ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEPARTMENT OF NURSING POSTGRADUATE PROGRAM

PARENTAL ROLE IN PEDIATRIC CANCER TREATMENT DECISION MAKING AT TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA, 2020 G.C.

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Full title of the research project	Parental role in pediatric cancer treatment decision making at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: 2020,G.C. (Mixed method study)
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Total cost of the project	24700 ETB
Address of investigator	Phone number: 0912768452 Email: danielbetemariem@gmail.com

DEDICATION

This research is dedicated to all parents of children with cancer who are passing those difficult times of their life through the treatment process for their child.

STATEMENT OF DECLARATION

Through my signature below, I honestly declared that this research thesis on parental role in pediatric cancer treatment decision making at Tikur Anbessa specialized Hospital, Addis Ababa, Ethiopia is my own work and all the sources that I have used indicated and acknowledged by means of complete references and this work has not been submitted before for any other degree in any other institutions.

Name: Daniel Betemariem (BSc) Signature: _________ Date: ____________

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ABBREVIATIONS

AOR- Adjusted Odds Ratio

CPS- Control Preference Scale

CPS-P - Control Preference for Pediatric

DRPC - Department of Pediatric and Child health

FM- Family Members

GC- Gregorian Calendar

HMIS- Health Management Information System

KHOS- Krantz Health Opinion Survey

PI - Principal investigator

r- Persons Correlation Coefficient

RN- Registered Nurses

SDM- Shared Decision Making

SPSS- Statistical Package for Social Science

TASH- Tikur Anbessa Specialized Hospital

TDM- Treatment Decision Making

USA- United States of America

WHO- World Health Organization

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ABSTRACT

Background: In medical scenarios like cancer parents level of participation in treatment decision for their child to enhance a better outcome is significant. Though in Ethiopia little is known about the decisional role of parents. Due to that this study aimed to clarify the extent to which parents involve in treatment decision making for their child and also explores different factors that determine the treatment decisional role.

Objective: To assess parental role and associated factors in pediatric cancer treatment decision making at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia 2020 GC.

Methods: A total of 167 parents were enrolled in the cross sectional study using a census method and additional 11 parents were purposively selected for the qualitative phenomenological study. The study was employed from April to May 2020 G.C. at Tikur Anbessa Specialized Hospital Pediatric Oncology department. Quantitative data was entered to EpiData version 4.6 and exported to SPSS version 25 for analysis. Descriptive frequencies and percents were used and binary logistic regression assessed statistical association. After the qualitative in-depth interview the data was transcribed and translated to Amharic then analyzed using thematic analysis method. ATLAS .ti 7 software was employed to aid coding process.

Result: The actual role of parents in treatment decision making was 129(77.2%) for passive, 37(22.2%) for collaborative and 1(0.6%) for active. Also 138 (82.6%) of the participants reported having their preferred role. Interpersonal trust and parental informational preference were statistically significant factors. Three broad themes were identified for factors affecting parental role in treatment decisional role in the qualitative study which are parent health care provider relationship factor, parental factors and clinical factors.

Conclusion and recommendation : Parental role in treatment decision making was found to be passive and multitude of factors were identified affecting their roles so there needs to be improvements in enhancing more roles for parents.

Key words: Actual role, preferred role, treatment decision, interpersonal trust, communication.

1. INTRODUCTION

1.1. Back ground

Even though Cancer is thought of as a disease of adults, especially the elderly, child hood cancer is becoming the leading cause of death for children worldwide, according to the international incidence of childhood cancer study approximately 300,000 children aged 0-19 years old are diagnosed with cancer each year (1). Usually not appreciated is the fact that the highest rate of childhood cancer occurs during the first year of life when the infants developmental processes are advancing rapidly and the parents are often in the early stages of their family life cycle (2).

Coming to Ethiopia an estimated 6000 new cases of pediatric cancer are diagnosed each year according to clinical record finding in Tikur Anbessa specialize Hospital and most children presented are late, with advanced disease, and in pain (3).

Parents of ill children's on the due process after diagnosis often accompany patients into the consultation, supply emotional, informational, or practical support, and participate in medical decision-making .They may change the dynamics of the consultation, influence the relationship among patient's with the physician, and increase the complexity of the encounter, they regularly attend consultations and can contribute information and participate in medical decision-making. Studies indicated that a majority of cancer patients (49–84%) and family members (54–59%) prefer family participation in decision-making to some extent (4–6).

Parental involvement in children's health care is generally associated with positive outcomes for both parents and children. Parents have reported less stress and better emotional wellbeing when they rated care as family involved (7).

According to the shared decision-making model (SDM) in which health professionals and patients share the responsibility in making decision, the involvement of the family during all stages of the process is recognized, with both the health provider and patients participate in decision making which creates an agreeable atmosphere (8,9). Although models of health care delivery, such as family-centered care, endorse the inclusion of parents in medical care (10).

1.2. Statement of the problem

Each year, the parents of approximately 15,300 kids will hear the words “your child has cancer.” Across all ages, ethnic groups and socio-economic, but the role they played in due process of seeking medical help and the outrageous benefits they provide in managing of the disease outcome is undermined (2,11,12).

Although multiple study outcomes indicated the involvement of parents in clinical decision making (including diagnosis and treatment) of an ill child is preferred either by the child himself or by the health provider under the assent of ‘helpful’(11,13,14). The prevalence and extent of involvement is very limited. A study made by the university of Bath specifically prevails that the involvement of parents on decision making for their child’s treatment alternative is found to be two times less compared to the health providers(62.47% for Doctors and 29.42% for parents) (15).

Due to high interconnection and interdependence existed among children and their parents the benefit of involving them on every aspect of clinical care is enormous. On this trajectory period the decision made through every treatment path under the health provider to the child also affects the family members throughout the duration of the treatment and it tremendously influence the extent of positive outcome for the ill child (14,16).

In extrapolating the role of parents toward the health provider and other care givers, according to Paul Stallard (child psychological therapist) the capability of managing anxiety and distress of this traumatized children’s is found depleted (17). Also the role the parents have as co-therapists in interventions to reduce feelings of pain in medical procedures such as vain puncture, lumbar puncture and parentral medication administration has been diminished (18).

In case of a resource limited countries like Africa the role of family inherits a different dimension. According to international society of pediatric oncology study made on the treatment abandonment in children from developing countries indicates unlike provision of support for effective diagnosis and productive outcome parents were found to play a role in treatment abandonment and withdrawal. This also in lined with the meta-analysis done on treatment abandonment in Sub-Saharan countries in which even if factors like educational status socio economic levels of the parents made some inconsistencies, still it’s being the challenge through curving the direction of involvement (19,20) .

Coming to Ethiopia, even though treatment coverage of children with cancer is increasing from time to time as to the knowledge of the researcher there was a scanty literatures in assessing the parents role in treatment decision making. This paper work builds on the knowledge that parental involvement in treatment decision making is a prerequisite for the better outcome of a child with cancer (9,21). So this study tried to fill the knowledge gap among health professionals and other stake holders on the role of parents on treatment decision making and had also explored reasons that parents identified as affecting their involvement for better outcome of their child's treatment and better utilization of scarce resources.

1.3. Significance of the study

Improving shared decision making in pediatrics can be accomplished when there is an understanding of how parents make, and wish to make, medical decisions for their children. Due to that the health care provider needs to incorporate the preferences and actual treatment decisional role of parents for the betterment of children’s health outcome. However studies suggesting those issues had not been addressed in Ethiopia previously so, this research will be an informational tool in feeling the knowledge gap.

Also the finding of this study will be the base line for policy makers and health care institutes as a mirror image of the current parental role in treatment decision making for their child with cancer and initiate planners to plan for the betterment of parents role play through educational sessions and programs targeted on parental role enhancement.

