with time to death. The hazard of died from congenital anomalies among male infants was 1.4 times significantly higher compared to female infants [AHR: 1.4(95% CI: 1.0-1.8)] ($p<0.05$). The hazard of died from congenital anomalies among low birth weight infants (<2500 grams) was 1.6 times significantly higher compared to infants with birth weight ≥2500 grams [AHR: 1.6 (95% CI: 1.2-2.3)] ($p<0.01$). Also, the hazard of died from congenital anomalies who received the surgical intervention was 0.5 significantly lower compared to infants who received medical care [AHR: 0.5 (95% CI: 0.3-0.8)] ($p<0.01$) (Table 7).

Table 7: Predictors of survival of infants with congenital anomalies in Addis Ababa, Ethiopia, 2020

Covariate	Alive Number (%)	Dead Number (%)	Crude HR (95%CI)	Adjusted HR (95%CI)
Sex of the child				
Male	97(53)	131(62.1)	1.3(0.9-1.7)	**1.4(1.0-1.8) ***
Female	86(47)	80(38)	1	1
Birth weight				
<2500 gm	45(24.6)	93(56)	**1.8(1.4-.2.4) *****	**1.6(1.2-2.3) ****
≥2500 gm	138(75.4)	118(56)	1	1
Gestational age				
≤36 weeks	17(9.1)	40(19)	**1.8(1.2-2.5) *****	1.2(0.8-1.8)
≥37 weeks	166(90.7)	171(81)	1	1
Interventions				
Surgery	175(95.6)	189(89.6)	**0.5(0.3-0.7) *****	**0.5(0.3-0.8) ****
Medication	8(4.4)	22(10.4)	1	1
Maternal education				
No education	14(7.7)	22(10.4)	1.4(0.9-2.1)	1.4(0.9-2.1)
Primary & above	169(92.4)	189(89.6)	1	1
Paternal education				
No education	13(7.1)	8(3.8)	0.6(0.3-1.2)	0.7(0.3-1.5)
Primary & above	170(93)	203(96.2)	1	1
Mother ANC Visits				

≤3 Visits	51(27.9)	82(38.9)	**1.5(1.1-1.9) ****	1.2(0.9-1.6)
≥4 Visits	132(72.1)	129(61.1)	1	1

NB. *=P-Value <.05, **= P-Value ≤.01 and ***=P-Value ≤.001, HR= Hazard Ratio

6. Discussion

Congenital anomalies are emerging public health which significantly increasing in developing countries likes Ethiopia. According to Moorthie and his colleague's (2018) fetal death, disability, premature deaths are the possible outcomes of congenital abnormalities in the absence of interventions (69). This study reported valuable data on survival status and their determinants among infants in Addis Ababa.

In this study, the median survival time was 6 days (95% CI: 5 to 7). This result is comparable with other studies conducted in the United States of America (USA), University of North Carolina Hospitals, and Scotland, Glasgow Register of Congenital Anomalies, 3 days and 11 days was reported as median survival time for infants with congenital anomalies respectively (9, 60). Another study conducted in Israel reported the mean age of full-term infant death due to congenital anomalies causes was 7.6 days (±5.8 days, range: 1 to 26 days) (70). Despite, the studies are conducted in developed countries, the results imply infants with congenital anomalies are at risk of premature death and much emphasis should be given to alleviate the problem. Premature death may have negative consequences on the mother, including loss of self-esteem results from a woman's inability to rely on her body and from carrying defective genes. The mother and other family members may also need psychosocial support to prevent pathological grieving due to perinatal death.

In this study, the 7 days, 28days, and 1-year survival probability was 70.3%, 50.0%, and 46.5%, respectively, and the Down syndrome was 60.0% one-year survival probability. This finding is different from reported in other studies on a 25-year survival analysis among New York children born with congenital anomalies a population-based study; the overall 7 days, one month and year survival probability was 93.8%, 91.6%, and 87.1% and greater than 90% survival probability for down syndrome (71). The reason for higher survival probability as compared to this study is due to socioeconomic status, sample size, healthcare quality, and study period. This finding indicates that programs and policies should focus on the strengthening of the quality of care in neonatal units of health institutions. Improving the quality of care could be important to avoid the negative attitude of mothers towards the services provided by health institutions.

The survival probability of Circulatory system anomalies was 7 days (66.7%), and the one-year survival probability was 43.3% in this study. This finding on 7 days survival was similar to a

study conducted at Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based study, the reported 7 days survival probability of circulatory system anomalies was 66%. However, the one-year survival probability was different from this study which was 27% (23). On the contrary, another study conducted in Florida, USA, based on the Florida Birth Defect Registry (FBDR), reported the highest first-year survival probability among infants with any CHD cases, 96.7% and 85.3% among infants with critical CHD cases (62). However, both studies were conducted in developed countries with advanced healthcare systems.

The one-year survival of chromosomal system anomalies was 60.5% in this study. This was lower than the study conducted in the United Kingdom (UK) was 88.3% (72) and another study conducted in the USA, MACDP, reported that 92.9% (95% CI: 90.9%- 94.9%) of infants with Down syndrome were survived to 1 year of age (73). The chromosomal anomalies are potentially lethal and may also relate with other systems and it may reduce the survival probability of infants.

In this study, the one-year survival of infants with nervous system congenital anomalies was 40.9% (95% CI: 31.7-49.9). This was lower than the study reported from the USA, the one-year infant survival with Spinal Bifida was 92.1% and the one-year survival of infants with encephalocele was 79.1% (74). Similarly, another study conducted at Children's Hospital of Pittsburgh reported higher one-year survival of nervous system congenital anomalies, which was 84 % of infants with MMC, was survived in the first year of life. According to this study, mortality is more recurrent in symptomatic infants presenting before one year of age (10). One of the reasons for the improved survival status of infants with NTD in developed countries is due to a multidisciplinary team approach with delivery at tertiary hospitals (75).

