

ADDIS ABABA UNIVERSITY
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DEPARTMENT OF NURSING AND MIDWIFERY

ASSESSMENT OF PARENTS' INVOLVEMENT AND ASSOCIATED
FACTORS IN DECISION MAKING REGARDING TREATMENT FOR THE
CRITICALLY ILL NEONATES IN THE NEONATAL INTENSIVE CARE
UNIT OF PUBLIC HOSPITALS, ADDIS ABABA, ETHIOPIA.

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This thesis by **Seada Jemal Seid** is accepted in its present form by the board of examiners as satisfying thesis requirement for degree of masters of Science in **child health nursing**.

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Acronyms

AACAHB: Addis Ababa City Administration Health Bureau

AAP: American Academy of Pediatrics

AAU: Addis Ababa University

AIDS: Acquired Immune Deficiency Syndrome

FMOH: Federal Ministry of Health

HCP: Health Care Professional

HIV: Human Immunodeficiency Virus

LSMT: Life Sustaining Medical Treatment

NICU: Neonatal Intensive Care Unit

NM: Neonatal Mortality

NMR: Neonatal Mortality Rate

UN: United Nation

WHO: World Health Organization

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Abstract

Background: There are 130 million babies born every year worldwide. Of those births, 15% are born premature, 5% of those premature infants are born weighing less than 1kilogram, and 75% of those infants will survive. A significant controversy has emerged regarding the role of parents, relative to health care providers, in relation to treatment decision for critically ill children. Little research has actually been conducted that explores whether and how parents are involved in the decision making process especially in developing countries.

Objective: The objective of this study is to assess Parents' Involvement and Associated Factors in Decision Making Regarding Treatment for the Critically Ill Neonates in the Neonatal Intensive Care Unit of Public Hospitals, Addis Ababa, Ethiopia.

Methods: Institution based cross-sectional design which was supported by a qualitative study was conducted in five public hospitals with Neonatal intensive care unit in Addis Ababa from December 2013 to June 2014. A total of 160 parents were selected from the five public hospitals using systematic random sampling method. A pre-tested and structured questionnaire was used for data collection.

Conveniently selected eligible study participants (Neonatologists and neonatal nurses) were interviewed during the qualitative study.

Result: The study found that most of the respondents 112(70%) were not participated in decisions. Majority of them 133(83.1%) believed that HCPs were the responsible person to decision making. More than half 86(53.8%) of the parents preferred shared decision making. Most 131(81.9%) of the parents were satisfied with parent-staff therapeutic relationship. Multiple logistic regression model revealed that mother's residence and prior history with premature, disabled, or any death of a child were found to be associated with parental involvement in treatment decisions [AOR (95%CI) =7.024(2.151, 22.936)] and [AOR (95%CI) =106.704(10.779, 1056.309)] respectively. Similarly mother's age, educational

status, and satisfaction with parent-staff therapeutic relationship have a statistically significant association with parental involvement in treatment decisions for their critically ill neonate.

Conclusion & Recommendation: The study showed a lower involvement of parents in treatment decisions of their critically ill neonates. Therefore government, health administrators and concerned stakeholders should make an effort empower parents to make decisions on their neonate's treatment.

1. Introduction

1.1 Back ground

The World Health Organization (WHO) defines “neonatal mortality” (NM) as the “death of a live born during the period which starts at birth and ends 28 completed days after birth”.

There are 130 million babies born every year worldwide. Of those births, 15% are born premature, 5% of those premature infants are born weighing less than 1kilogram, and 75% of those infants will survive (1).

Of the total births about 4 million die during the neonatal period. Of those deaths in the world, 99% occur in developing countries. The highest rates of neonatal mortality occur in Sub- Saharan Africa. According to recent reports (2007) of the U.N, Ethiopia’s Neonatal Mortality Rate (NMR) is 39 per 1000 live births with neonatal deaths totaling 119,500 annually. Infections are the most common causes of death, followed by low birth weight due to poor nutrition, asphyxia, congenital problems and other causes(2).

Premature birth can roughly be defined as childbirth occurring before 37 weeks of gestation, but after approximately 28 weeks of gestation. Normally it is not only the gestational period that is taken into consideration in determining whether a baby is premature or not, but also the birth weight (3).

The shorter term of pregnancy is the greater the risk of complications (4). Infants born prematurely have an increased risk of mortality in the first year of life. These fragile babies are very vulnerable as they are also at greater risk of developing serious health problems, such as cerebral palsy and chronic lung disease, gastrointestinal problems, mental retardation and vision or hearing loss(5). Babies who are also in danger of being denied treatment or who face possible rejection are critically-ill neonates with visible congenital defects such as myelomeningocele, gastroschisis, or cleft lip or palate. Conjoined twins or babies with serious but invisible defects,

such as congenital cardiac defects or those with acquired conditions like HIV/AIDS, are also at risk of rejection(6).

Until relatively recently, it would not have been possible to do much for the baby and most extremely premature babies would have died at birth or soon afterwards. Many critically-ill babies would also not have been able to survive for more than a few weeks or months after birth (7). “Doubtless it was simpler when babies with severe disability had no prospect of remaining alive. No ethical code was needed to reach conclusions—ultimately, nature decided for us” (8).

Advances in medical science have been accompanied by an increase in the survival rate of premature and critically-ill neonates. However, the risk of morbidity increases as the gestation period decreases (7). The morbidity experienced includes both mental handicaps and physical handicaps (4). Clearly there are situations in which continued medical treatment essentially prolongs the inevitable death process rather than prolonging life. Yet the specifics of when and how to set limits on medical intervention remain complex and controversial (9). And the law has not kept up with the advances in neonatal medicine, and this has consequently given rise to uncertainty about the legal position, both for health care professionals and for parents(3).

A significant controversy has emerged regarding the role of parents, relative to health care providers, in relation to treatment decision for critically ill children. In most cases, the decision to stop or limit treatment is made with senior medical and nursing staff (10).

Parents need to be closely involved in the care and decision-making process associated with their infant. Health-care providers must provide parents with accurate information to help them make decisions about the treatments for their infant. To reinforce parents’ confidence in the information they receive, a relationship of trust must be built between them and the health-care provider. The parents’ trust is based on good communication and the belief that the health-care provider truly cares about their infant. The experience in the Neonatal Intensive Care Units

(NICU) is extremely difficult and stressful for parents, and support throughout their infant's stay is imperative (11).

1.2 Statement of the Problem

The newborn intensive care unit (NICU) is a common setting for difficult ethical challenges, often involving life-and-death decisions. These may include withholding treatment or withdrawing life-sustaining medical treatment (LSMT). Such decisions are frequently faced because of the high morbidity and mortality of some conditions commonly encountered in this setting, such as extreme prematurity, perinatal asphyxia, and major congenital anomalies. Since infants are not capable of making decisions for them, ethical dilemmas concerning the nature, extent and duration of care for imperiled neonates become the primary responsibility of the often unprepared family.

The joy parents feel when looking forward to the birth of their baby is replaced by fear and anxiety when the baby is premature or is very ill at birth (1). Parents concern is not only for the future of their baby, but also for the future of the family, since having a premature or critically-ill neonate will inevitably influence the family as a whole, not only emotionally, but also financially (3).

Historically, parent involvement in treatment decisions for their children was minimal. A physician's recommendation was usually accepted without question. A paternalistic approach by the physician was accepted not only by the parents, but also by the medical community (12). Recently, there has been increasing recognition of patient autonomy with concurrent support for family participation in decision making and parents prefer more involvement in reaching treatment decisions for their children than in the past (13).

According to a study in South Africa, joint decision making was rare (14%), and < 10% of parents themselves made life support decisions for their infant. Less than 10% of parents

preferred doctors to make life-support decisions without consultation. In general parents preferred greater input in decision making than they perceived they had been given (14).

However, parents need information given in understandable terms, in a timely fashion, and with compassion. They often need information repeated. Explaining terminology and preparing parents for what may happen next serves to keep them oriented to the course of events as they unfold (9).

But it is still an immense, heartbreaking responsibility for parents to decide to withdraw life sustaining treatments for their infant. They face the challenge of comprehending the medical information provided to them and using the information to decide whether they should allow their child to live or die. From the parents' perspective, the situation is not necessarily about ethics but about making decisions in the best interests of their child (15).

Similarly, health-care providers are confronted with the ethical dilemma to continue or withdraw care of critically ill neonates. These decisions are based on future quality of life, severity of handicaps, and projections of longevity and often reflect the values of parents and health-care providers. Shared decision making between health-care providers and parents raises a number of troublesome issues (16).

Although parents need to be closely involved in the care and decision-making process associated with their infant, little research has actually been conducted that explores whether and how parents are involved in this decision making process especially in developing countries. There is no study exploring this phenomenon in Ethiopia.

Therefore, this study will assess parents' involvement in the treatment decision for their critically ill neonates in the context of public hospitals in Addis Ababa, Ethiopia.

1.3 Significance of the Study

- The finding of the study estimated parents' involvement in decision making and the factors associated with parent's decision making about neonates in NICU.

- It helps the health care providers especially nurses as an advocate of a patient; to pay attention to the patient autonomy or parents autonomy (in neonatal patients) of being involved in end of life care and treatment decisions for the critically ill neonates.
- It will also help the policy makers and health facilities to develop appropriate plans and intervention to reduce the problem.
- In addition, since it is new in our country it will serve as base line for those who wish to conduct study on this area.

2. Literature Review

2.1 Decision Making Process on Treatment of the Critically Ill Neonates

With the increased survival of ever smaller premature infants and the salvage of previously nonviable, malformed or critically ill infants, many moral and ethical dilemmas have intensified (18). Historically, parent involvement in treatment decisions for their children was minimal. A paternalistic approach by the physician was accepted not only by the parents, but also by the medical community (12). But now parents prefer more involvement in reaching treatment decisions for their children than in the past (13).

An American study showed that 83% parents participated in decision (19). While a Canadian survey of parents of extremely low birth weight survivors, neonatologists, and neonatal nurses showed; nearly all parents either agreed or strongly agreed that the parents should have the final word regarding the initiation or the limitation of treatment but they agreed or strongly agreed 50-75 % of the time that doctors should make the final decision (20).

An international study group in Pacific Rim countries showed that in locations except Melbourne and Australia, the majority of parents (75-86%) perceived that there was joint decision making between the physician and the parents. In Melbourne, three-quarters of the parents perceived that the physicians made the decision alone. A majority of parents at all sites (62-95%) preferred the model of joint decision making (21).

A study in Europe showed that 56% of parents were involved to decide to stop treatment, with three-quarters of those believing that it has been their decision alone and one-quarter believing that the decision had been made in conjunction with the physicians. Eighty three percent of parents believed that the correct person(s) had made the decision (22).