2. LITERATURE REVIEW

2.1 Introduction

The experience of cancer affect not only the child but also his or her family. The life treating nature of the disease the prolonged treatment period , pain experiences, complications and the unpredictability of the illnesses causes emotional distress in parents. Because cancer is a chronic and life-threatening illness, parents are less able to use effective coping strategies, and most parents are usually unprepared to deal with illness-related issues(22–24).

Making treatment decisions for dependent children is one of the most challenging roles that parents of children with cancer face. Childhood cancer typically presents suddenly, with limited time for parents to speculate something is wrong and participate in making major decisions about how their child is to be treated. After the diagnosis of cancer, parents feel an exceptional sense of stress and urgency, they use words such as "shocked" or "stunned"(25–27).

After the child started attending Hospital as different studies indicate the decision making role of parents is huge . Because it is unavoidable and stressful part of dealing with chronic illnesses like cancer, parents of children with cancer must make many decisions related to their Childs treatment, this includes a decision made during diagnosis and during treatment (12).

During treatment Parents are present a considerable amount of time by staying at the bedside, being physically present during threatening events and participating in the decision-making process. Even though parents do not want to make the final decision, they do want to be involved in the decision making process and they desire increased input in to the child's treatment, a narrative review made among 55 relevant articles in 2015 resulted most parents prefer active role in decision making of their children (28–30).

Though according to a study made in land university the extent of parental decision making and children's involvement in decisions for their own were found to be questions raised. Some studies indicated that stuffs believe parents should be partly involved in decisions concerning their child's care and other do not think parents should participate. According to Whitney etal. decisional model which suggests that during a single best decisions the clinicians will assume decisional priority, but if there are two or more clinically reasonable choices they should encourage parents (and children when appropriate) to assume decisional priority (29,31–33).

2.2. Level of parents participation in decision making process

As to Pyke-Grimm study on parents preference of participation in treatment decision making for a child with cancer Manitoba University Hospital, Canada, the investigator modified the tool used to measure adult preference of participation which is Control Preference Scale (CPS) (34) to Control Preference scale for pediatrics(CPS-P)(35), this tool incorporates five cards containing statements that describe different roles placed in an ordered manner and the parent is expected to choose one, based on that they classify the parents as active, collaborative and passive role in treatment decision making.

Based on the above enrolment the study identifies that the most preferred TDM role both during the time of diagnosis and the time of interview was collaborative 52%, followed by passive 34% at the time of diagnosis and 29% during the interview, the final one is active which holds 14% at the time of diagnosis and 19% during the interview (35). Another study made using the same tool on Parents of children with cancer on Mid-Western Canada University Hospital 50% of parents were found to have a collaborative role where as 28% had a passive role and 22% had an active role(36).

Through the use of CPS-P tool Harvard medical center, USA, study on Parents decision making preference resulted 58.5% of parents in the sample reported a preference for a collaborative role in treatment decision making with 28% chooses an active role and 13.6% endorsing a passive role(37). Also survey conducted at Dana Farber Cancer Institute and Children Hospital, Boston, about two third (66%) had a collaborative role in treatment decision making for a child with cancer and 26% retain an active role and the remaining 8% wishes to delegate a full responsibility to the physician, whereas 64% of parents reported that the role they actually held in decision making was their preferred role(38).

Another study made at Queens medical center, United Kingdom, parental involvement were assessed using 'responsibly for treatment choice' tool. Where the parents divide two different circles consecutively, the first circle is on how they felt certain parties including them self's contribute and the second one is on how they would have preferred responsibility for the treatment decision to be distributed, so the finding indicates that preferred participation was 32.6% and the actual was 29.42% for parents of children with cancer (15).

Decision making role and level of participation changes over time as Missouri University Colombia study, four patterns of decisional role was noticed. The first is professional dominated where the role of parents was compromised, second is participatory, the other is challenging, in which they becomes a strong advocates for their child and confront in every medical decisions and the final one is collaboration where they felt equal power in making decision. In all those Phases the main weapon for the parents to take part on one of the roles was the level of information they accumulated through times (12).

Rebekah Laidsaar-Powells study on family involvement in cancer treatment decision-making, influencing the decision process for their siblings was noticed as a main role. She stated that through the influencing process four overarching types of participation were identified, no influence is the first one The second was family influence through proximal actions where they are involved in provision of emotional and informational support, another large response was ‘Shared’ patient and family influence that FM’s influence over the decision was considered equivalent to that of the patient, the last where a minority response is dominant family influence(14).

2.3. Factors affecting parental decision making

Diversity of factors that contribute to the decision making role of parents on treatment of child cancer was shown with different studies. Which include, the relationship with the physician, the nature of communication, trust in the physician, the parents’ and physician’s experience and knowledge, and the perceived importance of the parental role(36). Another studies made in stated prior hospitalization of the child, longer time frames of treatment in cancer patients, provider recommendations as a major factors that affect the role of parents in treatment decision making of a child with cancer (39–41).

2.3.1 Parental factor

The knowledge of parents of children with cancer in relation to educational background and information on their child disease condition predominantly affects the role parents perceived in treatment decision making. Ruccione K. and Kramer RF.'s results explains that parents of children with cancer who had a higher education level expressed greater satisfaction with information received and a higher degree of autonomy in making decisions about their Childs treatment. At the same time felt increased need of information and frustration with the lack of time to make decisions was noticed (42,43).

McMaster University, Canada study on clinicians proposed that actively involved FMs tended to be middle aged (compared to elderly or young adult FMs), female, well-educated and possessed professional medical or allied health experience (14). Which is contrary to a study made by Mckenna k., Collier j, USA, younger parents both received and desired more family involvement in treatment decisions ($r = -0.299$, $p < 0.05$ for both) (15).

In addition Parental gender was also found to have association with the level of participation in treatment decision making, on a study made at Nationwide Children’s Hospital, USA mothers with previous knowledge on Pediatric cancer therapy reported and preferred more Doctor involvement compared to Fathers ($t(58) = -2.339$, $P < 0.05$ and $t(58) = -3.147$, $P < 0.01$) and also on the same study parents who have a previous knowledge on pediatric cancer therapy are tended to desire more participation from the oncologist other than having a collaborative role($P < 0.05$) (15).

The time lapse since diagnosis was also found as one factor in shaping the extent of involvement in treatment. A study made on the dynamics of change of involvement among patients with cancer at Australia resulted, when patients attained for the first time they were found to seek a greater involvement in contrast to patients experienced change after some follow up which delegates more decisional responsibility to their doctors(chi-square = 7.9, $P < 0.05$) (44).

Though the finding was not true at every results. In accordance to Elizabeth M. and Christopher J. Harvard medical school, even though the extent of involvement differs from parent to parent the amount of time elapsed since diagnosis was not found significantly correlate with the degree of parental desire for control in treatment decision making(rho=0.159, p = 0.103) (37).

In the African Country Ghana, a qualitative study made on the factors affecting health-seeking decision making, the lack of previous knowledge on Pediatric cancer were found as the major factor affecting decisional role, most of the parents associated the diagnosis of cancer with death and their most decisional thought is treatment abandonment and search for alternative therapies, so the importance of informing parents about the disease condition well was implicated (45).

2.3.2 Parent health care provider relationship factor

In a clinical setup decision making relationship during patient treatment is a continuous process. Through this process, as in pediatrics, the patient/ parent full responsibility for the decision (autonomous decision making)and the physician inheriting full responsibility (paternalistic decision making) are the two extremities. This is where shared responsibility aspired and working together becomes the ideal assumption(46–48).

Triangulated insight made by Rebekah Laidsaar-Powells indicates many clinicians believed families tended to be more involved in decision-making when they had a strong and close relationship with the patient(14).

In the parents health care provider relationship for chronically ill children’s, trust and communication were found to be the major corner stone's, for determining the role of parents in treatment decision making. When we say trust it is to mean a person's belief that the physician's words and actions are credible and can be relied upon (49). As to Kirschbaum and Knafl trust between the parents and the physician is important in developing a mutually respectful relationship. Also emphasized the importance of trust in which as the parents trust maximize, reliance (total dependence) on the health care provider have been shown on decision concerning alterations on the child's outcome (36,50).