Infant sex is a predictor in this study being male is a factor for the survival of infants with congenital anomalies. On contrary, different articles found that sex is not an independent predictor for survival (23), (72). Different literature supports that male infants are more vulnerable to adverse neonatal outcomes. Male infant mortality can be decreased by giving antenatal steroids and surfactants (76). This shows antenatal follow up could improve survival for male infants.

Low birth weight is a major predictor for the survival of infants even without major morbidity. According to Watkins and his colleagues, low birth weight is associated with an increased

mortality rate not only in infancy but also through adolescence (77). In this study, 35% of infants with congenital anomalies were low birth weight. Additionally, low birth weight was a significant predictor for the survival of infants with congenital anomalies which was supported by different similar studies conducted in North of England (72), UK, Northern Congenital Abnormality Survey (NorCAS) (29), USA, MACDP (11), Hong Kong (64), USA (74), UK, British Isles Network of Congenital Anomaly Registers (BINOCARs) (30), Iran (78), USA, MACDP (73), USA, North Carolina Birth Defects Monitoring Program (NCBDMP) (67), USA, New York (71), India (8). These results build on existing evidence of low birth weight can affect the survival status of infants and increase the risk of health-related consequences. Preventing low birth weight is an important public health goal to improve the survival of infants with congenital anomalies which required holistic and upstream strategies. Prenatal care is important to reduce the incidence of low birth weight by medical, nutritional, and educational interventions. These improve time of hospitalization and reduced the risk of low survival of low birth weight babies by improving in neonatal intensive care unit delivery services.

Steady over time improvement in survival of infants with congenital anomalies indicates that recent advances in treatment and surgery intervention may play a key role. Recent studies reported significant improvement in survival of children with Down syndrome, CHD, EA, and TEF which could be related to advancement in rates of surgery and interventions (8, 79, 80). In this study, another predictor for survival was surgical interventions; infants with congenital anomalies who received the surgical intervention were 2 times more likely to survive up to the first year of age. This implies early intervention could be important to improve the health outcomes of infants with congenital anomalies.

According to different literature, preterm was significantly associated with worsen outcome and one-year survival status of infants with congenital anomalies North of England (72), UK, NorCAS (29), Australia (61), Texas (81), USA (74), UK, BINOCARs (30), USA, MACDP (73), USA, NCBDMP (67), Iran (78), USA, MACDP (23). However, the association between gestational age and one-year survival status was not statistically significant in this study. The observed discrepancy could be due to variation in sample sizes and periods of follow-up.

7. Strength and limitation

7.1 Strength

- The findings could be generalized to congenital anomalies patients who live in Addis Ababa and who had a follow-up in public hospitals.
- Substantial measurement was taken to maintain data quality and reduce research bias.

7.2 Limitation

- The study was based on a short study period.
- The study scope is limited to congenital anomalies patients' who live in Addis Ababa and are admitted to public hospitals.

8. Conclusion

The overall 1-year survival probability for infants with congenital anomalies was 46.5% (95%CI: 41.5%-51.3%). The lowest 1-year survival probability was found among infants with nervous system congenital anomalies cases 40.9% (95%CI: 31.7%-49.9%). The median survival time among infants with congenital anomalies died was 6 days (95%CI: 5-7days). The major predictors found for the survival of infants with congenital anomalies are male infant, low birth weight, and received a surgical intervention to the first year of life.

9. Recommendation

Policy Makers and Local leaders

- Holistic, integrated effective interventions are required to improve the survival probability of infants with congenital anomalies.
- ANC follow-up should be strengthened to reduce the proportion of low birth weight, especially nutritional counselling should be provided for pregnant mothers. Nutritional interventions should be designed to improve the nutritional status of newborns with congenital anomalies which was one of the predictors for survival probability of infants with congenital anomalies.
- The accessibility and quality of surgical interventions also need emphasis to improve the survival probability of infants with congenital anomalies. Collaborative and advanced care should be considered for infants with congenital anomalies.

Health Professionals and Health Institutions

- Health professionals should provide integrated care for newborn babies with congenital anomalies to improve their survival probability and the follow-up should be regular and continuous through their infancy.
- Pregnant mothers should attend regular ANC follow-up and early diagnosis of congenital anomalies is vital to improve the quality of care provided for newborns and to reduce the probability of low birth weight.
- Nutritional counselling must be provided for pregnant mothers to improve the nutritional status of newborns.
- Surgical interventions and advanced care centers should be available for newborns with congenital anomalies. The center should well equip with the required materials and human resources.

Researcher

- A qualitative study should be conducted to explore the possible psychosocial support for mothers who lost their babies due to congenital anomalies.

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Annexes

Annex I: Information sheet hospital data extractor

Title: Survival status of infants with congenital anomalies in the selected hospital, Addis Ababa, Ethiopia.

My name is _____. I am here on the behalf of Mahdere Tsegaye research work from Addis Ababa University College of Health Science for partial fulfillment of the requirements for the degree of Master of public health in reproductive health. We are conducting a research entitled 'Survival status of infants with congenital anomalies in the selected hospitals, Addis Ababa, Ethiopia'. The main aim of the study is to know the survival status of infants with congenital anomalies. The purpose of this study is to assess the survival status of infants with congenital anomalies and their determinants for survival.

The data collection format will be used to extract information from medical records related to congenital information. The data extraction process will respect patient privacy and keep all information privates. Study records will be identified by the identification number. Name from medical records will not be extracted and patient identity will not be shared with anyone except the principal investigator. The results of the study may be published for scientific purposes. However, patient identity is not being given out.