A study in Baltimore showed that 40% of treatment decisions were actually shared between the physicians and the parents (23).

According to a study in Israel, the great majority of respondents felt that both the parents (89%) and the physicians (94%) should be involved in medical ethical decision-making. Thirty four per cent also felt it extremely important that a religious authority be involved in making such decisions. Only 10% of our respondents felt that an ethics committee should be involved (18).

A Norwegian study showed 92% of cases involved the parents in the decision; in all cases but one, the parents agreed with the decision (24). Another qualitative study from Norway revealed that most parents believed that the physician should be the one to make the final decision on an end of life question but that the decision should be made with parental involvement (25).

A qualitative study in Maryland revealed that all parents wanted to participate to some degree in decision making regarding treatment for their critically ill neonates. Most parents wanted to decide with physicians, whereas some wanted to decide alone. Most parents felt that their decisions were not affected by physicians' typically grim predictions regarding the infant's possibility of survival or disability (26).

According to a study in South Africa the majority of parents indicated that doctors had played a primary role in NICU decisions about resuscitation and life support decisions. While a majority (88%) agreed with physician recommendations, most parents reported that doctors had made decisions either without consulting them (41%) or after consulting them (37%). Joint decision making was rare (14%), and < 10% of parents themselves made life support decisions for their infant (14).

Regarding the optimal process for making decisions for NICU infants, 49% of parents preferred joint decision making with physicians and 37% felt that physicians should make the final decision after consulting parents. Less than 10% of parents preferred doctors to make life-support decisions without consultation, and < 10% preferred making decisions without physician involvement. Overall, parents preferred greater input in decision making than they perceived they had been given ($p < 0.01$, Wilcoxon's signed-rank test) (14).

2.2 Factors affecting parental decision on the treatment of their neonate

According to a study in Pacific Rim countries more than 90% of parents believed that the physicians' opinion was important in decisions regarding treatments for their critically ill infants (21).

A study in New England stated that families report their decision-making is influenced mostly by hope, emotion, spirituality, and religion (23).

While an Israeli study showed the level of religious observance, regardless of which religion, was found significantly to impact upon medical ethical decision-making. Mothers who described themselves as ultraorthodox/ fundamentalist constituted a higher proportion of those selecting maximally aggressive medical intervention (25% v 17% of the total population; $p < 0.01$). Conversely, mothers who described themselves as secular were proportionately more represented among those selecting minimal intervention (31% v 20% of the general population; $p < 0.01$). Maternal country of origin (birth place) also influenced responses ($p < 0.01$). The odds ratio for requesting maximal intervention for mothers born in the USSR as compared with mothers born in Israel was 0.49 (CI 0.27, 0.80; $p = 0.005$); and was 0.53 (CI 0.78, 0.98; $p = 0.002$) for mothers who described themselves as being secular as compared with ultraorthodox/fundamentalists and orthodox. Other factors like prior infertility problems, a previous premature baby, and/or having had a child with brain damage or severe physical disability were not affect decision-making of parents (18).

According to a qualitative study from Norway families emphasized health care professionals' experience and knowledge and the parents' incapability to make a rational decision should be considered during decision making but the parents' need to be taken seriously and listened to (25).

A study by Wocial stated that a clear, accurate, and timely exchange of information and a trust between parents and providers promoted confidence in parents about information received and the decision reached (15).

A qualitative study in Maryland revealed that, parents were influenced by their own sense of the possibility of survival or disability, which was nearly uniformly positive. Religion, spirituality, and hope are the primary values that parents apply to decision-making regarding treatment for their critically ill neonates. Regardless of the medical information, parents maintained hope that everything would be fine. Parents explained that what they needed most from health care providers was compassion and hope that the infant could survive. Parents described several reasons why physicians' predictions were not central to their decision-making, including difficulty of understanding the information, feeling emotionally overwhelmed, and enduring their own medical crises (26).

A study in South Africa showed parental language/culture had an influence to involvement in decision making. Zulu-speaking parents were less likely than non-Zulu-speaking parents to report that doctors should make the final decision (25% vs 63%, $p < 0.01$, chi-square analysis). No relationships between parental age, religion or education and optimal counseling were statistically significant (14).

2.3 Health professionals' perspective on Decision Making

In a Canadian survey of parents of extremely low birth weight survivors, neonatologists, and neonatal nurses; more than three-quarters of the health care professionals either agreed or strongly agreed that the parents should have the final word regarding the initiation or the limitation of treatment. Eighty four percent of them agreed attitudes of parents were important but they agreed or strongly agreed nearly 100% of the time that the doctors should make the final decision and thought it unethical to save infants with potentially severe disabilities (20).

A group of prominent North American neonatologists, pediatricians, and intensive care physicians concluded that “parents, in consultation with physicians who has provided ongoing care to the child, are in the best position to make the difficult decision to discontinue support.” The group also concludes that “physicians should be careful to separate their personal views... from current medical, legal, and moral standards of care for such children” (27).

The American Academy of Pediatrics (AAP) Committee on Fetus and Newborn published guidelines in the initiation and withdrawal of treatment for high risk newborns and recommended an active role of parents in decision making. However, they state, “physicians should not be forced to under treat or over treat an infant if, the treatment is not compliance with the standard of care for that infant” (28).

A European survey showed that only 3% of physicians and 6% of nurses believe that parents should make the ultimate decision to with hold and withdraw life sustaining medical treatment (LSMT). Rather, parents should be involved but should not be solely responsible for decision making (22).

A recent survey of New England neonatologists showed that more than three-quarters of the neonatologists believed that they and the parents should make the final decision together. However, only 40% of the neonatologists believed that both parties actually made the final decision. Half the neonatologists reported that they made the final decision alone, in reality. Regarding their role in consultations with parents, 58% of the neonatologists believed their primary role in discussing resuscitation strategies with parents was providing factual information, in contrast to the 40% who believed that their primary role was assisting the parents in weighing the risks and the benefits of resuscitation options. Predictors of shared decision making believed that the primary role of the neonatologist was to assist parents in weighing their options (odds ratio [OR] = 4.1, p = 0.004). Smaller numbers of neonatologists indicated that discussing uncertainty or differences in parental preferences was part of their prenatal consultations. Most

(>75%) reported exploring parents' preferred decision-making role, and 64% ~~always~~ "always" or "frequently" explored parents' prior experience with premature or disabled infants. Fewer neonatologists surveyed reported exploring quality of life (42%), prior experience with death and dying (30%), or parental religious or spiritual beliefs (25%) (23).

Conceptual Frame work

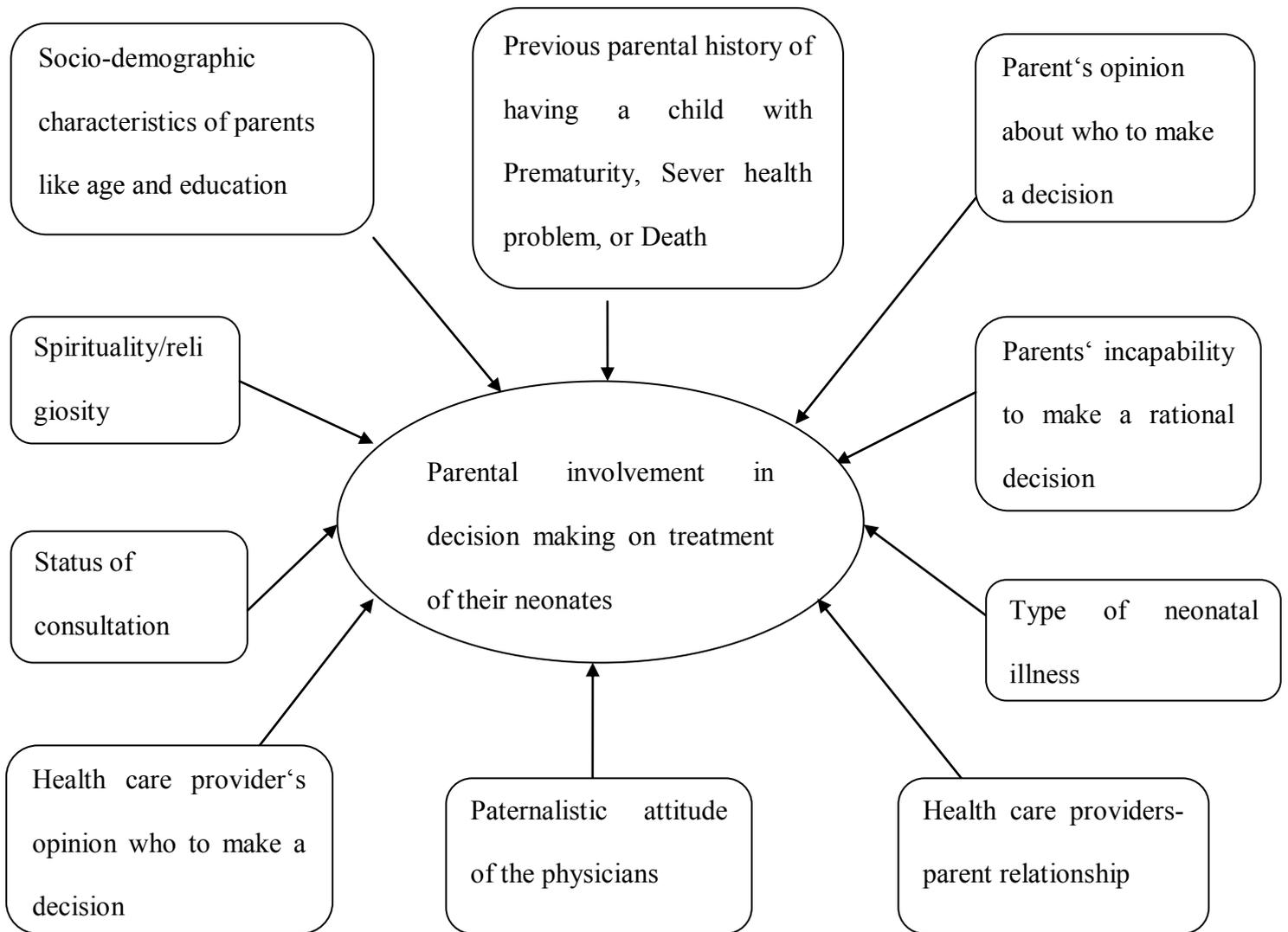


Fig 1. Conceptual frame work for parental involvement in decision making regarding treatment for the critically ill neonates (prepared by the researcher based on the literature review).

3. Objective

3.1. General Objective

To assess Parents' Involvement and Associated Factors in Decision Making Regarding Treatment for the Critically Ill Neonates in the Neonatal Intensive Care Unit of Public Hospitals, Addis Ababa, Ethiopia.