Trust was also found as a significant factor under the study of Jennifer W. Mack and Joanne Wolfe on parental roles in decision making for children with cancer, the analytical output indicated that Parents who were highly involved in decision making than they wished were more likely to trust their Childs physicians judgment (37).

In contrary mistrust among parents on healthcare providers lead them to take an active role both in searching for trustful relationship and vigilance for all medical interventions for their children's (51,52).

An integrative review on 52 articles made at the University of Missouri-Colombia States, in all of the reviewed articles trust was found important in between the parents and the health care provider relationship, also during early stages of the relationship it was very high which they call it ‘naïve truest’ and makes the parents to take a passive role in decision making and if this bond brakes due to mistrust the role shifted from passive to active in making decisions for their children’s (12).

Regarding communication it is difficult for parents to participate in decisions when they are not aware of the alternatives available, Angest and Deatrick's and also Kirschbaum and Knafl studies found that parents’ TDM preferences were related to their style of communication with the physician. Active parents wanting the physician to provide information so they could make the decision and passive parents wanting the physician to listen to their concerns when making a decision (50,53).Dana Farber Children Hospital, Boston survey supports the above findings that, parents who holds a grater passive role than they preferred felt that communication was less prominent (38).

The main reasons for poor communications according to Mark Avis are competency gap of the professionals, the use of technical language (medical terms) among those health care providers or the different purpose that patients and professionals have in communication (54).

It is known that professionals have medical and nursing knowledge and experience of Hospital routines rather as of Inger Hallstorm's observational study, Sweden, for parents and patients the environment is quit unknown and they need to be familiarized. He also mentioned that due to lack of information and the non negotiation of roles, they had faced problem of participation on treatment decision making. So that to improve the level of participation effective communication was required (29).

Through parent health care provider relationship, Information preference and behavioral involvement of parents was also conceived as a main factors in shaping the control of parents in treatment decision. In which by using the Karts Health Opinion Survey (KHOS) as those factors improves the preference of involvement shifted from passive role to active according to Dana-Farber cancer institute study by a linear trend analysis (F=5.83, p=0.004) (37).

In addition at Athens general public hospital a collaborative role preference was noted among cancer patients who have a greater informational preference on the disease and treatment than patients who preferred passive collaborative and a complete passive role ($p < 0.001$) (55).

2.3.3 Illness factor

The prognosis of a Childs illness affects parental treatment decision making. According to Gloria Jean Gross, Nebraska Medical center study on mothers decision making process regarding health care for their child, seriousness of the disease condition and the child's condition were one of the most sited factors that are directly related to the mothers decision making priority. As one mother stated " I would rate seriousness high for decision making as a factor, as this is how serious this condition would be for my child" (56).

Another retrospective study made on parents of children who had died of cancer, Houston ,found that parents took an increased role in making decisions when a child was not expected to survive and they hypothesized this might be due to reduced consequences when the outcome is known to be terminal (33).

An in-depth interview conducted on fifty eight custodial Parents of children with cancer at Pediatric Oncology facility of mid western Canada, Parents identified the situational context as influenced their treatment decision making role, 22% of them described a feeling of shock, nervousness or of being overwhelmed which they stated impaired their ability to make decisions, one parent said " you are so overwhelmed by everything that is going on" (36).

As stated in the introductory part of this proposal most of the studies made in developing countries in Africa (45,57,58), parents were mostly involved in treatment abandonment. This is as their papers indicated is due to the fear and anxiety they experienced after identifying the diagnosis is cancer and the severity of its status so that they lose hope for the alternative medication provided by the health care group.

2.4. Conceptual frame work

The conceptual frame work hypothesized that parental socio-demography, parent health care provider relationship and child's illness conditions directly relate with the outcome variable which is parental role in treatment decision making.

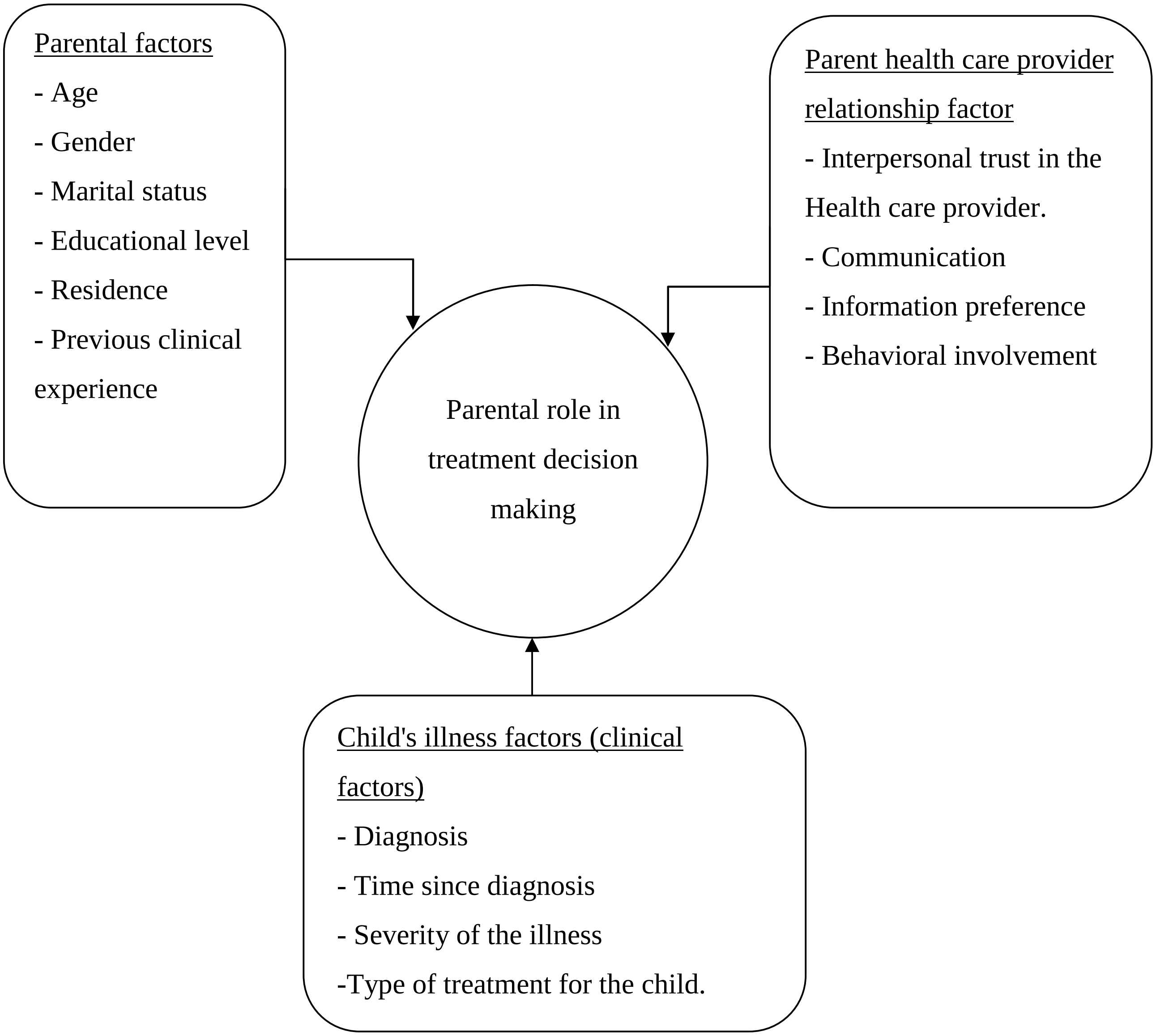

Figure 1:Conceptual frame work for Parental role in Pediatric Cancer treatment decision making at TASH, Addis Ababa, Ethiopia, 2020 GC.

(Source: This framework is constructed integrating (14,15,35–38,44,50,53) literatures.)