The security of medical records will be maintained, and health facilities' security regulation of medical records will be respected throughout the process. The data extraction will be supervised by health facilities' personnel and all data will be extracted within the facilities. The confidentiality, privacy, and security regulation specified by the government and health will always be respected . The study was ethically approved by the Institutional Review Board, college of health science, Addis Ababa University.

If you need any clarification, you can ask the principal investigator of the study using the following contact address, Mahdere Tsegaye, Mobile +251 911713836, or Email: mahderetsegye@gmail.com.

Annex II: Informed consent hospital data extractor

The health facility has been informed about the study, which plans to study on the survival status of infants with congenital anomalies in the selected hospitals, Addis Ababa, Ethiopia. The objective, purpose, benefit, harm, and confidentiality of the study were briefly explained to us.

It is therefore with a full understanding of the situation that the health facilities agreed to give the informed consent voluntarily to the researcher to extract information from patient health records (Hospital cards) for the proposed study.

Signature of the Health facility representative _____

Name of reviewer _____

Date _____

Thank you!

Annex III: Hospital data extractor format

Addis Ababa University

College of Health Science

School of Public Health

Code	Variable	Response
101	Address	Respondent Code _____ Hospital name _____ Sub city _____ Kebele/Woreda _____ House No. _____ Tel. No. _____
102	Type of Congenital anomaly (Specify if there are multiple anomalies)	1. Cleft palate 2. Cleft lip 3. Hypospadias 4. Club foot 5. Omphalocele/ Exomphalos 6. Gastroschisis 7. Down syndrome 8. Spina bifida 9. Hydrocephalus 10. Small intestine obstruction 11. Tracheoesophageal fistula 12. Ambiguous genitalia 13. Meningomyelocele 14. Bladder exstrophy 15. Imperforated anus 16. Encephalocele

		17. Pyloric obstruction 18. Choanal atresia 19. Congenital heart disease 20. Others (specify) _____
103	Birth Weight	_____ grams
104	Sex of the baby	1. Male 2. Female 3. Indeterminate sex 4. Unknown
105	Duration of gestational age in completed weeks (estimated based on last menstrual period or ultrasound determination) at birth	_____ weeks
106	Age of the baby on admission	_____ hours
107	Duration of hospital stay	_____ hours _____ days
108	Did the mother have ANC follow up	1. Yes 2. No
109	If the mother has followed up, number of antenatal care follow up	Number _____
110	Who attended the delivery?	1. Gynecologist/Obstetrician 2. General Practitioner 3. Midwife 4. Health officer 5. |Nurse

		6. Other (Specify)_____
111	Number of babies delivered with the index child.	Number _____
112	Was it referred from a lower-level facility?	1. Yes 2. No
113	Diagnosis from a referral site	Diagnosis _____
114	Findings from radiologic diagnosis	Radiologic diagnosis _____ _____
115	Interventions performed during admission **List possible interventions**	1. Medical 2. Surgery 3. Rehabilitation 4. Palliative care
116	Status of the baby at the time of exit from the hospital	1. Alive 2. Dead
117	If dead, what is the age at death?	Age _____ hours _____ days

Annex IV: Information sheet English version

Title: Survival status of infants with congenital anomalies in the selected hospital, Addis Ababa, Ethiopia.

Dear Respondent,

My name is _____. I am here on the behalf of Mahdere Tsegaye research work from Addis Ababa University College of Health Science for partial fulfillment of the requirements for the degree of Master of public health in reproductive health. We are conducting a research entitled 'Survival status of infants with congenital anomalies in the selected hospitals, Addis Ababa, Ethiopia'. The main aim of the study is to know the survival status of infants with congenital anomalies. The purpose of this study is to assess the survival status of infants with congenital anomalies and their determinants for survival. If you decide to participate in the study, we will ask you various questions on factors that could cause death in infants with congenital anomalies. There is no major risk associated with this study. Your participation is completely voluntary, and you have the right to refuse to be in this study. You can stop at any time after giving your consent. This decision can not affect in any way your current or future medical care or any other benefits to which you are otherwise entitled. We respect your privacy and keeping all your information private. Your study records identify you by identification number. Your name will not be written in the questionnaire and your identity will not be shared with anyone except the principal investigator. The results of the study may be published for scientific purposes. However, your identity is not being given out. You are asked for the signature of the agreement. This is to make sure that your agreement to participate in the study is on a volunteer and informed basis. Otherwise, there is no other reason for signing.

No one can participate in the study without giving her/his consent and agreement. You have the full right to get full information about study procedures and other related issues with languages of your choice. We will take approximately 20 minutes to complete the questionnaire. If you need any clarification, you can ask the principal investigator of the study using the following contact address, Mahdere Tsegaye, Mobile +251 911713836, or Email: mahderetsegye@gmail.com.

Annex V: Informed consent English version

I have been informed about the study, which plans to study the survival status of infants with congenital anomalies in the selected hospitals, Addis Ababa, Ethiopia. The objective, purpose, benefit, harm, and confidentiality of the study were briefly explained to me.

It is therefore with a full understanding of the situation that I agreed to give the informed consent voluntarily to the researcher to give information for the study.

Signature of the participant _____

Name of interviewer and signature _____

Date _____

Thank you for your participation!