3.2. Specific Objectives

- To determine parents' involvement in decision making regarding treatment for the critically ill neonates in the NICU of Public Hospitals in Addis Ababa
- To identify factors associated with parents involvement in decision regarding treatment for the critically ill neonates in the NICU of Public Hospitals in Addis Ababa
- To explore health care providers' perspective with decision-making for critically ill neonates and parent involvement in decisions

4. Methods and Materials

4.1 Study area

This study was conducted in the public hospitals of Addis Ababa. Addis Ababa is the capital city of Ethiopia. It is the largest city in Ethiopia, with a population of 3,384,569 according to the 2007 population census. There are 51 hospitals in Addis Ababa out of which 17 are governmental hospitals, and the rest 34 hospitals are run by private investors and nonprofit organizations (29).

Out of these 17 governmental hospitals 12 of them are under the Federal ministry of health (FMOH), Addis Ababa city administration health bureau (AACAHB) and Addis Ababa University (AAU). Among these twelve hospitals, five of them have a basic neonatal intensive care unit (NICU), namely- Tikur Anbessa, St. Paul, Zewditu Memorial, Gandhi memorial, and Yekatit 12 hospitals. Tikur Anbessa hospital is a specialized referral teaching hospital with 40 beds in NICU which is managed by AAU and with a patient flow of 212 Neonates per month in average. ; Saint Paul hospital is also a referral teaching hospital which is managed by the FMOH with 16 beds in NICU and with a patient flow of 86 neonates per month in average; Yekatit 12 hospitals is under AACAHB with a total of 35 beds in NICU and with patient flow of 180 neonates per month in average; Zewditu Memorial hospital is also under AACAHB with a total of 24 beds in NICU and with patient flow of 102 neonates per month in average; and Gandhi memorial hospital the only maternity hospital in Addis Ababa with 20 beds in NICU, which is under AACAHB and with patient flow of 120 neonates per month in average.

4.2 Study design and Period

Institution based cross-sectional study with a qualitative design was conducted. The study was conducted from December 2013 to June 2014. The data collection period was from March 11th – 20th, 2014.

4.3 Source Population

- All parents/care givers of critically ill neonates who admitted in NICUs of public hospitals in Addis Ababa was used as source population.
- All heads of the NICUs (Neonatologists and neonatal nurses) who provide health care service in NICUs of public hospitals in Addis Ababa was used as the source population for the qualitative study.

4.4 Study Population

- The study population was parents/care givers whose neonates are admitted in NICU of public hospitals in Addis Ababa during the study period.
- The study was also conducted among heads of the NICUs (Neonatologists and neonatal nurses) who provide health care service in NICUs of public hospitals in Addis Ababa during the study period.

4.4.1. Inclusion criteria

- ✓ All parents/care givers whose child is admitted in NICU and who gave consent to be involved in the study during the study period.
- ✓ Stayed in the hospital for at least 5days

4.4.2. Exclusion criteria

- ✓ Very seriously ill, unconscious mothers who are admitted in obstetrics ward and those who cannot hear.

4.5. Sample Size Determination

The sample size was calculated using single population proportion based on the following assumptions.

$$n = \frac{[Z_{\alpha/2}]^2 \cdot p \cdot (1-p)}{w^2}$$

-----The minimum sample size for a very large population (N>10,000)

Where,

α = Significance level was calculated at 95% confidence interval = 0.05 or $Z_{\alpha/2} = 1.96$

p = since the estimated proportion of parental involvement in treatment decision is not known,

p taken as 50% (0.50)

w = margin of error to be tolerated = 5% (0.05)

$$n = \frac{(1.96)^2 \cdot p \cdot (1-p)}{(0.05)^2}$$

$$n = \frac{(1.96)^2 \cdot p \cdot (1-p)}{(0.05)^2} = \frac{0.9604}{0.0025} = 384$$

$$n = 145$$

➤ Since the population is less than ten thousand,

N = the total population during the study period is 234.

$$n = \frac{n}{1+n/N}$$

$$n = \frac{384}{1+384/234}$$

$$n = 145$$

Therefore, 145 samples with 10% of expected non-response [a total of 160 samples] was included in this study.

4.6 Sampling Technique and Procedures

Among the five public hospitals to be studied in Addis Ababa, the total sample size (n=160) was allocated proportionally according to the total number of patient flow in each hospital. Then the

study subjects from each hospital were selected using systematic random sampling method where every 2 parents/care givers was included in the study.

At each selected Hospital, conveniently selected eligible study participants; head of the NICUs (Neonatologists and neonatal nurses); who gave their consent to participate in the study during the study period was interviewed during the qualitative study.

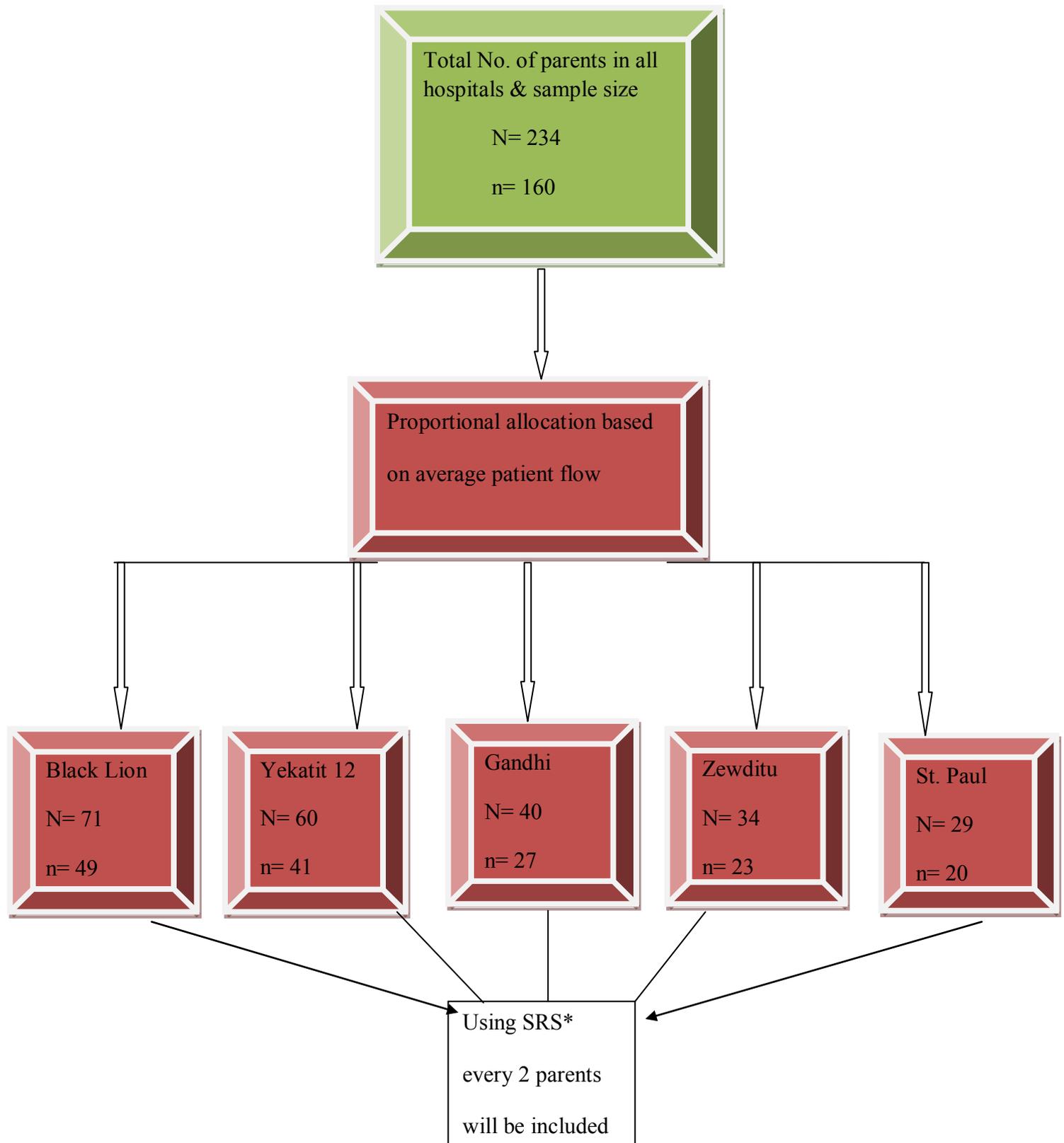


Fig. 2: Schematic presentation of the sampling procedure.

*= Systematic random sampling

4.7 Data Collection Tools and Techniques

Structured interviewer administered questionnaire was developed in English for data collection. The questionnaire was translated into Amharic (national language) by language experts. Matching was made on the exact fitness of the two versions. A pretest was conducted among study participants that were not included in the study. The pretest as well as the study was conducted by principal investigator and three trained data collectors who are at least 12th grade complete individuals who knew Amharic and who had experience in data collection. Any ambiguous and unsuitable questions were modified after the pretest is conducted.

In depth interview was carried out to support the quantitative study with head of the NICUs (Neonatologists and neonatal nurses). Participants were recruited on the basis of homogeneity, convenience, and willingness to participate in the study. In each Hospital, in depth interview was carried out with key informants. All interviews were conducted in Amharic (the local language) by a team of two, including a moderator and note taker. Qualitative data collection was continued till the gathered information was saturated and new ideas were no longer emerge.

4.8 Study Variables

4.8.1. Dependent Variable

- Parental involvement in treatment decision

4.8.2. Independent Variables

- Socio-demographic factors like parent's age, religion, ethnicity, residence, educational and occupational status.
- Status of consultation/ being informed

- Health care providers-parent relationship
- Health care provider's opinion of parental involvement in treatment decision
- Prior infertility problems
- Previous Death of a child
- Previous premature baby or having had a child with severe health problem
- Types of neonatal illness
- Parents opinion about who to make a decision (parents, health care provider, joint)
- Spirituality/religiosity
- Care providers compassion and hope that the infant can survive
- Parents' incapability to make a rational decision
- Paternalistic/negative attitude of the physicians

4.9. Operational Definitions

Neonates: a newborn infant, especially one less than 4 weeks or 28 days old (30).

Parental involvement: participation of parents in the treatment decision for their baby either actively through shared decision making or through being consulted before any decision has made.

Critically ill neonate: preterm or term infants with serious health problems, such as cerebral palsy, chronic lung disease, gastrointestinal problems, mental retardation, vision or hearing loss, congenital defects such as myelomeningocele, gastroschisis, or cleft lip or palate, conjoined twins or babies with serious but invisible defects, such as congenital cardiac defects or those with acquired conditions like HIV/AIDS (5, 6).

Treatment Decision: decisions to withhold or withdraw life sustaining treatment when the balance between the benefit and the burdens of the intensive care is uncertain, or even clearly unfavorable. (25)

Health care providers-parent relationship: the means by which a therapist and client/parents hope to engage with each other, and effect beneficial change in the patient (31).