3. OBJECTIVE

3.1 General objective

To assess parental role and associated factors in pediatric cancer treatment decision making at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2020GC.

3.2 Specific objectives

1. To determine the actual role of parents in treatment decision making for their child with cancer.
2. To describe the preferred role of parents in treatment decision making for their child with cancer.
3. To explore factors affecting actual parental role in treatment decision making of children with cancer.

Research questions

1. What role parents had in different treatment decision makings for their child with cancer?
2. what is the parents preferred role treatment decision making for their child with cancer?
3. What are the key factors that prevent and enable parents participation in treatment decision making ?

4. METHODS

A convergent mixed method approach was used, the quantitative analysis had determined the role of Parents on treatment decision making and assessed effect of different factors identified. The qualitative exploration added more reasons from parents perspective on the level of involvement on treatment decision making of parents for their children with cancer.

4.1. Study setting

The study was conducted at pediatric oncology clinic, Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia. The Hospital was chosen due to it's the largest health facility incorporating pediatric oncology clinic in the country. TASH was opened in 1972 as a government teaching Hospital and located at Kirkos sub-city, Addis Ababa the capital city of Ethiopia (59).

The institute has 700 beds with 379 Nurses, 200 Doctors and 115 other health professionals dedicated to providing health care services. The Hospital also has 950 permanent and contract administrative staff to support the Hospital activities. In addition, almost all regional and federal Hospitals in Addis Ababa are affiliated to the School of Medicine as clinical services and training sites.

The Hospital incorporates the only Oncology pediatric department in the capital city containing two inpatient wards and one outpatient clinic. The first inpatient ward is found at the main building which accompanies 20 beds and the remaining inpatient and outpatient clinic is located at the Hospitals cancer center which also incorporates 14 beds, 9 registered Nurses and 3 Pediatrics Oncology Specialist Doctors. In general both wards and the outpatient clinic together serves on average 8000-10,000 patients annually.

4.2. Study Period

The study was conducted in Tikur Anbessa Specialized Hospital pediatric oncology clinic from April 14 to May 14/2020.

4.3. Quantitative methods

4.3.1. Study design

Institutional based cross-sectional study design was conducted among parents of children with cancer treatment at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

4.3.2. Description of the population

4.3.2.1. Source population

All Parents of children with cancer under treatment during the data collection period at Tikur Anbessa Specialized Hospital Pediatric Oncology department.

4.3.2.2. Study population

Due to census was used the study population were the same as the source population. In which all parents of children with cancer under treatment during the data collection period were involved.

4.3.3. Eligibility criteria

4.3.3.1. Inclusion criteria

A child was diagnosed with any type of cancer and attending pediatric oncology ward or outpatient department.

The child was at least one month post-diagnosis, this helped to allow parents to experience decision making about their child's treatment condition.

The parent was the child’s primary caregiver.

4.3.3.2. Exclusion criteria

Parents with known mental health condition.

Parents of children who were receiving treatment in a palliative setting.

Parents of children who were critically ill during the data collection period.

4.3.4. Sampling methods

4.3.4.1. Sample size

Complete enumeration was intervened among parents of children with cancer which were attending the pediatric oncology clinic during the data collection period. The final number of parents found was 167.

4.3.4.2. Sampling technique

All parents of children with cancer who fulfill the inclusion criteria during the data collection period were included in the study using a census technique.

4.3.5. Data collection tools and procedure

Data on parental role was collected by trained nurses through face to face interview using a structured questionnaire. Control Preference Scale for Pediatrics (CPS-P), which was adopted to depict parents role in treatment decision making asked parents to choose among five different scenarios, which were presented in a form of single statement for each scenario and this five statements represent a continuum from 'I prefer to make the final decision about which treatment my child will receive' to ' I prefer to leave all decisions regarding my child's treatment to my doctor' and for their actual role the tense was changed to past.

The scale was first developed at a study made by Kimberly Pyke-Grimm at Manitoba Hospital, Canada (1999) (35). The modified Control Preference Scale for Pediatrics which was adopted in this study was from Danger and Sloan (1992) (34) to make it applicable to parents of pediatric patients. In this study subjects were presented with all 5 scenarios simultaneously and asked to choose their preferred level of activity in treatment decision making a ‘pick one’ method was used.

The other tool used was Krantz Health Opinion Survey (KHOS) to assess information preferences and behavioral involvements of parents. The tool incorporates two subscales KHOS-I and KHOS-II, KHOS-I reflects the tendency of parents to seek health-related information actively (7 items) (i.e. ‘I usually ask the doctor or nurse lots of questions about the procedures during a medical exam.’) and KHOS-II parents' preferences for the degree of control or involvement in their own care (9 items) (i.e. ‘If it costs the same, I’d rather have a doctor or nurse give me treatment than to do the same treatments myself.’). Both scales used a binary (agree/disagree) response format. Higher scores on the KHOS were associated with enrollment in medical self-help classes, asking questions during clinic visits, and choosing one’s own medication. Lower scores have been associated with seeking medical help for minor illnesses (60).

Trust in the physicians scale was also used to assess the interpersonal trust among the parent and health care provider which is composed of 11 assessing questions in Likert scale format and communication assessment tool to measure the extent of communication in between the parent and the health care provider containing 6 questions which were derived from 'Development of the trust in physician scale' (61) and 'The Consumer Assessment of Health Plans Study (CAHPS)'(62) respectively. A nine item questionnaires containing socio-demographic of the parent and his/her child, child's disease, severity of the illness and medical treatment provided were also has been filled using clients Hospital card and interviewing the parents.

The tools were adopted in English language and translated to Amharic language and then back translated to English language to see if the Amharic version complies with the original document. The Amharic version of the questionnaire was reviewed by 5 primary care givers incorporated from Nurses and Doctors working on the area of the study and necessary modifications were made. Before the data collection begins two data collectors which were nurses were selected and training was provided for the data collectors.

Data collection started by obtaining permission from department of Pediatric and Child health. Parents of children with cancer who meet the inclusion criteria after discussing with their doctor and nurse clinician who looks after the patient got an explanation about the purpose of the study and reassured confidentiality.

Those who were willing to participate in the study were part of the interview questionnaire. The data collection was performed in private with each parent during an Inpatient admission and Outpatient clinic visits.

4.3.6. Data quality

To assure the data quality, data collection tools were adopted after intensive reviewing of relevant literatures and similar studies. The scales had been validated and proven reliable in a number of studies,(35–37).The cronbach's alpha for KHOS was reported as 0.54–0.76 (KHOS-I) and 0.72–0.77 (KHOS-II) (59).

Also the internal consistence for trust in the physicians scale as measured by Cronbach alpha was 0.9 and (61) and communication was ranged from 0.73 to 0.86(62).

Training was given for data collectors by the principal investigator regarding familiarizing them with the tools and consistence throughout the process. The questionnaire was Pretested on 10 parents which were not the part of the full scale study to check acceptability, consistence, clarity and completeness. Based on the result some questions were found to have a clarity issues and modification has been made. Finally after the main data collection the collected data was checked for completeness before data entry.

4.3.7. Data analysis

All the returned questionnaires were checked for completeness and clarity and entered in to Epi-data software version 4.6 to assess for further completeness, categorized and coded in to numerical digits, then was exported and analyzed by Statistical Package for Social Science (SPSS) version 25. Frequencies, distributions and also diagrams were used for describing the study population in relation to relevant variables. Bivariate analysis was used to assess the association for each independent variable with the outcome variable.

Predictor variables with a p-value less than 0.25 and variables presumed important by the principal investigator were further analyzed through multivariate analysis with 95% confidence level to see if there is a significant association between them and the outcome variable and the statistical significance was declared at $p\text{-value} < 0.05$.

4.3.8. Variables

4.3.8.1. Dependent variables

- Role of parents of children with cancer in treatment decision making.