Annex VI: Questionnaire English version

Addis Ababa University

College of Health Science

School of Public Health

Identification

Code:
Hospital name:
Sub city:
Woreda:
House no.:
Area code:
Telephone:

Part I. Socio-Economic characteristics

Q. Code	Questions	Response	Skipping Pattern
101	Observe the main material on the floor of the dwelling.	1. Earth/sand 2. Wood planks 3. Vinyl or asphalt strips/plastic tile 4. Ceramic tiles 5. Cement	

		6. Carpet 7. Other (specify) _____	
102	Observe the main material of the roof of the dwelling.	1. Thatch/mud 2. Rustic mat/ plastic sheet 3. Wood planks 4. Metal/corrugated iron 5. Calamine/cement-fiber/asbestos 6. Cement 7. Other (specify)	
103	Observe the main material of the exterior walls of the dwelling.	1. Cane/palm/trunks/bamboo/ 2. Bamboo with mud 3. Stone with mud 4. Uncovered adobe 5. Reused wood 6. Cement 7. Cement blocks 8. Other (Specify) _____	
104	Where is the water source located?	1. In own dwelling 2. In own yard/plot 3. Elsewhere	If the answer is 1or 2 skip 107 & 108
105	What is the main source of drinking water for members of your household?	1. Piped into dwelling 2. Piped to yard/plot 3. Piped to neighbor 4. Public tap/standpipe	

		5. Protected well/Spring 6. Unprotected well/Spring 7. Bottled water 8. Other (Specify) _____	
106	What is the main source of water used by your household for other purposes such as cooking and handwashing?	1. Piped into dwelling 2. Piped to yard/plot 3. Piped to neighbor 4. Public tap/standpipe 5. Protected well/Spring 6. Unprotected well/Spring 7. Bottled water 8. Other (Specify)_____	
107	If the water is located elsewhere, how long does it take to go there, get water, and come back?	1. _____ Minutes 2. Don't know	
108	Who usually goes to this source to fetch the water for your household?	1. Adult woman 2. Adult man 3. Female child Under 15 years old 4. Male child Under 15 years old 5. Other (specify) _____	
109	In the past two weeks, was the water from this source not available for at least one full day?	1. Yes 2. No 3. Don't Know	
110	Do you do anything to the water to make it safer to drink? **Not include bottled water**	1. Yes 2. No	If the answer is 2 skip

			111
111	What do you usually do to make the water safer to drink? **Record All Mentioned.**	1. Boil 2. Add bleach/chlorine 3. Strain through a cloth 4. Use water filter (ceramic/ sand/composite/etc.) 5. Solar disinfection 6. Let it stand and settle 7. Other (specify) _____ 8. Don't know	
112	What kind of toilet facility do members of your household usually use? **If not possible to determine, ask permission to observe the facility.**	1. Ventilated improved pit latrine 2. Pit latrine with slab 3. Pit latrine without slab/open pit 4. Bucket toilet 5. No facility/bush/field 6. Other (specify)_____	If the answer is 5 skip 113
113	Do you share this toilet facility with other households?	1. Yes 2. No	If the answer is 2 skip 114
114	Including your own household, how many households use this toilet facility?	No. of households _____	
115	Where is this toilet facility located?	1. In own dwelling 2. In own yard/plot	

		3. Elsewhere	
116	What type of fuel does your household mainly use for cooking?	1. Electricity 2. Natural gas 3. Biogas 4. Kerosene 5. Charcoal 6. Wood 7. No food cooked in household 8. Other (specify) _____	If the answer is 7 skip 117
117	Where is the cooking usually done?	1. In the house 2. In a separate building 3. Outdoors 4. Other (specify)_____	
118	Do you have a separate room which is used as a kitchen?	1. Yes 2. No	
119	How many rooms in this household are used for sleeping?	Rooms _____	
120	Does your household have: **Ask each question**	Yes No 1. Electricity 1 2 2. Radio 1 2 3. Television 1 2 4. Non-mobile telephone 1 2 5. Computer 1 2 6. Refrigerator 1 2 7. Table 1 2 8. Chair 1 2 9. Bed with cotton/sponge/ spring mattress 1 2	

		10. Electric mitad 1 2 11. Kerosene lamp/ pressure lamp 1 2	
121	Does any member of this household own? **Ask each question**	Yes No 1. Watch 1 2 2. Mobile phone 1 2 3. Bicycle 1 2 4. Motorcycle/scooter 1 2 5. Animal-drawn cart 1 2 6. Car/truck 1 2 7. Baggage 1 2	
122	Does any member of this household have a bank account?	1. Yes 2. No	
123	Can you please show me where members of your household most often wash their hands?	1. Observed, fixed place 2. Observed, mobile Not observed, 3. Not indwelling/yard/plot 4. Not observed, no permission to see 5. Not observed, other reason	If the answer is 3,4,5 skip 124
124	Observe the presence of water at the place for handwashing.	1. Water is available 2. Water is not available	
125	Observe the presence of soap, detergent, or other cleansing agents at the place for handwashing.	1. Soap or detergent (bar, liquid, powder, paste) 2. Ash, mud, sand 3. None	

Part II. Parental related characteristics

Question Code	Question	Response	Skipping Pattern
201	Age of the mother at delivery to the index child	_____ years	
202	Age of the father at birth to the index child		
203	Number of children ever born including the index child	_____ number	
204	Number of babies delivered	1. Singleton 2. Twin or more	
205	Has the mother can read and write?	1. Yes 2. No	If the answer is no skip Q. 207
206	What is the highest grade the mother has attended?	_____ Grade Informal ☐	
207	Has the father can read and write?	1. Yes 2. No	If the answer is no skip Q. 209
208	What is the highest grade the father has attended?	_____ Grade Informal ☐	
209	Do the parents have one or more	1. Relationship of second	

	ancestors in common no remote than a great grandparent /second cousin (Consanguinity)	cousin or closer 2. Not related or relationship more distant than the second cousin 3. Not known	