4.10 Data Quality Control

The following measures will be taken to maximize the quality of data:

- The experts reviewed the structured interview Questionnaire before conducting the pretest. They were asked to comment on the content, the appropriateness and clarity of questions.
- The use of a face-to-face interview and the use of a structured interview questionnaire improved the reliability of this study.
- Pre-test of data collection instrument was carried out among parents of neonates in the study area that will not be included in the study. It was conducted 1 month before actual data collection, since neonates above 28 days cannot be admitted in NICUs.
- Planned and informed supervisions were made during data collection.
- Training of data collectors

4.11 Data Processing and Analysis

Each completed questionnaire was coded. The data entry and clearance was performed by principal investigator using Epi-info. Then, the entered data was exported to and analyzed using Statistical Package for Social Sciences (SPSS) version 20. The data was analyzed using descriptive statistics presented with diagrams, tables, figures to explain the study participants in relation to study variables. Both bivariate and multivariate logistic regression analysis was used to identify factors associated with parental involvement in treatment decision. The strength of the association was presented by odds ratio with 95% confidence interval (C.I). Results was summarized in frequencies and percentages and presented in tables.

A thematic analysis by transcription, translation, categorization, and thematization of the in depth interview was conducted. Then the result was presented in narration.

4.12 Dissemination of Results

The final finding of the research was presented and submitted to Addis Ababa University, school of post graduate studies, to Federal Ministry of Health, to Addis Ababa Health Bureau and to administrative offices of the studied hospitals. Attempts will be made to publicize in national and international peer-reviewed journals.

4.13 Ethical Consideration

The thesis research was submitted to the Institutional Review Board of Addis Ababa University, School of Health Science, Department of Nursing and Midwifery. After ethical clearance is obtained, a formal letters of permission was provided from the department to different hospitals that were included in this study. Participants were provided with information sheet about the objective of the study and confidentiality of the information obtained during data collection. The data collector confirmed that participants have the right to stop at any time or skip any question that they do not wish to answer or think that it affects their privacy and this will not influence the way they are treated in the health institution or in the community.

Then verbal informed consent was obtained from study participants.

5. Results

Part I: Quantitative Results

5.1 Socio-demographic Characteristics

The total numbers of study participants enrolled for this study were 160 which made the response rate 100%.

From the total number of study participants involved for quantitative method of the study regarding age distribution; 56(35.0%) were between 25 and 29, and 10 (6.3%) were between 35 and 39 years. Related to residence; 112(70.0%) were urban and 48(30.0%) were rural. As of religion; 40(25.0%) were Muslims, 95(59.4%) were Orthodox, and 25(15.6%) were protestant followers. About ethnicity; 67(41.9%) were belonging to Oromo ethnic group followed by Amhara 49 (30.6%), Tigray 22(13.8%), and Guraghea 22(13.8%). Regarding occupational status; 73(45.6%) were employees, followed by 58(36.3%) were house wives. About educational level; 22(13.8%) were illiterate, 53(33.1%) were secondary school, and 25(15.6%) were diploma and above. Related to economic status; 55(34.4%) have earned less than 500 birr per month. Whereas 34(21.3%) have earned higher monthly income; above 2000 Ethiopian birr.

Table 1: Distribution of frequencies and percentages of neonate's parents by socio demographic data in Public hospitals, AA, 2014.

Socio-demographic data		Frequencies	Percentage
Age	15-19	16	10.0
	20-24	54	33.8
	25-29	56	35.0
	30-34	24	15.0
	35-39	10	6.3
	Total	160	100
Residence	Urban	112	70.0
	Rural	48	30.0
	Total	160	100
Religion	Muslim	35	25.0
	Orthodox	95	59.4
	Protestant	25	15.6
	Total	160	100
Ethnicity	Amhara	49	30.6
	Oromo	67	41.9
	Tigray	22	13.8
	Guraghea	22	13.8
	Total	160	100
Mother's occupation	Employee	73	45.6
	House wife	58	36.3
	Merchant(Business)	29	18.1
	Total	160	100
Mother's education	Illiterate	22	13.8
	Read and write	20	12.5
	Primary school	40	25.0
	Secondary school	53	33.1
	Diploma and above	25	15.6
	Total	160	100
Monthly household income	Less than 500	55	34.4
	500-1000	36	22.5
	1000-2000	35	21.9
	Above 2000	34	21.3
	Total	160	100

5.2 Obstetric History

Concerning parity of the mothers; most of the mothers 122(76.2%) had 1-2 children. Related to the neonate's gestational age; majority of them 112(70.0%) were between 37 and 42 weeks. About the neonate's age; 67(41.9%) of them were 1 week old. As of the neonate's sex; 113(70.6%) of them were male. Related to birth weight of the neonates; majority of them 102(63.8%) were between 2.5 and 4.0 kilo gram. Regarding place of delivery; 94(58.8%) of mothers were delivered in health centers and no mother were delivered at home from the participants.

Table 2: Distribution of frequencies and percentages of parents' by obstetrics data in NICU in Public hospitals, AA, 2014.

Variables		Frequencies	Percentage
Parity	1-2	122	76.2
	3-4	32	20.0
	>4	6	3.8
	Total	160	100
Neonate's age	1week	67	41.9
	2weeks	65	40.6
	3weeks	28	17.5
	Total	160	100
Neonate's sex	Male	113	70.6
	Female	47	29.4
	Total	160	160
Neonate's gestational age	<37weeks	48	30.0
	37-42weeks	112	70.0
	Total	160	100
Neonate's Birth weight	<2.5 kilo gram	58	36.3
	2.5-4.0 kilo gram	102	63.8
	Total	160	100
Place of delivery	Hospital	66	41.2
	Health center	94	58.8
	Total	160	100
Prior history of similar problem	Yes	30	18.8
	No	130	81.2
	Total	160	100

5.3 Decision making process

Concerning medical reasons reported for admission of the neonate's; 85(53.1%) were critical medical condition, 45(28.1%) were prematurity, and 30(18.8%) were potentially severe disabilities.

Related to sufficient information provision about their infants' health status; most of the parents, 135(84.4%) were provided with sufficient information. About HCPs' consultation of parents; almost half of the parents 81(50.6%) were consulted before any decisions made. Regarding parents' involvement in treatment decisions; only 48(30%) were involved in decisions. Of those who were involved in decisions; 34(70.8%) of them were involved all the time of stay in the hospital. Related to the responsible person for treatment decision to the neonates; majority of the parents 133(83%) believed HCP were the responsible person for decision making.

Table 3: Distribution of frequencies and percentages of parental participation in decision making process in NICU in Public hospitals, AA, 2014.

Variables		Frequencies	Percentages	
Information provision	Yes	135	84.4	
	No	25	15.6	
	Total	160	100	
Parent's Consultation before decision	Yes	81	50.6	
	No	79	49.4	
	Total	160	100	
Parental involvement indecision	Yes	Always	34	21.25
		Occasionally	14	8.75
		Total	48	30
	NO	112	70	
	Total	160	100	
Responsible person to decision making	HCP	133	83	
	Parent	4	2.5	
	Jointly	23	14.4	
	Total	160	100	

Concerning parents' preference on the role of decision making; more than half of the parents 86(57.3%) preferred shared decision between parents and HCP, 40(26.7%) parents prefer to leave the decision role to HCP after consulting them, 18(11.3%) parents prefer to leave the decision role to HCP alone without consulting them, and only 11(6.9%) parents prefer to decide by themselves.

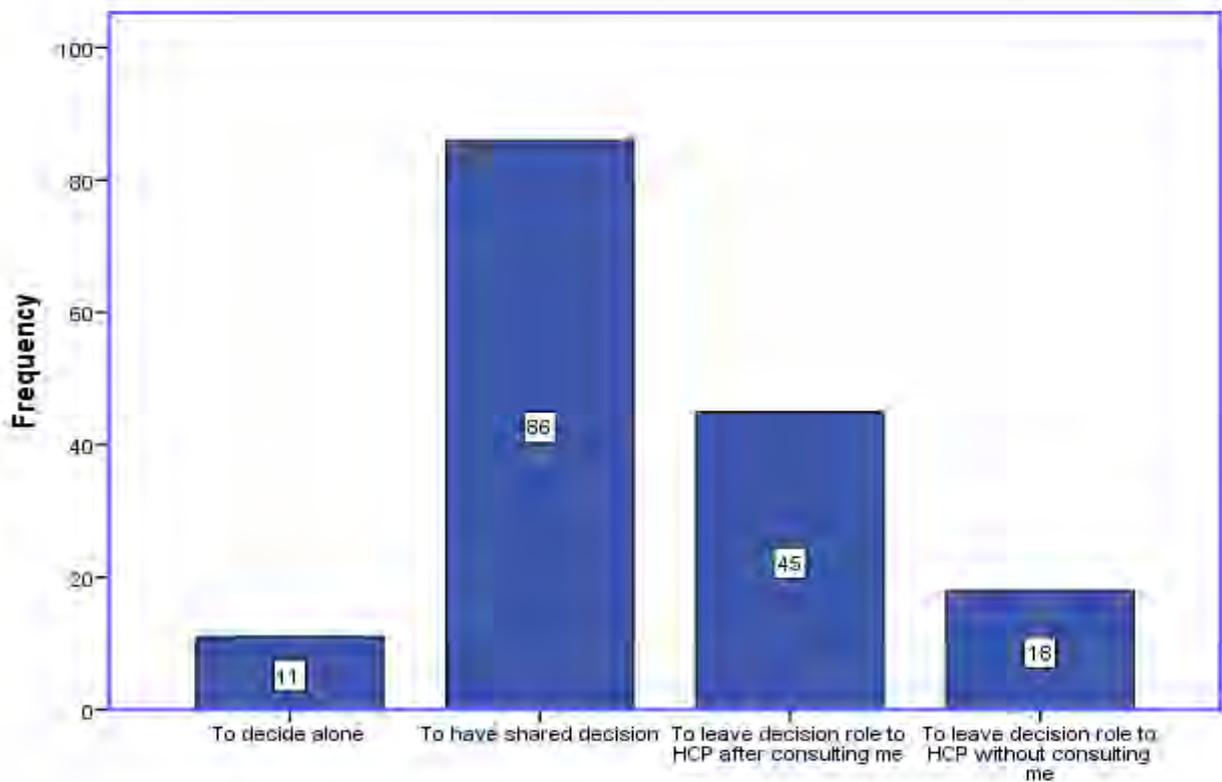


Figure 3: A bar graph showing a frequency of parent's preference on the role of decision making regarding treatment of the critically ill neonates in NICU in public hospitals, AA, 2014.