4.3.8.2. Independent variables

- Socio demographic factors of the parents and their children with cancer.
- Clinical factors.
- Parent health care provider relationship factors.

4.3.9. Operational definitions

Parental treatment decision making role will be assessed based on the control preference scale for pediatric tool; If the parent selected the statement A. ' I made the final decision about which treatment my child will receive' and B. 'I made the final selection of my Childs treatment after seriously considering my doctors opinion' was considered to have an Active role.

If the parent selected the statement C. ' I made my child's doctor and I share responsibility for deciding which treatment is best for my child' was considered to have a Collaborative role.

If the parent selected the statement D. ' I made my doctor to make the final decision about which treatment will be used, but after seriously considers my opinion' and E. 'I left all decisions regarding my child's treatment to my doctor' was considered to have a Passive role (35–37).

4.4. Qualitative methods

4.4.1. Study design

Descriptive phenomenological design was used to navigate the lived experience for determinants of parental role in treatment decision making from parents them self's at Tikur Anbessa Hospital, Addis Ababa, Ethiopia.

4.4.2. Study participants

Parents of children with cancer whose child's were on treatment at Tikur Anbessa Specialized Hospital Pediatric Oncology clinic from April 14 to May 14/2020 was participated in the study.

4.4.3. Sampling methods

4.4.3.1. Sample size

The data was collected among 11 parents of children with cancer. Number of participants for the in-depth interview was determined by informational redundancy or saturation, the point at which no new information or categories were emerged from the data. To ascertain saturation, the researcher moved back and forth through the data in order to find, compare, and verify the categories. After gained an insight of what the emerging categories were and ensured interviews were no longer generating new categories it assured that saturation had reached.

4.4.3.2. Sampling technique

Purposive sampling technique was used to select parents who meet the eligibility criteria for the study. During participant selection, variation in age, gender, marital status, residence, educational status and cancer stage of the child was considered.

4.4.4. Data collection tools and procedure

Parents were asked an open ended questions on factors affecting their treatment decision making role which took place at a private room on one to one bases using SONY tape recorder. The questions were first developed in English language and translated to Amharic language and then back translated to English language to see if the Amharic version complies with the original document. It included parents demographic data, preference of participation and actual role then a logical reasoning from parents perspectives and discussed different factors that promote or diminish their role. In addition minimal prompts such as “What else was hard?”, “Can you tell me more?” and “What else have you done?” to clarify or expand on participant responses.

Interviews began with warm-up questions and general questions about the parents demography and their child’s cancer history. As the interview continuous the questions focused on their role in treatment decision making and factors they identify as affecting their role was discussed in details. The interviews were audio recorded and field not was taken with assistance from one note taker for all of the participants. The audio taped interview ranged from 12 minutes to 30 minutes.

4.4.5. Trustworthiness

The trustworthiness of a qualitative study was determined by the extent to which it was dependable, confirmable, credible and transferable. The researcher adhered to this principles for the study, as stated below.

Credibility

From the perspective of establishing credibility, researcher used different strategies: the first was to spend prolonged engagement in research site, which helped the researcher gain an insight to the context of the study and minimized the distortion of information, that might arise due to the presence of the researcher. The second was use of peer debriefing, during writing the reports the researcher received comments from peers, which helped in developing the conclusion of the study.

Dependability

Dependability was established through using different methods, the first was an audit trial where the advisor as auditor checked the row data, the interview notes and records collected from the field and asked explanation for any changes made, and second way was step wise replication in which the principal investigator with one co-investigator analyzed the data separately and compared the results, any inconsistence was addressed.

Conformability: To confirm the interpretation of the findings are not figments of the investigators imagination but are clearly derived from the data, the researcher used strategies as reflexive journal and bracketing journals, which includes all events that happen on the field, personal reflections in relation to the study, phenomena that arises during the investigation and also includes the researchers personal history.

Another strategy which were used to assure conformability was assessing integrity of research findings. This method deals with misinformation and lies from the informants that occurred due to loss of interest to supply information to the researcher or dislike to the researcher. In this situations the investigator was skeptical if the information was incorrect and tried to create rapport and trust through prolonged attachment with the informants to clear up the doubt.

Transferability

To facilitate the transferability judgment by a potential user of the document to other contexts with other respondents the investigator used thick description which involved the researcher had elucidate all the research processes, from data collection, context of the study to production of the final report.

The second way used to construct the transferability judgment was purposive sampling technique which had helped the researcher to focus on key informants that are particularly knowledgeable of the issues under investigation and it provided greater in-depth findings than other probability samplings.

4.4.6 Data analysis

The qualitative data was analyzed using qualitative thematic analysis method. Each audio taped interviews were transcribed verbatim in the language of interview concurrently after each interview. Transcribed data was translated in to English language by an individual who is expert in both Amharic and English languages.

Based on the empirical data inductive coding was performed. In this process the principal investigator reviewed the transcripts line by line several times. Thereafter, texts were broken down into meaningful units which were key phrases in the text. Coding criteria was developed through novel themes that emerges from the data. Subsequently, meaningful units were condensed and labeled with codes.

ATLAS .ti 7 software was employed to aid coding process. The coding framework was subject to continuous update. Then, the codes, according to similarities and differences, were allocated into subcategories. Similar subcategories were grouped into categories. Finally, the themes were determined as the expression of the latent meaning of the text.

4.5. Ethical consideration

Ethical clearance and official letter of cooperation were obtained from Addis Ababa University, Colleague of Health Science, School of nursing and Department of Pediatric and Child health (DRPC) ethical committees respectively to proceed to the data collection.

Written consent was obtained from each study participants. Privacy and anonymity was maintained during data collection, transcription, analysis & report. Information about them that were collected from the study was stored in a file, which have pseudonyms on it replacing their original names and was maintained throughout the process.

4.6. Dissemination of the result

After collection and analysis of the data had undertaken the finding was reported to Addis Ababa University Colleague of health science School of Nursing and the copied research report was given to Tikur Anbessa Specialized Hospital pediatric and child health department.

The findings were also be communicated to health planners and other relevant stake holders. Publication in peer reviewed national or international journals were also considered. The finding will also be communicated through presentations on national and international conferences.

5. RESULT

5.1 Quantitative Study Result

A total of 167 parents of children with cancer who were on treatment at TASH paediatric oncology clinic during the data collection period were involved in the study and all of the respondents successfully completed the interview.

5.1.1 Socio demography characteristics of the parents

The participants were between the age of 15- 65 years with a mean age of 36 years and standard deviation of ± 9.11 years. Sixty four percent of the study participants were aged between 30 to 43 years and 97(58%) were female. Majority (89.2%) of the participants were living with a partner and 115(68.9%) were employed. Half (50.3%) of the respondents were urban residents while 57(34%) were uneducated and 63(37.7%) had attended secondary school and above.

Table 1: Socio demographic characteristics of the study participants at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2020.

Socio-demographic variable		Frequency(n)	Percent(%)
Age in years	15 to 29	37	22.2
	30 to 43	107	64.1
	above 43	23	13.8
Sex	Mother	70	41.9
	Father	97	58.1
Marital status	Living along	18	10.8
	Living with a partner	149	89.2
Residence	Urban	84	50.3
	Rural	83	49.7
Level of education	Uneducated	57	34.1
	Primary school	47	28.1
	Secondary school and above	63	37.7
Occupation	Employed	115	68.9
	Unemployed	52	31.1

5.1.2 Demographic characteristics of the child

The participants children were between the age of less than 1 year to 15 years with a mean age of 6.3 years and standard deviation of ± 3.89 years. Seventy one (42.5%) of the children's were in between 5 to 10 years old and 96 (57.5%) were males. Eighty eight (52.7%) of children's were diagnosed less than a year ago and a relatively high number (44.3%) of participants children's were diagnosed with Leukaemia. Disease severity was intermediate among 77 (46%) of the children and 122 (73.1%) of participants children's received single modality treatment.

Table 2: children's demographic characteristics at Tikur Anbessa Specialized Hospital, 2020.