Part III. Child Related Characteristics

Question Code	**Question**	**Response**	**Skipping Pattern**
301	When was your baby born?	____/_____/ _____ Day/Month/Year	
302	Sex of the baby	1. Male 2. Female 3. Indeterminate sex 4. Unknown	
303	Is the baby still alive?	1. Yes 2. No	If the answer is no skip Q. 304
304	How old was at last birthday	_____ years	
305	How old was when the baby died?	_____	
306	Where the baby died?	1. Hospital 2. Home	
307	When the baby was diagnosed with having a congenital anomaly	1. Immediately at birth 2. Within 24 hours 3. Less than 1 week	

		4. 1-4 weeks 5. 1-12 months 6. Don't know	
308	Mode of delivery	1. Spontaneous vaginal delivery 2. Cesarean section 3. Instrumental delivery	
309	Place of delivery	1. Home delivery 2. Institutional delivery 3. Other (specify) _____	

Part IV. Risk Factor Related Characteristics

Question Code	**Question**	**Response**	**Skipping Pattern**
401	Did the mother have the following habits during her pregnancy **Record All Mentioned.**	1. Alcohol use 2. Smoking 3. Chat chewing 4. Shisha 5. Drug	
402	Did the mother expose to the following factors? **Record All Mentioned.**	1. Environmental/ occupational chemicals (dioxin, organic solvent, pesticides, heavy metals (lead, mercury), fertilizers 2. Radiation 3. Drugs (Thalidomide, anticonvulsant, bendectin)	

403	Is there a Family History of congenital anomaly	1. Yes 2. No	
404	Is there a previous malformed sibling	1. Yes 2. No	
405	Did the mother had an illness during the first 20 weeks of pregnancy that can affect fetal development	1. Yes 2. Yes, but no information available 3. No 4. Not known	If the answer is 2, 3, or 4 skips 406
406	What was the illness during the first 20 weeks of pregnancy? **Record All Mentioned.**	1. Gestational Diabetes 2. Folic acid deficiency 3. Thyroid deficiency 4. Others (specify) _____	
407	Did the mother had an infection during the first 20 weeks of pregnancy that can affect fetal development	1. Yes 2. Yes, but no information available 3. No 4. Not known	If the answer is 2, 3, or 4 skips 408
408	What was the infection during the first 20 weeks of pregnancy? **Record All Mentioned.**	1. Rubella 2. Syphilis 3. Toxoplasmosis 4. Others (specify) _____	
409	Medication was taken in the first trimester.	1. Yes, medication is taken in the first trimester 2. No medication is taken in the first trimester	

		3. Medication was taken, but the timing unknown 4. Not Known	

Annex VII: Information sheet Amharic version

መረጃ መግለጫ

<u>የጥናቱ ርዕስ፡-</u>አብሮ ከተወለደ በሽታ ጋር የሚኖሩ ህፃናትን በህይወት መኖርን ይመለከታል።

እኔ ስሜ _____ እባላለሁ:: ከአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ በድህረ ምረቃ ትምህርት ፕሮግራም ከህብረተሰብ ጤና ትምህርት ክፍል ማህደረ ፀጋዬን ወክዬ ነው የመጣሁት። ጥናት ለማድረግ መረጃ እየሰበሰብኩ ነዉ። የመጠይቁ ዓላማ አብሮ ከተወለደ በሽታ ጋር የሚኖሩ ህፃናትን በህይወት መኖርን እና ለሞት ሊዳርጉ የሚችሉ ተጓዳኝ ምክንያቶችን ለመለየት የተዘጋጀ ነው። ለመሳተፍ ፈቃደኛ ከሆኑ አንዳንድ ጥይቄዎችን እጠይቅዎታለሁ። በጥናቱ ላይ መሳተፍዎ ሙሉ በሙሉ የሚመሰረተዉ በራስዎ ፍላጎትና ፍቃደኝነት ላይ ነዉ። ከመጀመሪያዉ በጥናቱ ላይ መሳተፍም ሆነ ላለመሳተፍ ይችላሉ። ካልተስማማዎት በመሀል የማቋረጥ መብትዎ ሙሉ በሙሉ የተጠበቀ ነዉ። ያልገባዎትን መረጃ ለመመለስ አይገደዱም። ይሄ ዉሳኔ በአሁኑም ሆነ ለወደፊት ባለው የህክምና ህይወትዎ ላይ ተፅእኖ አያመጣም።ስምዎት ከመረጃዉ ጋር አይካታትም፡ የሰጡኝን መረጃ ሁሉ በሚስጥር እነደምጠብቅልዎ ቃል እገባለሁ። ለሳይንሳዊ አላማ ለህትመት ሊበቃ ይችላል። ስምምነትዎን በፊርማዎት እንዲያረጋግጡልን ስንጠይቅ ፈቃደኛነትዎን ለማረጋገጥ ብቻ ነው። ጥያቀዉ የምወስደዉ ግዜ በአማካይ 20 ደቂቃ ብቻ ነዉ። ተጨማሪ ማብራሪያ ካስፈለገዎ በሚቀጥለዉ አድራሻ መጠየቅ ይችላሉ። ማህደረ ፀጋዬ ስልክ ቁጥር 0911713836, Email: mahderetsegaye@gmail.com

Annex VIII: Informed consent Amharic version

በመረጃ ላይ የተመሰረተ የፍቃደኝነት ቅፅ

አብሮ ከተወለደ በሽታ ጋር የሚኖሩ ህፃናትን በህይወት መኖርን በተመለከተ ጥናት ለማድረግ እንደታሰበ መረጃ ተሰቶኛል። ስለ አላማው፣ ጥቅሙ፣ ጉዳቱ እና ሚስጥራዊነት በደንብ ተገልፆልኛል።

ስለዚህ ስለጉዳዩ ሁሉንም በመረዳት ለዚህ ጥናት የሚረዳ መረጃ ለመስጠት በፈቃደኝነት እስማማለሁ።

የተጠያቂ ፊርማ _____

የጠያቂው ስም እና ፊርማ _____

ቀን _____

ስለተሳተፉ እናመሰግናለን!!