Concerning the primary values that parents consider to decision making regarding treatment for the critically ill neonates; most of the parents 142(88.8%) consider spirituality, 121(75.6%) consider religion, followed by hope that everything will be fine, compassion from HCP and

physicians prediction regarding morbidity and death 99(61.9%), 63(39.4%), 59(36.9%) respectively.

Regarding the reasons that influence parent's involvement in treatment decisions; most of the parents 117(73.1%) believe parents' incapability to make rational decision, followed by 85(53.1%) believed paternalistic attitude of the HCP, and lack of experience in our setup in family centered care, history of diseased infant or death of a child, language or culture of the parents, mothers' educational status, and age of the mother 76(47.5%), 41(25.6%), 39(24.4%), 15(9.4%) respectively.

About parents' expectation from HCPs in the future; 116(72.5%) believe that the HCP should do everything they could and the rest is in God's hand, 25(15.6%) believed that the HCPs should decide themselves if the infant can no longer survive, 19(11.9%) believed that the HCPs should decide themselves if the infant will be full of disability in the future.

Regarding parent's satisfaction with parent- HCP therapeutic relationship; most of the parents 131(81.9%) either very satisfied or satisfied while only 29(18.1%) either satisfied or very dissatisfied with the therapeutic relationship. Related to parent's satisfaction with the overall neonatal services provided in public hospitals; most of the parents 131(81.9%) either very satisfied or satisfied while only 29(18.1%) either satisfied or very dissatisfied with the overall neonatal services provided in public hospitals. About parent's recommendation to others with critically ill neonates to the public hospitals; most of them 132(82.5%) recommend others to admit their infants to the public hospitals.

5.4 Determinants of parental involvement in treatment decisions of the critically ill neonates

In the bivariate analysis; mother's age, residence, educational status, prior history with similar problem, and satisfaction with parent-staff therapeutic relationship were found to be

significantly associated with parental involvement in treatment decisions with P-value <0.05 (Table 4).

Mothers between the age of 15 and 19 years, 20 and 24 years, 25 and 29 years were less likely participate in treatment decisions of the neonates respectively as compared to mothers between the age of 30 and 35 years [OR (95%CI) =0.15(0.24, 0.955)], [OR (95%CI) =0.071(0.013, 0.382)], and [OR(95%CI)=0.054(0.01, 0.296)] respectively.

Mothers who are illiterate, read and write, primary school, and secondary school were less likely participate in treatment decisions of the neonates as compared to mothers who are diploma and above [OR (95%CI) =0.231(0.065, 0.824)], [OR (95%CI) =0.262(0.073-0.946)], [OR (95%CI) =0.196(0.065-0.594)], and [OR (95%CI) =0.340(0.127-0.909)] respectively.

Mothers who live in urban were 2.78 times participate in treatment decisions of the neonates as compared to rural dwellers, [OR (95%CI) =2.789(1.185, 6.511)].

Mothers who had prior history with premature, disabled, or any death of a child 23.261 times more likely to participate in treatment decisions of the neonates as compared to mothers without prior history [OR(95%CI) =23.261(8.054, 67.180)].

Mothers who are satisfied with parent-staff therapeutic relationship were less likely participate in treatment decisions as compared to mothers who are not satisfied [OR (95%CI) =0.376(0.164, 0.858)].

When controlled for possible confounding effects of other covariates that showed significant association with parental involvement in treatment decisions in chi-square test & bivariate analysis only residence, and prior history with premature, disabled, or any death of a child were found to be associated with parental involvement in treatment decisions. Mothers who live in urban were 7.024 times participate in treatment decisions of the neonates as compared to rural dwellers, [AOR (95%CI) =7.024(2.151, 22.936)].

Mothers who had prior history with premature, disabled, or any death of a child 106.7 times more likely to participate in treatment decisions of the neonates as compared to mothers without prior history [AOR(95%CI) =106.704(10.779, 1056.309)].

But variables like mother's age, educational status, and satisfaction with parent-staff therapeutic relationship which are significant or /and p-value < 0.05 in bivariate analysis were not statistically significant with parent involvement in treatment decisions in the multiple logistic model (Table 4).

Table 4: Association between some selected variables and parental involvement in treatment decisions in NICU of public hospitals, AA, 2014.

VARIABLES	Participation in decisions		Crude OR 95% CI	Adjusted OR 95% CI
	YES%	NO%		
Age of mother				
15-19	6(37.5%)	10(62.5%)	0.24(0.15-0.995)*	
20-24	12(22.2%)	42(77.8%)	0.071(0.013-0.382)**	
25-29	10(16.8%)	46(82.1%)	0.054(0.01-0.296)**	
30-34	12(50.0%)	12(50.0%)	1.00	
Residence				
Urban	40(35.7%)	72(64.3%)	2.778(1.185-6.511)***	7.024(2.151-22.936)**
Rural	8(16.7%)	40(83.3%)	1.00	1.00
Educational status				
Illiterate	5(22.7%)	17(77.3%)	0.231(0.065-0.824)*	
Read and write	5(25.0%)	15(75.0%)	0.262(0.073-0.946)*	
Primary school	8(20.0%)	32(80.0%)	0.196(0.065-0.594)**	
Secondary school	16(30.2%)	37(69.8%)	0.340(0.127-0.909)*	
Diploma and above	14(56.0%)	11(44.0%)	1.00	
Prior experience				
Yes	25(83.3%)	5(16.7%)	23.261(8.054-67.18)***	106.704(10.779-1056.309)**
No	23(17.7%)	107(82.3%)	1.00	1.00
Sat. with Tx relationship				
Satisfied	34(70.8%)	97(86.6%)	0.376(0.164-0.858)*	0.478(0.182-1.255)
Dissatisfied	14(29.2%)	15(13.4%)	1.00	1.00

*= p<0.05, **=p<0.01, ***=p<0.001

Part II: Qualitative Results

The total numbers of study participants enrolled for the qualitative study were Eight.

Regarding to age distribution; 2(25.0%) were between 25 and 29, 4 (50%) were between 30-34, and 2 (25%) were between 35 and 39 years. Related to sex 6(75.0%) were female while 2(25%) were male. As of religion; 2(25.0%) were Muslims while 6(75.0%) were Orthodox followers. About ethnicity; 4(50.0%) were belonging to Amhara ethnic group followed by 3 (37.5%) Oromo and the rest1 was Guraghea. Related to marital status, 3(37.5 %) were single while the rest 5(62.5%) were married. Regarding profession of the respondent, 5(62.5%) of them were nurses while the rest 3(37.2%) were physicians.

HEALTH CARE PROFESSIONALS' PERSPECTIVE OBTAINED THROUGH IN-DEPTH INTERVIEW

The common medical reasons for admission of neonates in NICU: Majority of the participants were agreed that –prematurity, neonatal sepsis, congenital pneumonia, perinatal asphyxia, jaundice, congenital heart disease, spinal bifida, cleft palate/lip, and down's syndrome are the common medical reasons for admission of neonates in NICU.”

Parents' involvement in treatment decision to neonates: Most of the participants were agreed with that –most parents are not interested in participating in decisions and they leave the decision role to health care professionals (HCP) believing that they are incapable of making rational decisions and HCP are the one who know everything and able to make sound decision.”

They were also agreed that –some parents especially who are educated want to participate and ask questions to know everything about their neonate.”

At this time HCPs provide them with factual medical information but they do not leave the decision role to the parents on choosing treatment options or deciding whether or not to forgo life sustaining treatment because HCPs believe that –parents do not know which the best option and we do not withdraw life sustain treatment whether the parents want it or not.”

Most of them agreed that “we do our best to save the neonate even if we are sure that the infant can no longer survive.”

The reasons that affect parents’ involvement in decision making: Majority of study participants involved in the qualitative part of this study agreed that “lack of experience in our setup to involve parents in decision making, educational status of parents, previous death of a child or history of infertility, age of the parents, culture or religion of the parents to be the reason that affect parents’ involvement in decision making.”

The primary values to decision making on neonates: The common theme from participants’ discussion on the primary value they consider during decision making regarding the critically ill neonate or potentially disabled neonates was that “religion, spirituality, and hope that everything will be fine and sometimes medical science’s prediction regarding morbidity and death.”

Preference to have a role in decision making: Most of the participants were preferred to provide parents with the factual medical information about their neonates’ health status and to consult them before any decision but to make the final decision by themselves. Some of the participants were preferred to decide jointly with parents’ of the neonates. But none of the participants preferred to leave the decision role to the parents only.

6. Discussion

Historically, parent involvement in treatment decisions for their children was minimal. A physician's recommendation was usually accepted without question. A paternalistic approach by the physician was accepted not only by the parents, but also by the medical community (12). Recently, there has been increasing recognition of patient autonomy with concurrent support for family participation in decision making and parents prefer more involvement in reaching treatment decisions for their children than in the past (13).

This study is the first of its kind in Ethiopia to assess parent's involvement in treatment decisions for the critically ill neonates in NICUs.

As per the study 48(30%) of the participants were participated in decisions regarding treatment of the critically ill neonates which is higher than that found in the study in South Africa (2004) where only 22% of parents were participated in decisions(14). This may be due to parents in this study may consider consultation before decision making as participation in decisions and with the time gap there will be an increase in recognition of patient/parent autonomy.

But lower than the study in Baltimore, Europe, Norway, and America where 40%, 56%, 83%, and 92% of parents were participated in decisions respectively. This may be due to developed countries have experience in family centered care (19, 22, 23, 24).

Of the participants who were participated in decisions; only 2.5% of parents perceived it was their decision alone, 14.4% had a shared decision between them and the HCPs, and 83.1% of parents perceived HCP made the final decision which is similar with a study in South Africa where, only 14% had shared decision, and <10% made the decision alone(14). But the finding is lower than the study in Europe where three-quarters of those who participate in decisions believing that it has been their decision alone and one-quarter believing that the

decision had been made in conjunction with the physicians and the international study group in Pacific Rim countries where, majority of parents (75-86%) perceived that there was joint decision making between the physician and the parents (21, 22). This shows there is lowest rate of parent involvement in decisions in developing countries.

Regarding parent's consultation before any decision is made; 81(50.6%) of respondents were consulted before the HCP made decisions Which is higher than that found in South Africa where, only 37% of the respondents had been consulted(14). The possible reasons for this may be with the time gap there will be an increase in recognition of patient/parent autonomy.

Regarding the parents' preference on the role of decision making; 57% of parents preferred to have shared decisions which is higher than that found in South Africa where, 49% of the parents preferred joint decision making with physicians (14). The possible reason may be with time gap parents' awareness about their right of being involved in all aspect of their neonate's health may increase.

But it is lower than the study in Israel and Melbourne where 89% and 62-95% of parents shared decision making respectively (18, 21). And a qualitative study in Maryland and Norway also revealed that all parents wanted to participate to some degree in decision-making regarding treatment for their critically ill neonates. Most parents wanted to decide with physicians, whereas some wanted to decide alone (25, 26).