Socio-demographic variable		Frequency (n)	Percent (%)
Age	< 5 year	64	38.3
	5 to 10 years	71	42.5
	11 to 15 years	32	19.2
Sex	Female	71	42.5
	Male	96	57.5
Diagnosis	Carcinoma	56	33.5
	Leukemia	74	44.3
	Lymphoma	19	11.4
	Sarcoma	18	10.8
Time since diagnosis	< 1 year	88	52.7
	> 2 year	40	24.0
	1-2 year	39	23.4
Disease severity	Low risk	41	24.6
	Intermediate risk	77	46.1
	High risk	49	29.3
Treatment	multi-modality treatment	28	16.8
	single modality treatment	122	73.1
	Others*	17	10.2
	Total	167	100.0

* Blood transfusion, Vitamine B12 supplémentassions, Immunothérapie

5.1.3 Parent and health care provider relationship factors

5.1.3.1. Information preference

Krantz Health Opinion Survey (KHOS) was used to measure information preference and behavioral involvement among parents of children with cancer. The total score ranged from 0 to 13 with a mean of 4.7 and standard deviation of ± 2.88. For the subscales Information preference (KHOS-I) the mean was 3.5 and the standard deviation was ± 2.38. Majority 119(71.3%) of the participants agreed to the question ' I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately' and 102 (61.1%) disagree to the question 'I usually don't ask the doctor or nurse many questions about what they are doing during the medical exam'.

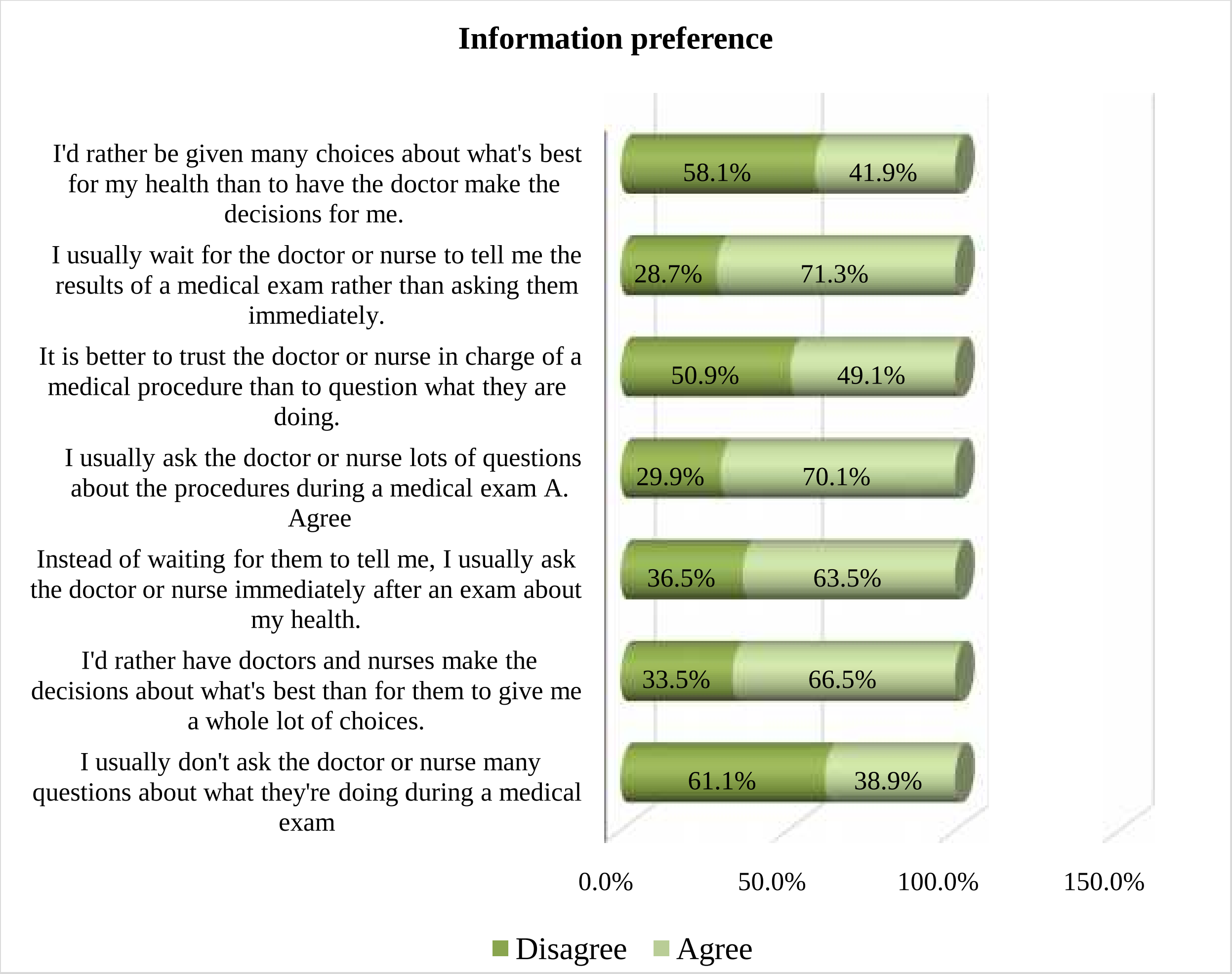

Figure 2: Participants information preference of children with cancer at TASH Ethiopia,2020GC.

5.1.3.2. Self care behavioral involvement

The self care behavioral involvement subscale is a scale concerned with attitudes toward self-treatment and active behavioral involvement in medical care of parents and used in this study if those personal characters reflect on their child's medical care as well. It contained nine questions each with 'agree' and 'disagree' response format. The score ranges from 0 to 6 with mean 1.18 and the standard deviation was ±1.63.

Almost all (92.8%) of the participants disagree to the question 'It is better to rely less on the physicians and more on your own common sense when it comes to caring for your body'. One hundred sixty four (98%) of the participants agree for the question 'Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves.