Annex IX: Questionnaire Amharic version

አዲስ አበባ ዩኒቨርሲቲ

ጤና ሳይንስ ኮሌጅ

ህብረተሰብ ጤና ትምህርት ክፍል

<u>መጠይቅ</u>

የአካባቢ መለያ

የመጠይቁ መለያ ቁጥር፡
የሆስፒታሉ ስም፡
ክፍለ ከተማ፡
ወረዳ፡
የቤት ቁጥር፡
የአካባቢው ልዩ ስም፡
ስልክ፡

ክፍል ኣንድ፡ ማህበራዊ እና ኢኮኖሚያዊ መረጃን በተመለከተ

ተ.ቁ	ጥያቄዎች	ምላሽ	እለፍ
101	የመኖሪያ ቤቱ ወለል የተሰራበትን እቃ አስተውልና ሙላ	1. አፈር 2. ጣውላ 3. ፕላስቲክ ምንጣፍ 4. ሴራሚክ ታይልስ 5. ሴራሚክ 6. ምንጣፍ	

		7. ሌላ (ያገለፅ)_____	
102	የመኖሪያ ቤቱ ጣሪያ የተሰራበትን እቃ አስተውልና ሙላ	1. የሳር ክዳን 2. ፕላስቲክ 3. ጣውላ 4. ቆርቆሮ 5. አስቤስቶስ 6. ሴራሚክ 7. ሌላ (ያገለፅ)_____	
103	የመኖሪያ ቤቱ የውጭ ግድግዳ የተሰራበትን እቃ አስተውልና ሙላ	1. ሸንበቆ 2. ጭቃ 3. ድንጋይ 4. ያልተሸፈነ ጡብ 5. እንጨት 6. ስሚንቶ 7. ሌላ (ያገለፅ)_____	
104	ውሃ ከየት ያገኛሉ?	1. ከመኖሪያ ቤት ውስጥ 2. አጥር ግቢ ውስጥ 3. ሌላ ቦታ	መልሱ 1 ወይም 2 ከሆነ ጥይቄ 107 እና 108 ን ይለፉ
105	የመጠጥ ውሃ አቅርቦት በዋናነት የምታገኙት ከየት ነው?	1. የግል ቧንቧ 2. የጋራ ቧንቧ 3. የጉረቤት	

		4. የቦኖ ውሃ 5. ከተጠበቀ የጉድጓድ/የምንጭ ውሃ 6. ካልተጠበቀ የጉድጓድ/የምንጭ ውሃ 7. የታሸገ ውሃ 8. ሌላ (ያገለፅ)_____	
106	ለምግብ እና ለእጅ መታጠቢያ ውሃ አቅርቦት በዋናነት የምታገኙት ከየት ነው?	1. የግል ቧንቧ 2. የጋራ ቧንቧ 3. የጉረቤት 4. የቦኖ ውሃ 5. ከተጠበቀ የጉድጓድ/የምንጭ ውሃ 6. ካልተጠበቀ የጉድጓድ/የምንጭ ውሃ 7. የታሸገ ውሃ 8. ሌላ (ያገለፅ)_____	
107	ውሃው ከሌላ ቦታ የሚመጣ ከሆነ ውሃውን ለማምጣት ምን ያህል ግዜ ይፈጃል?	1. _____ ደቂቃ 2. አላውቅም	
108	አብዛኝውን ጊዜ ውሃውን ለመቅዳት ማን ይሄዳል?	1. አዋቂ ሴት 2. አዋቂ ወንድ 3. ከ 15 አመት በታች ያለች ሴት ልጅ 4. ከ 15 አመት በታች ያለ ወንድ	

		ልጅ 5. ሌላ (ይገለፅ)_____	
109	የቧንቧ ውሃ ባለፉት ሁለት ሳምንታት ቢያንስ ለአንድ ሙሉ ቀን ጠፍቶ ያውቃል	1. አዎ 2. አያውቅም 3. አላውቅም	
110	የመጠጥ ውሃውን ለማጣራት ሞክረው ያውቃሉ። **(የታሸገ ውሃን አይጨምርም)**	1. አዎ 2. አላውቅም	መልሱ 2 ከሆነ ጥይቄ 111 ን ይለፉ
111	ውሃውን ለማጣራት ምን ይጠቀማሉ **(ከአንድ በላይ መልስ ማክበብ ይቻላል)**	1. ማፍላት 2. ማጣሪያ መጨመር (ክሎሪን) 3. በልብስ ማጥለል 4. በአሸዋ ማጣራት 5. በፀሀይ 6. አስቀምጦ እንዲዘቅጥ ማድረግ 7. ሌላ (ይገለፅ)_____ 8. አላውቅም	
112	የቤተሰቡ አባላት የሚጠቀሙበት የመፀዳጃ ቤት ዓይነት ምንድን ነው? **(መለየት ካቃታቸው ፈቃድ ጠይቀህ አስተውልና ሙላ)**	1. የተሻሻለ ሽታ አልባ የጉድጓድ መጸዳጃ ቤት 2. የጉድጓድ መጸዳጃ ቤት/በግንብ/በሲሚንቶ 3. ባህላዊ የጉድጓድ መጸዳጃ ቤት/ያለግንብ ሲሞላ	መልሱ 5 ከሆነ ጥይቄ 113 ን ይለፉ