The possible reason may be they may have experience in family centered care and most parents are educated so that they want more involvement than those less educated.

Twenty seven percent of parents preferred the HCP to decide after consulting them, which is lower than the study in South Africa where 37% of parents felt that physicians should make the final decision after consulting them.

Only 11% preferred the HCP to decide alone without consulting them and 7% preferred to decide by themselves without HCPs involvement which is almost similar with that found in

South Africa where, 10% of parents preferred doctors to make life-support decisions without consultation and < 10% preferred making decisions without physician involvement (14).

Concerning the primary values that parents consider to decision making; 88.8% of parents considered spirituality, 75.6% considered religion, 61.9% considered hope that everything will be fine, 39.4% considered compassion from the HCPs. Similarly the study in New England and Maryland stated that religion, spirituality, and hope are the primary values that parents apply to decision-making regarding treatment for their critically ill neonates (23, 26).

Thirty seven percent of parents considered physicians' prediction regarding morbidity and death as the primary values that parents consider to decision making which is lower than the study in Pacific Rim countries where more than 90% of parents believed that the physicians' opinion was important in decisions regarding treatments for their critically ill infants (21). The possible reason may be the parents in the area may be more educated and believe in physician's prediction regarding morbidity and death.

Regarding the factors that may influence parental involvement in decision making; 73.1% of parents agreed with parent's incapability to make a rational decision, 53.1% agreed with paternalistic attitude of the HCP, 47.5% agreed with lack of experience in our setup, 29.4% agreed with having a history of premature, disabled or any death of a child, 25.6% agreed with language or culture of the parents, 24.4% agreed with mother's educational status, and 9.4% agreed with age of the mother as the factors that may influence parental involvement in decision making.

As per the study mother's residence has shown a statistically significant association with Parents participation in decision making ($p < 0.01$). In the same way Israeli study showed maternal country of origin (Residence) has a statistically significant association with Parents participation in decision making ($p < 0.01$) (18).

This study showed there is no association between parental language/culture. But a study in South Africa showed parental language/culture had an influence to involvement in decision making ($p < 0.01$, chi-square analysis) (14).

The study also showed that mother's age, educational status, and satisfaction with parent-staff therapeutic relationship were found to be significantly associated with parental involvement in treatment decisions with P-value < 0.05 . Mothers who are illiterate, read and write, primary school, and secondary school were less likely participate in treatment decisions of the neonates as compared to mothers who are diploma and above [OR (95%CI) =0.231(0.065, 0.824)], [OR (95%CI) =0.262(0.073-0.946)], [OR (95%CI) =0.196(0.065-0.594)], and [OR (95%CI) =0.340(0.127-0.909)] respectively. But the study in South Africa showed no relationships between parental ages, religion or education were statistically significant. The possible reason may be mothers who are educated need more involvement than mothers who are less educated.

This study also showed prior experience with premature, disabled or any death of a child has a statistically significant association with parents participation in decision making ($p < 0.01$). Mothers who had prior history with premature, disabled, or any death of a child 23.261 times more likely to participate in treatment decisions of the neonates as compared to mothers without prior history [OR (95%CI) =23.261(8.054, 67.180)]. But the study in Israel showed prior experience with premature, disabled or any death of a child were not affect decision-making of parents (18). The possible reason may be parents may have higher involvement in decisions in the area, their participation may not be affected whether they have prior experience or not.

As per the qualitative study most of the participants were agreed with that ~~most~~ parents are not interested in participating in decisions and they leave the decision role to health care professionals (HCP) believing that they are incapable of making rational decisions and HCP

are the one who know everything and able to make sound decision. But some parents especially who are educated want to participate and ask questions to know everything about their neonate.”

This study showed most of the participants were preferred to provide parents with the factual medical information about their neonates' health status and to consult them before any decision but to make the final decision by themselves. Some of the participants were preferred to decide jointly with parents' of the neonates. In the same way a Canadian survey of parents of extremely low birth weight survivors, neonatologists, and neonatal nurses; more than three-quarters of the health care professionals either agreed or strongly agreed that the parents should have the final word regarding the initiation or the limitation of treatment but they agreed or strongly agreed nearly 100% of the time that the doctors should make the final decision (20).

In the contrary a recent survey of New England neonatologists showed that more than three-quarters of the neonatologists believed that they and the parents should make the final decision together. A group of prominent North American neonatologists, pediatricians, and intensive care physicians concluded that ~~p~~parents, in consultation with physicians who has provided ongoing care to the child, are in the best position to make the last decision and the American Academy of Pediatrics (AAP) Committee on Fetus and Newborn also published guidelines in the initiation and withdrawal of treatment for high risk newborns and recommended an active role of parents in decision making (23, 27, 28). The possible reason may be HCPs in the areas may pay attention to parent's psychological and psychosocial well-being, bonding with their child and responsible parenthood.

According to this study none of the participants preferred to leave the decision role to the parents only. But the European survey showed that few HCPs believe that parents should make the ultimate decision to with hold and withdraw life sustaining medical treatment

(LSMT) (22). The possible reason may be HCPs in the areas may have more positive attitude towards the capability of parents to make a rational decision.

7. Strength and Limitation of the Study

7.1 Strength

The study utilized both qualitative and quantitative methods (triangulation of designs) so; scope and depth of the study was addressed well.

This study used a structured questionnaire to interview which in turn increased the quality of information obtained. The study is the first of its kind in Ethiopia. Therefore, it will be helpful to give insight on the issue for further studies.

7.2 Limitation

Due to the absence of similar studies in our country, comparisons were difficult to be made.

8. Conclusion and Recommendation

8.1 Conclusion

Based on the findings of this study, the following conclusions were made:

- The study found that although there is lower parental involvement in decision making, most of the parents preferred to have shared decision between HCPs and them.
- Majority of the parents believed that HCPs were the responsible person to decision making.
- Majority of the parents believed that religion, spirituality, hope, compassion, and HCPs' opinion were the primary values that they consider during decision making.
- Most of them believed that parents' incapability, paternalistic/ negative attitude of HCPs, lack of experience in our setup, and history of other diseased infant influence parents' involvement in decision making.
- Mother's age, residence, educational status, prior experience with premature, disabled, or any death of a child and satisfaction with parent-staff therapeutic relationship have a statistically significant association with parental involvement in treatment decisions for their critically ill neonate.
- Mothers who are rural dwellers have lower participation in treatment decisions of their neonates.
- Mothers with prior history of similar problem have higher participation in treatment decisions of their critically ill neonate.
- HCPs' general opinion towards parents' involvement in treatment decision for neonates was ~~in~~volving parents in every aspect of their infants' treatment or family centered care is not practiced in our set up."

8.2. Recommendation

Based on the findings and the conclusions made, the following recommendations were forwarded:

- The government should pay attention on parents' rights on behalf of their neonates
- Health institution administrators should create awareness to the HCPs regarding the rights of parents of ill neonates that they have a role in decisions and to avoid the paternalistic attitude of HCPs
- HCPs especially nurses as an advocate of the patient should be the one who safeguard the rights of the parent on behalf of their neonates
- Health institution administrators or HCPs should create awareness to the parents regarding their rights to participate in decisions
- Finally, further study is recommended on how parents can be empowered or being involved in all aspect of their neonates in NICU.

9. ANNEXES

9.1 Annex I: References

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9.2 ANNEX II: Structured English Questionnaire

I. INFORMATION SHEET (ENGLISH VERSION)

Information to be given to study participant before their participation in the study

My name is ----- . I am a Master's student from Addis Ababa University currently carrying out my research on 'Assessment of parent's involvement in decision regarding treatment for the critically ill neonates in the NICU of Public Hospitals, Addis Ababa, Ethiopia. You are randomly selected to participate in the study

The study will provide information that might enable the health personnel and the government to improve NICU services programs. The study and its procedures have been approved by the appropriate authorities. We would like to take your time to respond to our interview questions and it will take approximately half an hour. We request you to answer as truthfully as possible. Your answer will not be revealed to the health personnel or any other people, and the information you give will be treated anonymously and confidential. This research imposes no risk and therefore no compensation will be provided for your participation in this study. Your participation is totally voluntary and you can anytime withdraw or refuse to continue, and this will not influence the way you are treated in the health institution or in the community.

II. CONSENT FORM:

I have been explained all information and procedures that are part of this research study and I have understood the same. I understand that the research imposes no risk on my life and therefore no compensation would be provided.

I hereby agree to participate in this research study and give my voluntary consent. I hereby also give rights to the researcher for collecting the data that are required for the study.

Agreed _____ Disagreed _____

Date and time of interview _____

Name and signature of interviewer _____

I. QUESTIONS RELATED TO SOCIO-DEMOGRAPHIC VARIABLES OF PARENTS

1. Age of mother in completed years _____

2. Residence

1. Urban
2. Rural

3. Religion

- | | |
|-------------|------------------------|
| 1. Muslim | 3. Protestant |
| 2. Orthodox | 4. other(specify)_____ |

4. Ethnicity

- | | |
|-----------|------------------------|
| 1. Amhara | 3. Tigray |
| 2. Oromo | 4. Other(specify)_____ |
| 5. | |

5. Mothers' occupation

- | | |
|---------------|------------------------|
| 1. Employee | 3. Merchant |
| 2. House wife | 4. other(specify)_____ |

6. Mother's educational status

- | | |
|-------------------|---------------------|
| 1. Illiterate | 4. Secondary school |
| 2. Read and write | 5. Diploma & above |
| 3. Primary school | |

7. Monthly household income _____

II. Obstetrics History

8. Parity/Gravid _____

9. The neonate's gestational age in week _____

10. Your current Child's age in week _____

11. Child's Sex

- A. Male
- B. Female

12. Place of delivery

- | | |
|------------------|-------------------------|
| 1. home | 3. hospital |
| 2. health center | 4. other(Specify) _____ |

13. Birth weight _____

III. Questions Related to Decision Making Process

14. Medical reason(s) for admitting your neonate to NICU

1. Prematurity
2. critical medical condition(s)
3. potentially severe disabilities
4. others(specify)

15. Do you have prior experience with premature or disabled child or any death of a child in the past?

1. Yes, all
2. Yes, some
3. No

16. Are the health care professionals providing you with sufficient information about your child's status?

1. Yes
2. No

17. Have you been participated in decisions regarding treatment for your critically ill neonate?

1. Yes
2. No

18. If yes, how often have you been involved in decision making regarding treatment since admission of your neonate?

1. Always
2. Occasionally
3. Only once

19. In your opinion who is responsible to make decision regarding treatment of the critically ill neonates?

1. Health care professionals
2. Parents
3. Joint health care professionals and parents

20. Are the health care professionals consulting you before they make the decision?

1. Yes
2. No

21. What do you prefer to be your role in making decision regarding treatment of the critically ill infant?[Multiple answers are possible]