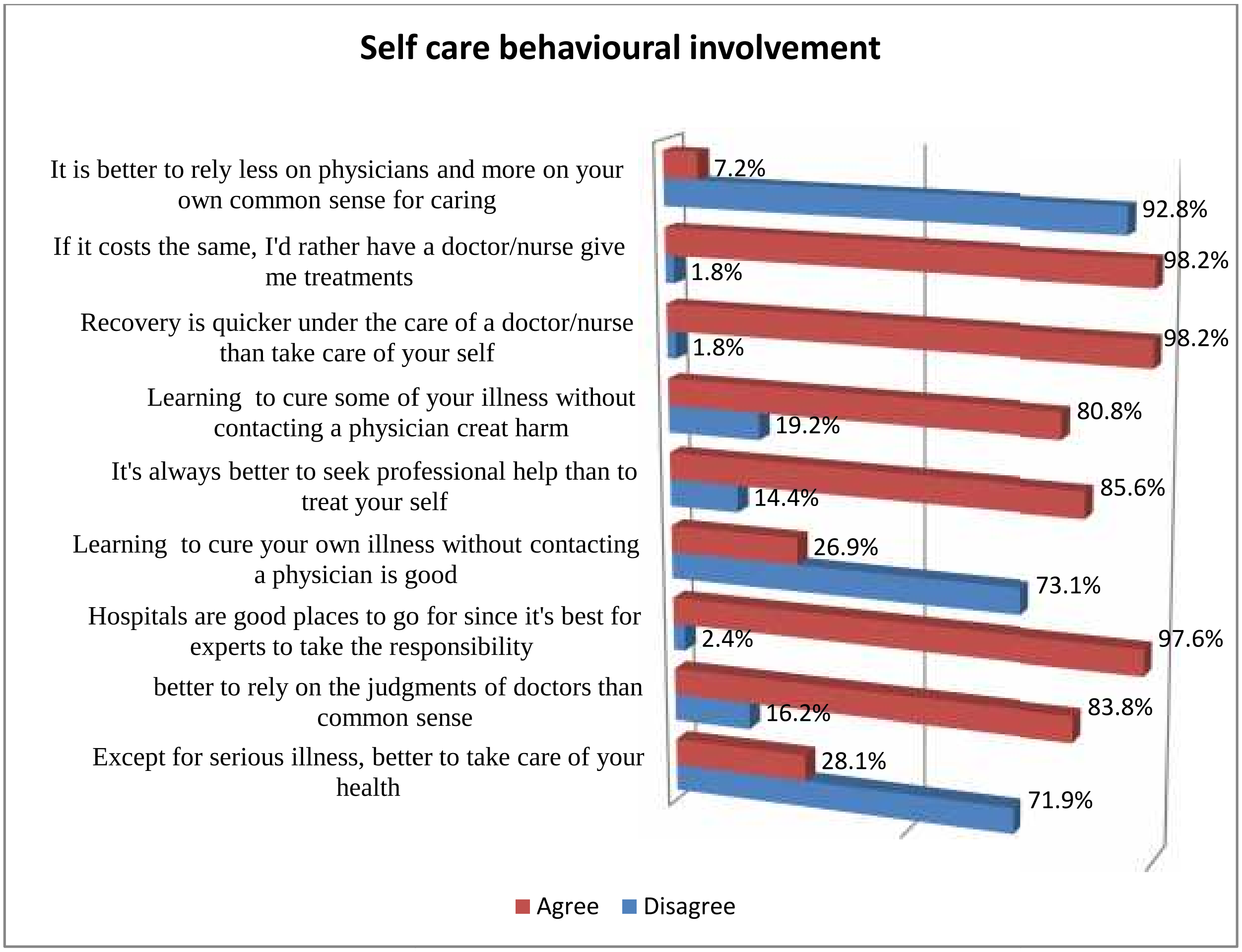

Figure 3: Self care behavioral involvement sub-scale (KHOS II) among parents of children at TASH, Addis Ababa, Ethiopia, 2020 GC.

5.1.3.3. Interpersonal trust in the HCP

Interpersonal trust in the health care provider scale contained eleven questions each with five alternative choices from 'strongly agree' to 'strongly disagree'. The scale tried to answer the level of interpersonal trust among parents on health care providers. The mean value was 32.7 and the standard deviation was ± 7.5. Most (83%) of the participants strongly agree on the question ' I trust my doctor so much that I always try to follow his/her advice.' and 73 (43.7%) of the participants strongly disagree on the question 'I trust my doctor to tell me if a mistake was made about my treatment'.

Table 3: Interpersonal trust on the health care provider of the study participants at TASH, Addis Ababa, Ethiopia, 2020.

Interpersonal trust assessing scales	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I doubt that my doctor really cares about me as a person.	60.5%	16.1%	0.0%	9.0%	14.4%
My doctor is usually considerate of my needs and puts them first.	12.0%	7.2%	0.6%	29.3%	50.9%
I trust my doctor so much I always try to follow his/her advice.	0.6%	3.6%	0.0%	12.6%	83.2%
If my doctor tells me something is so, then it must be true.	15.6%	12.0%	0.6%	7.1%	64.7%
I sometimes distrust my doctor's opinion and would like a second one.	57.5%	13.2%	0.0%	13.7%	15.6%
I trust my doctor's judgments about my medical care.	0.6%	2.4%	0.0%	19.2%	77.8%
I feel my doctor does not do everything he/she should for my medical care.	49.1%	17.4%	0.6%	13.1%	19.8%
I trust my doctor to put my medical needs above all other considerations when treating my medical problems.	3.0%	9.6%	0.6%	22.8%	64%
My doctor is a real expert in taking care of medical problems like mine.	1.8%	3.0%	1.8%	21.0%	72.4%
I trust my doctor to tell me if a mistake was made about my treatment.	43.7%	16.8%	4.8%	8.4%	26.3%
I sometimes worry that my doctor may not keep the information we discuss totally private.	32.9%	30%	1.2%	10.2%	25.7%

5.1.3.4. Parent and health care provider communication

The communication scale contained six questions each with four alternative choices from 'Never' to 'Always'. The scale assessed the communication of health providers with patients. The mean value was 11.4 and the standard deviation was ± 5. The values ranged from 0 to 18. More than half (59.3%) of the participants believed that health care providers gave them understandable answers for their questions. While 60(35.9%) of them stated health care providers never provide them information without their intention to ask.

Table 4: Parent and health care provider communication of the study participants at TASH, Addis Ababa, Ethiopia, 2020.

Questions	Never	Sometimes	Usually	Always
The physician took time to answer my questions.	12.0%	21.5%	15.6%	50.9%
The health care provider provided me as much medical information as I wanted.	9.0%	24.6%	21.6%	44.8%
They provided me information without my intended need to ask	35.9%	24.6%	19.7%	19.8%
They made me feel listened to.	16.2%	22.8%	29.9%	31.1%
We had communicated in a sensitive manner	8.4%	21.0%	19.2%	51.4%
They provided me understandable answer.	10.2%	16.2%	14.4%	59.2%

5.1.4 Parental role in treatment decision making

From the total of 167 participants 102 (61.1%) of them preferred to have a passive role in treatment decision making for their children's and also 130 (77.8%) participants had an actual passive role. Whereas seven parents (4.2%) preferred active role in treatment decision and one parent (0.6%) had an actual active role. One hundred thirty eight (82.6%) of the participants reported having their preferred role and 101 (60.5%) preferred and have passive decisional role.

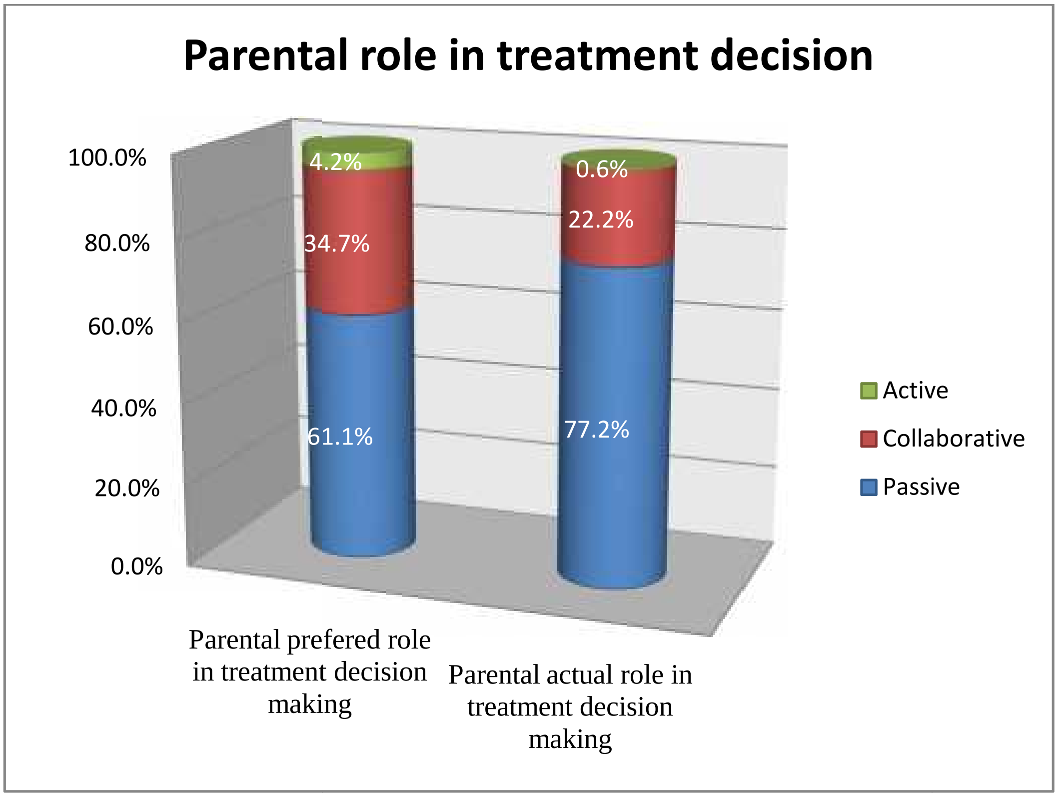

Figure 4: Preferred and actual role of the study participants in Pediatric Cancer treatment at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2020.