		4. ባልዲ/ተንቀሳቃሽ 5. መጸዳጃ ቤት የለውም 6. ሌላ (ያገለፅ)_____	
113	መፀዳጃ ቤቱን ከሌላ ቤተሰብ ጋር ይጋራሉ?	1. አዎ 2. አልጋራም	መልሱ 2 ከሆነ ጥይቄ 114 ን ይለፉ
114	ይህንን መፀዳጃ ቤት የእናንተን ቤተሰብ ጨምሮ ምንያህል ቤተሰብ ይጠቀማል	ቁጥር _____	
115	መጸዳጃ ቤቱ የት ይገኛል?	1. ከመኖሪያ ቤት ውስጥ 2. አጥር ግቢ ውስጥ 3. ሌላ ቦታ	
116	ቤተሰቡ በአብዛኛው ለምግብ ማብሰያ ምን ይጠቀማል?	1. ኤሌክትሪክ 2. የተፈጥሮ ጋዝ 3. ባዮ ጋዝ 4. ነጭ ጋዝ 5. ከሰል 6. እንጨት 7. አላበስልም 8. ሌላ ካለ ይገለፅ _____	መልሱ 7 ከሆነ ጥይቄ 117 ን ይለፉ
117	በአብዛኛው ቤተሰቡ ምግብ የትነው የሚያበስለው?	1. ቤት ዉስጥ 2. በተለየ ማብሰያ ክፍል 3. ከቤት ውጪ የተሰራ	

		4. ሌላ ካለ ይገለፅ _____	
118	ለማዕድቤት የተለየ ክፍል አለ?	1. አዎ 2. የለም	
119	ቤቱ ስንት መኝታ ቤት አለው?	_____ ክፍል	
120	ቤተሰቡ ከእነዚህ እቃዎች የቱን ይጠቀማል/ አለው? **ማስታወሻ፡- እያንዳንዱ ይጠየቃል**	አለ የለም 1. ኤሌክትሪክ 1 2 2. ሬድዮ 1 2 3. ቴሌቭዥን 1 2 4. የቤት ስልክ 1 2 5. ኮምፒውተር 1 2 6. ፍሪጅ/ማቀዝቀዣ 1 2 7. ጠረጴዛ 1 2 8. ወንበር 1 2 9. አልጋ ከ ስፖንጅ ፍራሽ 1 2 10. ኤሌክትሪክ ምጣድ 1 2 11. የጋዝ መብራት 1 2	
121	ከቤተሰቡ አባላት ውስጥ ከታች የተዘረዘሩትን ንብረቶች ያለው አለ? **ማስታወሻ፡- እያንዳንዱ ይጠየቃል**	አለ የለም 1. ሞባይል 1 2 2. ሳይክል 1 2 3. ሞተር ሳይክል 1 2 4. ጋሪ 1 2 5. መኪና 1 2 6. ሻንጣ 1 2	

122	ከቤተሰቡ አባላት ውስጥ ባንክ ደብተር ያለው አለ?	1. አዎ 2. የለም	
123	የቤተሰቡ አባላት በአብዛኛውን ጊዜ እጃቸውን የሚታጠብበትን ቦታ ሊያሳዩኝ ይችላሉ?	1. ቋሚ ቦታ ላይ፣ ታይቷል 2. ተንቀሳቃሽ ቦታ፣ታይቷል 3. መታጠቢያ ቦታ በቤት ውስጥ አልታየም 4. ፈቃድ ማግኘት አልተቻለም 5. በሌላ ምክንያት ማየት አልተቻለም	መልሱ 3፣4፣5 ከሆነ ጥይቄ 124 ን ይለፉ
124	የመታጠቢውያ ቦታ ውሃ እንዳለው አረጋግጥ	1. ውሀ አለ 2. ውሀ የለም	
125	የእጅ መታጠቢያ ቦታው ሳሙና ወይም ሌላ የመታጠቢያ ኬሚካል እንዳለ አረጋግጥ	1. ሳሙና ወይም ሌላ የመታጠቢያ ኬሚካል አለ(ደረቅ፣ፈሳሽ፣ዱቄት) 2. አመድ/ጭቃ/አሸዋ 3. የለም	

ክፍል ሁለት፡ የቤተሰብ ሁኔታዎች መረጃን በተመለከተ

ተ.ቁ	ጥያቄዎች	ምላሽ	እለፍ
201	የጤና ችግር የነበረበትን የመጨረሻውን ልጅዎን ሲወልዱ እድሜዎ በሙሉ ዓመት ስንት ነበር?	_____ ዓመት	
202	የጤና ችግር የነበረበት የመጨረሻው ልጅዎ	_____ ዓመት	

	ሲወለድ የአባቱ እድሜ በሙሉ ዓመት ስንት ነበር?		
203	የጤና ችግር ያለበትን ህፃን ጨምሮ በአጠቃላይ ስንት ልጆች በህይዎት ወለዱ?	_____ ቁጥር	
204	የጤና ችግር ያለበትን ህፃን ብቻውን ነው የተወለደው?	1. አዎ 2. የለም፤መንታ ወይም ከዚያ በላይ ነው	
205	ማንበብ እና መፃፍ ይችላሉን?	1. አዎ 2. የለም	መልሱ የለም ከሆነ ወደ ጥይቄ 207 ን ይለፉ
206	ያጠናቀቁት ከፍተኛ ክፍል ስንት ነው?	ክፍል _____ መደበኛ ያልሆነ ☐	
207	ባለቤትዎ ማንበብ እና መፃፍ ይችላሉ?	1. አዎ 2. የለም	መልሱ የለም ከሆነ ወደ ጥይቄ 209 ን ይለፉ
208	የትምህርት ደረጃቸው ምን ያህል ነው?	ክፍል _____ መደበኛ ያልሆነ ☐	

209	ባለቤትዎ እና እርስዎ የስጋ ዝምድና (ከአያት ባልራቀ ሁኔታ) አላችሁ?	1. የአጎት/ የአክስት ልጆች/የቀረበ ዝምድና አለን 2. የአጎት/ የአክስት ልጆች/የራቀ ዝምድና ነው ያለን 3. አናውቅም	