1. I want to decide alone

2. To have a shared decision between parents and the health care providers
 3. To leave the decision role to health care providers after consulting me
 4. To leave the decision role to health care providers alone without consulting me
 5. I want religious leaders to be involved in decision making
 6. Other (specify)_____
22. What are the primary values that you consider to decision making regarding your critically ill neonate?[multiple answers are possible]
1. Religion
 2. Spirituality
 3. Compassion from the health care providers
 4. Hope that everything would be fine
 5. Physicians prediction regarding morbidity and death
 6. Other (specify)_____
23. In your opinion, which of the following are reasons that can affect parents involvement in treatment decision?[multiple answers are possible]
1. Lack of experience of family centered care in our set up
 2. Parents' incapability to make a rational decision
 3. Paternalistic attitude of the physicians/neonatal nurse
 4. History of other diseased infant
 5. Precious child
 6. Age of the mother/care giver
 7. Language/culture of the mother/care giver
 8. Other (specify)_____
24. What do you expect from the health professionals in the future?[multiple answers are possible]
1. The health professionals should do everything they could, and the rest is ~~in~~ God's hands."
 2. The health professionals should decide themselves if the infant can no longer survive
 3. The health professionals should decide themselves if the infant will be full of disability in the future
 4. Other (specify)_____

25. To what extent do you agree with the following statement: There is a joint decision making between parents and the health care providers regarding treatment of the critically ill infant

- | | |
|-------------------|----------------------|
| 1. Strongly agree | 4. Disagree |
| 2. Agree | 5. Strongly disagree |
| 3. Neutral | |

26. How much satisfied are you with the overall quality of care/treatment provided for your critically ill child?

- | | |
|-------------------|----------------------|
| 1. Very satisfied | 4. Dissatisfied |
| 2. Satisfied | 5. Very dissatisfied |
| 3. Neutral | |

27. How much satisfied are you with parents- health care providers' therapeutic relationship for your critically ill child during your stay in this Hospital?

- | | |
|-------------------|----------------------|
| 1. Very satisfied | 4. Dissatisfied |
| 2. Satisfied | 5. Very dissatisfied |
| 3. Neutral | |

28. Would you recommend someone to admit his/her critically neonate to this hospital?

1. Yes
2. No

29. If yes, give your reason _____

UNSTRUCTURED INTERVIEW GUIDE QUESTIONS

(FOR PHYSICIANS/ NEONATAL NURSES)

1. Age_____
2. Sex_____
3. Profession_____
4. Work experience_____
5. For what Medical reason(s) do neonates usually be admitted to NICU in this hospital?
6. According to your opinion, do you think parents be involved in decisions regarding treatment for their critically ill neonate?
 - If yes, how often and in what extent? (do you provide them factual medical information or you assist them in weighing the risks and benefits of medical treatment options?)
 - If no, why?
7. According to your opinion, what are the factors that affect parental involvement in treatment decision? (i.e how do you think their language/culture, educational status, religion etc affect decisions regarding treatment of their critically ill infant?)
8. As neonatologist/neonatal nurse, what are your primary values that you apply to decision making regarding the critically ill neonate or potentially disabled infant?
9. As neonatologist/neonatal nurse, what do you prefer to be your role in making decision regarding treatment of the critically ill infant? (i.e do you want to make decisions alone or joint decision with parent? Should parents be involved to withhold/withdraw life sustaining medical treatment of infants with potential disabilities/ poor prognosis?)
10. Is there anything additional point you need to add?

9.3 Annex III: Structured Amharic questionnaire

I. ለጥናቱ ተሳታፊዎች በጥናቱ ሂደት ከመሳተፋቸው በፊት የሚሰጣቸው መረጃ:

እኔ በአዲስ አበባ ዩኒቨርሲቲ የሁለተኛ ዲግሪ ተማሪ ስሆን በአሁኑ ወቅት የመመሪቂያ ጽሁፌን/በአዲስ አበባ ከተማ አስተዳደር ስር በሚገኙ የመንግሥት-ሆስፒታሎች ውስጥ በጽኑ ታመው በጨቅላ ህጻናት ማገገሚያ ክፍል ውስጥ ህክምና እያገኙ ባሉ ህጻናት ላይ በሚደረጉ ውሳኔዎች ላይ የወላጆች ተሳትፎ ዳሰሳ/ በሚል ርዕስ እየሰራሁ እገኛለሁ። እርስዎ የተመረጡት ያለምንም ቅድመ ሁኔታ ነው።

የጥናቱ ውጤት ለመንግሥትና ለጤና ባለሙያዎች በጨቅላ ህጻናት ማገገሚያ ክፍል ውስጥ የሚሰጡ አገልግሎቶችን ለማሻሻል የሚያስችሉ ሀሳቦችን ያመነጫል። ጥናቱና የጥናቱ ሂደት በሚመለከተው ክፍል እውቅና የተሰጠው ነው። የቀረቡትን የቃለ መጠይቅ ጥያቄዎች ጊዜዎን ሰውተው በተገቢው መንገድ እንደሚመልሱ ተስፋ አደርጋለሁ። ጥያቄዎቹን ለመመለስ ወደ ግማሽ ሰዓት ሊወስድ ይችላል። ትክክለኛውን መልስ እንዲሰጡኝ በትህትና እጠይቃለሁ። የሚሰጧቸው መረጃዎች ሚስጥራዊነት የተጠበቀ ይሆናል። ይህ ጥናት ምንም አይነት አደጋ የሚያስከትል ስላልሆነ ምንም አይነት ማካካሻ አይኖርም። የእርሶ ተሳታፊነት በፈቃደኝነት ላይ የተመሰረተ ከመሆኑም ባሻገር በማንኛውም ሰአት መረጃውን ላለመስጠት ከፈለጉ ማቋረጥ ይችላሉ። ይህም በጤና ተቋማቱ በሚኖርዎት አገልግሎት ላይ ምንም አይነት ተጽዕኖ አይፈጥርም።

III. የሰምምነት-ማረጋገጫ

የጥናቱ ክፍል የሆኑ መረጃዎችና ሂደቶች ተብራርተዋል። እኔም በተብራራልኝ መሰረት ተረድቻለሁ። ስለሆነም ምንም አይነት አደጋም እንደሌለው የገባኝ ከመሆኑም ባሻገር ምንም አይነት ማካካሻ እንደሌለውም ተገንዝቤያለሁ። በዚህ ጥናት ውስጥ ለማሳተፍ ፈቃደኛ መሆኔን አረጋግጣለሁ። ለአጥኝዎም መረጃ ለማቀበል ተስማምቻለሁ።

ተስማቻለሁ አልተስማማሁ

ቃለመጠይቅ የተደረገበት ቀንና ሰዓት _____

ቃለመጠይቅ አድራጊው ስምና ፊርማ _____

Annex III: Structured Amharic questionnaire

II. ለጥናቱ ተሳታፊዎች በጥናቱ ሂደት ከመሳተፋቸው በፊት የሚሰጣቸው መረጃ:

እኔ በአዲስ አበባ ዩኒቨርሲቲ የሁለተኛ ዲግሪ ተማሪ ስሆን በአሁኑ ወቅት የመመሪያ ጽሁፌን/በአዲስ አበባ ከተማ አስተዳደር ስር በሚገኙ የመንግሥት ሆስፒታሎች ውስጥ በጽኑ ታመው በጨቅላ ህጻናት ማገገሚያ ክፍል ውስጥ ህክምና እያገኙ ባሉ ህጻናት ላይ በሚደረጉ ውሳኔዎች ላይ የወላጆች ተሳትፎ ዳሰሳ/ በሚል ርዕስ እየሰራሁ እገኛለሁ። እርስዎ የተመረጡት ያለምንም ቅድመ ሁኔታ ነዉ።

የጥናቱ ውጤት ለመንግሥትና ለጤና ባለሙያዎች በጨቅላ ህጻናት ማገገሚያ ክፍል ውስጥ የሚሰጡ አገልግሎቶችን ለማሻሻል የሚያስችሉ ሀሳቦችን ያመነጫል። ጥናቱና የጥናቱ ሂደት በሚመለከተው ክፍል እውቅና የተሰጠው ነው። የቀረቡትን የቃለ መጠይቅ ጥያቄዎች ጊዜዎን ሰውተው በተገቢው መንገድ እንደሚመልሱ ተስፋ አደርጋለሁ። ጥያቄዎቹን ለመመለስ ወደ ግማሽ ሰዓት ሊወስድ ይችላል። ትክክለኛውን መልስ እንዲሰጡኝ በትኩረትና እጠይቃለሁ። የሚሰጧቸው መረጃዎች ሚስጥራዊነት የተጠበቀ ይሆናል። ይህ ጥናት ምንም አይነት አደጋ የሚያስከትል ስላልሆነ ምንም አይነት ማካካሻ አይኖርም። የእርስዎ ተሳታፊነት በፈቃደኝነት ላይ የተመሰረተ ከመሆኑም ባሻገር በማንኛውም ሰዓት መረጃውን ላለመስጠት ከፈለጉ ማቋረጥ ይችላሉ። ይህም በጤና ተቋማቱ በሚኖርዎት አገልግሎት ላይ ምንም አይነት ተጽዕኖ አይፈጥርም።

IV. የስምምነት-ማረጋገጫ

የጥናቱ ክፍል የሆኑ መረጃዎችና ሂደቶች ተብራርተዉለኛል። እኔም በተብራራልኝ መሰረት ተረድቻለሁ። ስለሆነም ምንም አይነት አደጋም እንደሌለው የገባኝ ከመሆኑም ባሻገር ምንም አይነት ማካካሻ እንደሌለውም ተገንዝቤያለሁ። በዚህ ጥናት ውስጥ ለማሳተፍ ፈቃደኛ መሆኔን አረጋግጣለሁ። ለአጥኝዎም መረጃ ለማቀበል ተስማምቻለሁ።

ተስማቻለሁ

አልተስማማሁም

ቃለመጠይቅ የተደረገበት ቀንና ሰዓት _____

ቃለመጠይቅ አድራጊው ስምና ፊርማ _____

I. ሥለተጠያቂው ማህበራዊና ኢኮኖሚያዊ መረጃ

1 የወላጅ እድሜ በዓመት _____

2. የመኖሪያ አድራሻ

1. ከተማ

2. ገጠር

3. ሀይማኖት

1. ሙስሊም

4. ካቶሊክ

2. ኦርቶዶክስ

5. ሌላ(ግለፁ) _____

3. ፕሮቴስታንት

4. ብሄር

1. አማራ

3. ትግሬ

2. ኦሮሞ

4. ሌላ(ግለፁ) _____

5. የወላጅ ስራ

1. ተቀጣሪ

3. ነጋዴ

2. የቤት እመቤት

4. ሌላ(ግለፁ) _____

6. የወላጅ የትምህርት ደረጃ

1. ያልተማረች

4. የሁለተኛ ደረጃ ትምህርት

2. ማንበብና መጻፍ

ያጠናቀቀች

3. የመጀመሪያ ደረጃ ትምህርት

5. ዲፕሎማ እና ከዚያ በላይ

ያጠናቀቀች

7. ወርሀዊ ገቢ በብር_____

IV. ከወሊድ ጋር የተያያዘ መረጃ

8. ያለቸው የልጆች ብዛት/የዕርግዝና ሁኔታ_____

9. የጨቅላ ህጻኑ የዕርግዝና ጊዜ በሳምንት_____

10. የህጻንዎ እድሜ በሳምንት_____

11. የህጻኑ ያታ

1. ወንድ

2. ሴት

12. ህጻኑ የተወለደበት ቦታ

1. ቤትውስጥ

3. በሆስፒታል

2. በጠና ማዕከል

4. በሌላ(ግለፁ)_____

13. ሲወለድ የነበረው የክብደት መጠን_____

V. ከወሳኔ መስጠት ሂደቱ ጋር የተያያዙ ጥያቄዎች

14. በጨቅላ ህጻናት ማቆያ ወስጥ ልጅዎ የቆየበት የህክምና ምክንያት ምን ነበር?