ክፍል ሶስት፡ ከህመምተኛው ጋር የተያያዙ ጥያቄዎች

ተ.ቁ	ጥያቄዎች	ምላሽ	እለፍ
301	የጤና ችግር ያለበት ልጅዎ መቼ ነው የተወለደው	____/_____/ _____ ቀን/ወር/አመተ ምህረት	
302	የልጅዎ ጾታ ምንድን ነው?	1. ወንድ 2. ሴት 3. አሻሚ 4. አይታወቅም	
303	ልጅዎ በህይወት አለ/አለች	1. አዎ 2. የለም	መልሱ የለም ከሆነ ጥይቄ 304 ን ይለፉ
304	በህይወት ካለ/ች እድሜው/ዋ ስንት ነው	_____	
305	በህይወት ከሌለ/ች በስንት እድሜው/ዋ ሞተ/ች	_____	
306	በህይወት ከሌለ/ች የት ነው	1. ሆስፒታል	

	የሞተው/ሞተችው	2. ቤት	
307	መቼ ነበር በሽታው በህክምና የተረጋገጠው	1. እንደተወለደ 2. በ 24 ሰአት ውስጥ 3. በአንድ ሳምንት ውስጥ 4. ከአንድ እስከ አራት ሳምንት 5. በአንድ አመት ውስጥ 6. አላውቅም	
308	የጤና ችግር ያለበት ልጅዎን የተገላገሉት እንዴት ነው	1. በማህፀን ያለመሳሪያ ድጋፍ 2. በቀዶ ጥገና 3. በማህፀን በመሳሪያ ድጋፍ	
309	የጤና ችግር ያለበት ልጅዎን የተገላገሉት የት ነው?	1. ቤት ውስጥ 2. የጤና ተቋም ውስጥ 3. ሌላ ቦታ (ይገለፅ)_____	

ክፍል አራት፡ ከተጋላጭነት ጋር የተያያዙ ጥያቄዎች

ተ.ቁ	ጥያቄዎች	ምላሽ	እለፍ
401	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ ምን አይነት ልማድ ነበረብዎት? **(ከአንድ በላይ መልስ ማክበብ ይቻላል)**	1. መጠጥ መጠጣት 2. ሲጋራ ማጨስ 3. ጫት መቃም 4. ሺሻ ማጨስ 5. ሱስ የሚያስይዙ መድሀኒቶችን መጠቀም	
402	የጤና ችግር ያለበት ልጅ ነፍሰጡር እያሉ	1. ለአካባቢያዊ/ከስራ ጋር	

	ለየትኞቹ ነገሮች ተጋላጭ ነበሩ? **(ከአንድ በላይ መልስ ማክበብ ይቻላል)**	የተያያዙ ኬሚካሎች (ፀረ ተባይ፣ ማዳበሪያ፣ ዲዩክሲን፣ ሄቪ ሜታል(ሊድ፣ሜርኩሪ)፣የሚተኑ ኬሚካሎች (ቤንዚን፣አልኮል)… 2. ጨረር 3. መድሀኒት(ለሚጥል በሽታ የሚሰጥ…)	
403	በቤተሰብ ዉስጥ አብሮ የሚወለድ በሽታ ኖሮበት የተወለደ ሰው አለ?	1. አዎ 2. የለም	
404	ከዚህ በፊት አብሮ የሚወለድ በሽታ ኖሮበት የተወለደ ልጅ አለዎት?	1. አዎ 2. የለም	
405	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ በመጀመሪያው ሃያ ሳምንታቶች ውስጥ የልጁን እድገት ሊጎዳ የሚችል ህመም ነበረብዎ?	1. አዎ 2. አዎ ግን ምንም መረጃ የለኝም 3. የለም 4. አላውቅም	መልሱ 2፣3፣4 ከሆነ ጥይቄ 306 ን ይለፉ
406	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ በመጀመሪያው ሃያ ሳምንታቶች ውስጥ የልጁን እድገት ሊጎዳ የሚችለው የህመም አይነት ምንድን ነበር? **(ከአንድ በላይ መልስ ማክበብ ይቻላል)**	1. በእርግዝና ጊዜ የሚመጣ ስኳር 2. የፎሊክ አሲድ እጥረት 3. የታይሮይድ እጥረት 4. ሌላ ካለ ቢገለፅ _____	

407	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ በመጀመሪያው ሃያ ሳምንታቶች ውስጥ የልጁን እድገት ሊጎዳ የሚችል መመረዝ (ኢንፊክሽን) ነበረብዎ?	1. አዎ 2. አዎ ግን ምንም መረጃ የለኝም 3. የለም 4. አላውቅም	መልሱ 2፣3፣4 ከሆነ ጥይቄ 308 ን ይለፉ
408	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ በመጀመሪያው ሃያ ሳምንታቶች ውስጥ የልጁን እድገት ሊጎዳ የሚችለው የመመረዙ (ኢንፊክሽን) አይነት ምንድን ነበር? **(ከአንድ በላይ መልስ ማክበብ ይቻላል)**	1. ጀርመን ኩፍኝ 2. ቂጥኝ 3. ቶክሶፕላስሞሲስ 4. ሌላ ካለ ይገለፅ _____	
409	የጤና ችግር ያለበት ልጅዎን ነፍሰጡር እያሉ በመጀመሪያው አስራ ሁለት ሳምንቶች(ሶስት ወር) ውስጥ የሚዋጥ መድሀኒት ወስደው ነበር?	1. አዎ 2. የለም 3. መድሀኒት ወስጄ ነበር ግን ጊዜውን አላስታውሰውም 4. አላውቅም	