1. ጊዜውን ያልጠበቀ ስለነበር

3. ከፍተኛ የአካል ጉዳተኝነት

2. አሳሳቢ የህመም ሁኔታ

ሁኔታ በመኖሩ

ስለነበር

4. ሌላ(ግለፁ)_____

15. ከዚህ በፊት ጊዜው ያለደረሰ ወይም የአካል ጉዳት ያለበት ወይም የሞተብዎት ህፃን ነበር?

1. አዎ! ሁሉም

3. አይደለም!

2. አዎ! የተወሰኑት

16. የጤና ባለሞያዎቹ ስለልጅዎ ደህንነት ሁኔታ ተገቢውን ያህል መረጃ ሰጥተዎት ነበር?

1. አዎ!

2. አይደለም!

17. በፅኑ በታመመው ጨቅላ ህጻንዎ ህክምና ጉዳይ ላይ በተደረጉ ውሳኔዎች ወስጥ ተሳታፊ ነበሩ?

1. አዎ!

2. አይደለም!

18. መልሰዎ አዎ ከሆነ፡ ጨቅላ ህጻንዎ ወደ ማገገሚያ ክፍል ከገባ ጀምሮ በጨቅላ ህጻንዎ ህክምና ጉዳይ ላይ በተደረጉ ውሳኔዎች ወስጥ ለምን ያህል ጊዜ ተሳተፈዋል?

1. ሁሌም

3. አንድጊዜ

2. አልፎአልፍ

19. በእርሶ አስተያየት በፅኑ በታመመው ጨቅላ ህጻናት የህክምና እርዳታ ጉዳይ ላይ ሀላፊነት ያለበት ማን ይመስልዎታል?

1. የጤናባለሞያዎች

3. የጠና ባለሞያዎችና ወላጆች

2. ወላጆች

20. የጤና ባለሞያዎች ወሳኔ ከመወሰናቸው በፊት ያመክሮዎት ነበር?

1. አዎ!

2. አይደለም!

21. በፅኑ በታመመው ህጻንዎ ህክምና ሂደት ላይ በሚደረገው ውሳኔ የእርሶ ድርሻ ምን እንዲሆን ይመርጣሉ?
/ከአንድ በላይ መምረጥ ይችላሉ/

1. በራሴ ብቻ መወሰን እፈልጋለሁ

2. በወላጅና በህክምና ባለሞያዎች የጋራ ውሳኔ እንዲሰጥ እፈልጋለሁ

3. እኔን ካማከሩኝ በሁዋላ ወሳኔው በጤና ባለሞያዎች እንዲወሰን እፈልጋለሁ

4. እኔንም ሳያማክሩ ወሳኔውን የጤና ባለሞያዎች እንዲያከናውኑት እፈልጋለሁ

5. የሀይማኖት አባቶች በወሳኔ ላይ እንዲሳተፉ እፈልጋለሁ

6. ሌላ (ግለፅ)_____

22. በፅኑ በታመመው ህጻንዎ ጉዳይ ላይ የሚደረግ ወሳኔ በቅድሚያ ሊየተኩርባቸው የሚገቡ ጉዳዮች ምንድናቸው ይላሉ? /ከአንድበላይ መልስ መስጠት ይቻላል/

1. ሀይማኖት

2. መንፈሳዊነት

3. ከጤና ባለሙያዎቹ በኩል ያለው ቁርጠኝነት
4. ሁሉም ነገር ጥሩ ሊሆን እንደሚችል ያለ ተስፋ
5. የህኪሞቹ ግምት የሀመም እና የሞት ብዛትን አስመልክቶ
6. ሌላ (ግለፅ)_____

23. በእርስዎ አስተያየት፣ ከሚከተሉት ውስጥ የትኛው ምክንያት ወላጅን በህክምናው ጉዳይ ላይ ያለውን ተሳትፎ ይነካል?

1. በኛ ሁኔታ በቤተሰብ ደረጃ የሚካሄድ ህክምና አገልግሎት ልምድ አለመኖሩ
2. የወላጆች ምክንያታዊ የሆነ ወሰኔ የመስጠት አቅም እጥረት
3. የህኪሙ/የህጻናትነርሱ አባታዊ የሆነ አመለካከት
4. ሌላ የታመመ ህጻን ታሪክ
5. ዋጋ ያለው ህጻን
6. የእናትየው ወይም የሞግዚቷ እድሜ
7. የእናትየው ወይም የሞግዚቷ ቋንቋና ባህል
8. ሌላ(ግለፅ)_____

24. ከጤና ባለሙያዎች ለወደፊቱ ምን ይጠበቃሉ? /ከአንድ በላ መልስ መመለስ ይቻላል/

1. የጤና ባለሙያዎች ማድረግ የሚችሉትን ሁሉ ማድረግ አለባቸው። የተረፈውን ለፈጣሪ መስጠት ነው።
2. የጤና ባለሙያዎቹ በራሳቸው መወሰን አለባቸው ህጻኑ በህይወት መኖር የማይችል ከሆነ
3. የጤና ባለሙያዎቹ በራሳቸው መወሰን አለባቸው ህጻኑ ሙሉ ለሙሉ አካል ጉዳተኛ የሚሆን ከሆነ
4. ሌላ (ግለፅ)_____

25. በሚከተለው ሀሳብ ላይ ምን ያህል ይስማማሉ በጣም በታመመ ጨቅላ ህጻን ጉዳይ ላይ ቤተሰብና የጤና ባለሙያዎች በህክምናው ዙሪያ የጋራ ወሳኔ መስጠት አለባቸው።

- | | |
|---------------|-----------------|
| 1. በጣም እስማማለሁ | 3. ለመወሰን ይከብዳኛል |
| 2. እስማማለሁ | 4. አልሰማም |

5. በጣም አልሰማም

26. ለጨቅላ ህጻንዎ በተደረገው የህክምና እርዳታ ምን ያህል ረክተዎልዎት?

- | | |
|-----------------|---------------|
| 1. በጣም ረክቻለሁ | 4. አረካሁም |
| 2. እረክቻለሁ | 5. በጣም አልረካሁም |
| 3. ለመወሰን ይከብደኛል | |

27. በጣም የታመመው ልጅዎ በሆስፒታል በቆየበት ወቅት፣ ምን ያህል እርሶ በወላጆችና በጤናባለሞያዎች መካከል በነበረው መሰተጋብር እረክተዎልዎት?

1. በጣም እረክቻለሁ
2. እረክቻለሁ
3. ለመወሰን ይከብደኛል
4. አረካሁም
5. በጣም አልረካሁም

28. ጨቅላ ህጻኑ በፅኑ የታመመበትን ሰው ወደዚህ ሆስፒታል እንዲያስገቡ ይመክራሉ?

1. አዎ!

2. አይደለም!

29. አዎ ከሆነ መልስዎ ምክንያትዎን ይግለጹ።: _____

UNSTRUCTURED INTERVIEW GUIDE QUESTIONS (FOR PHYSICIANS/ NEONATAL NURSES)

1. እድሜ _____
2. ጽዎታ _____
3. ሞያ _____
4. ስራ ልምድ _____
5. ለምን አይነት የጤና ጉዳዮች ነው ጨቅላ ህጻናት ወደ ጨቅላ ህጻናት ጤና መንከባከቢያ ማዕከል የመጡት?
6. በእርሶ እይታ፣ ወላጆች በጣም በታመሙ ጨቅላ ህጻናቶቻቸው የህክምና ሂደት ላይ በሚደረገው ውድቅ ላይ ተሳታፊ መሆን አላባቸው?
 - አዎ! ከሆነ መልሰዎ ምን ያህል ጊዜና ደረጃ (ተከከላኛ ህክምና መረጃ ይሰጣሉ ወይስ በሚኖሩት ስጋቶችና ጠቃሚ የህክምና አማራጮችን ይመዘናሉ)
 - አይ! ለምን?
7. በእርሶ እይታ፣ በህክምና ወሳኔ ውላይ የወላጅን ተሳትፎ ተጽኖ የሚያደርጉ ነገሮች ምን ድን ሆኑ? (ቋንቋቸው/ባህላቸው፣ ትምህርት ደረጃው፣ ሀይማኖታቸው ወዘተ በጣም በታመሙ ህጻናቸው ህክምና ወሳኔ ላይ ተጽኖ ያደርሳሉ?)
8. እንደ ህጻናት ነርስነትዎ በጣም በታመሙ ወይም አካል ጉደተኛ ሊሆኑ በሚችሉ ህጻናት የህክምና ሁኔታ ላይ በሚደረገው ውድቅ ቅድሚያ በመስጠት የመተገብሯቸው ጉዳዮች ምን ድን ሆኑ?
9. እንደ ህጻናት ነርስነትዎ በጣም በታመመ ህጻን የህክምና ወሳኔ ላይ የእርሶ ድርሻ ምን እንዲሆን ይፈልጋሉ?
10. ሌላ ሊቸምሩ የሚፈልጉት ሀሳብ ካለዎት ይግለጹ።

Declaration

I, the undersigned, declare that this thesis is my original work, has not been presented for a degree in any other university and that all sources of material used for the thesis have been duly acknowledged.

Name: Seada Jemal (BSC.)

Signature _____

Place: Addis Ababa University, Ethiopia

Date of submission: 23/06/2014

This thesis work has been submitted for examination with my approval as university advisor.

Advisor:

Name: Mr. Endalew Gemechu (Bsc, Msc, RN)

Signature: _____

Date: _____