Table 5: Preferred versus actual role of parents in treatment decision making for their child with cancer at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2020

		Parental actual role in treatment decision making			
		Passive	Collaborative	Active	Total
Parental preferred role in treatment decision making	Passive	101	0	1	102
	Collaborative	22	36	0	58
	Active	6	1	0	7
Total		129	37	1	167

5.1.5 Association between parental role in treatment decision making for their children's and factors affecting role assumed.

The category of the outcome variable was minimized in to two, because due to the study was conducted in a short period of time the number of participants categorized under active decision making were very small. Therefore, active role and collaborative role was categorized together and factors associated with passive role were analyzed using logistic regression.

Using bivariate analysis; parental age, residence, educational level and informational preference were found to be statistically significant predictor of treatment decision making.

For multivariable logistic regression those variables with p value less than 0.25 and deemed important by the researcher were analyzed using enter method. Accordingly, interpersonal trust and informational preference, were found to be significant predictor of treatment decision making.

Variables which were significantly associated in the bivariate analysis such as parental age, residence, educational level were found to have no statistically significant association during multivariable analysis, whereas interpersonal trust which was not statistically significant in the bivariate analysis was found statistically significant in the multivariable analysis.

For every one-point increase in parental informational preference score the odds of parental passive role decreased by 40% [AOR (95%CI) = 0.6 **(**0.46-0.79)]. Also for every one-point increase in the interpersonal trust of the parents on the health care providers the odds of parental passive role multiplies by 1.16, [AOR (95%CI) =1.16 (1.02-1.22**)**].

Table 6: Association between parental role in treatment decision making and different factors affecting their roles at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2020.

Variable	Parental role in DM Collaborative	Passive	COR (95%CI)	AOR (95%CI)
Parental age in years				
15 to 29 years	14(37.84%)	23(62.16%)	**0.16(0.03-0.77)***	0.22(0.04-1.31)
30 to 43 years	21(19.63%)	86(80.37%)	0.39(0.09-1.8)	0.5(0.1-2.52)
Above 43 years	2(8.7%)	21 (91.3%)	1	1
Parents sex				
Mother	18(25.7%)	52(74.3%)	0.7(0.34-1.47)	0.8(0.23-2.75)
Father	19(19.6%)	78(80.4%)	1	1
Marital status				
Living alone	5(27.8%)	13(72.2%)	0.71(0.24-2.14)	0.8(0.19-3.32)
Living with a partner	32(21.48%)	117(78.52%)	1	1
Residence				
Urban	27(32.1%)	57(67.9%)	**0.29(0.13-0.65)****	0.5(0.16-1.59)
Rural	10(12%)	73(88%)	1	1
Educational level				
Uneducated	7(12.3%)	50(87.7%)	**2.64(1.01-6.94)***	0.64(0.16-2.58)
Primary school	13(27.7%)	34(72.3%)	0.97(0.41-2.26)	0.6(0.2-1.8)
Secondary and above	17(26.98%)	46(73.02%)	1	1
Occupation				
Employed	24(20.87%)	91(79.13%)	1.26(0.58-2.74)	0.54(0.13-1.98)
Unemployed	13(26%)	37(74%)	1	1
Child age				
Less than 5 years	17(26.6%)	47(73.4%)	0.87(0.4-1.89)	1.54(0.55-4.3)
5 to 10 years	17(23.9%)	54 (76.1%)	3.04(0.82-11.25)	4.83(0.91-25.69)
11 to 15 years	3 (9.4%)	29(90.6%)	1	1
Child sex				
Female	13 (18.3%)	58 (81.7%)	1.49(0.7-3.18)	1.78(0.66-4.77)
Male	24 (25%)	72 (75%)	1	1
Interpersonal trust			1.04(0.99-1.01)	**1.16(1.02-1.22)***
Information preference			**0.59(0.47-0.73)*****	**0.6(0.46-0.79)*****
Self care Behavioral involvement			1.21(0.93-1.58)	1.29(0.94-1.76)
Total	37(22.2%)	130(77.8%)		

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

5.2. Qualitative study result

A qualitative part in this study was introduced to further explore different additional factors parents identified as affecting their role in a form of enhancing or deteriorating treatment decision making for their children with cancer.

5.2.1 Socio demographic characteristics of the parents and their children

A total of 11 parents of children with cancer who were on treatment at TASH paediatric oncology clinic during the data collection period were included in the study. Seven mothers and four fathers of 11 children with cancer were involved. The age of the parents ranged from 26 to 50 years. Five (44.6%) of the participants didn't attained formal education and 3(27.3%) had a greater than high school education.

Almost all 10(91%) were married where as one parent was widowed. The residence of 6 (54.5%) participants were urban and the remaining were from rural. Six (54.5%) of the parents were housewives and a small number (18.8%) were farmers.

The age of the participants children ranges from 10 month to 14 years old. Six (54.5%) of the participants children were females while four (36.4%) of the diagnosis was sarcoma. The range for the time since diagnosis was from 1 month to 2 years. All of the participants children were taking a single treatment modality (chemotherapy).

The result was presented thematically relating to substantive subjects that appeared from qualitative analysis. Consequently, the issues related to parents' participation in the decision-making process were presented under the categories; parent-health care provider relationship factors which include communication and trust, clinical factors which include child's illness condition and patients understanding of the health providers in the health system and parental factors which includes parental values, the knowledge of the parents, level of satisfaction with the care givers and preferred level of involvement.

Table 7: Overview on themes affecting parental role in treatment decision making at TASH, 2020 GC.

Category	Sub-category	Illustrative quote
T1: Parent - health care providers relationship factor		
Communication	Health provider supply of information Parents seeking information Two way dialogue	"*...they really tells you everything even she(her ill child) knows about the disease and treatment of the condition*." Kemila(name changed) "*... we just don't ask that much questions we just want our child to get cured that's all...*" Almaz(name changed)
Trust	Faith on the health system Parental suspiciousness	*"... I was curious and consistently ask for a reason for every action they were taking through the process..." 5th*
T2: Parental factors		
Inner sense	A feeling of comfort Personal worth	" *firstly due to I'm the one who made decisions it relieves them from being convicted rather the responsibility will be mine..."* Fatima(name changed).
Knowledge level	False perceptions Level of understanding on the diagnosis and treatment Formal education Previous clinical experience	*"...you see its hard to make a decision on something that you don't know..."* Hagos (name changed). *"As a person who had a science based educational background and working in the clinical area I did involve in every treatment decisions made to my child"* Tariku (name changed).
Level of satisfaction with the care given	Well satisfied Mistreated	*"...It was a very upsetting experience so I decided to quit and took my child to a Holy water for some time..."* Almaz (name changed) .
Preferred level of involvement	Sharing of responsibility Extrapolating responsibility	*"If you made a decision together and if appropriate treatment is given the outcome will be worthy, I think"* Tariku (name changed). "*Deciding by themselves is ok for me but ...they should inform me what the alternatives are..."* Senke (name changed).
T3: Clinical factors		
Childs illness condition	Emotional disturbance Anxiety Progression of the disease Treatment process Urgency of the condition	" *The disease condition was one factor for me because the seriousness of the disease made me to be involved more and more...*" Tariku (name changed). "*I just wanted them to give him some sort of medication because he was extremity seek"* Senke(name changed).
Patients understanding of the Health providers in the HS	Friendly environment Considering only as a recipients	" *I can say all the health providers were cooperative and friendly, ... so I were the one who made all the decisions"* Fatima (name changed)

5.2.2. Data visualization

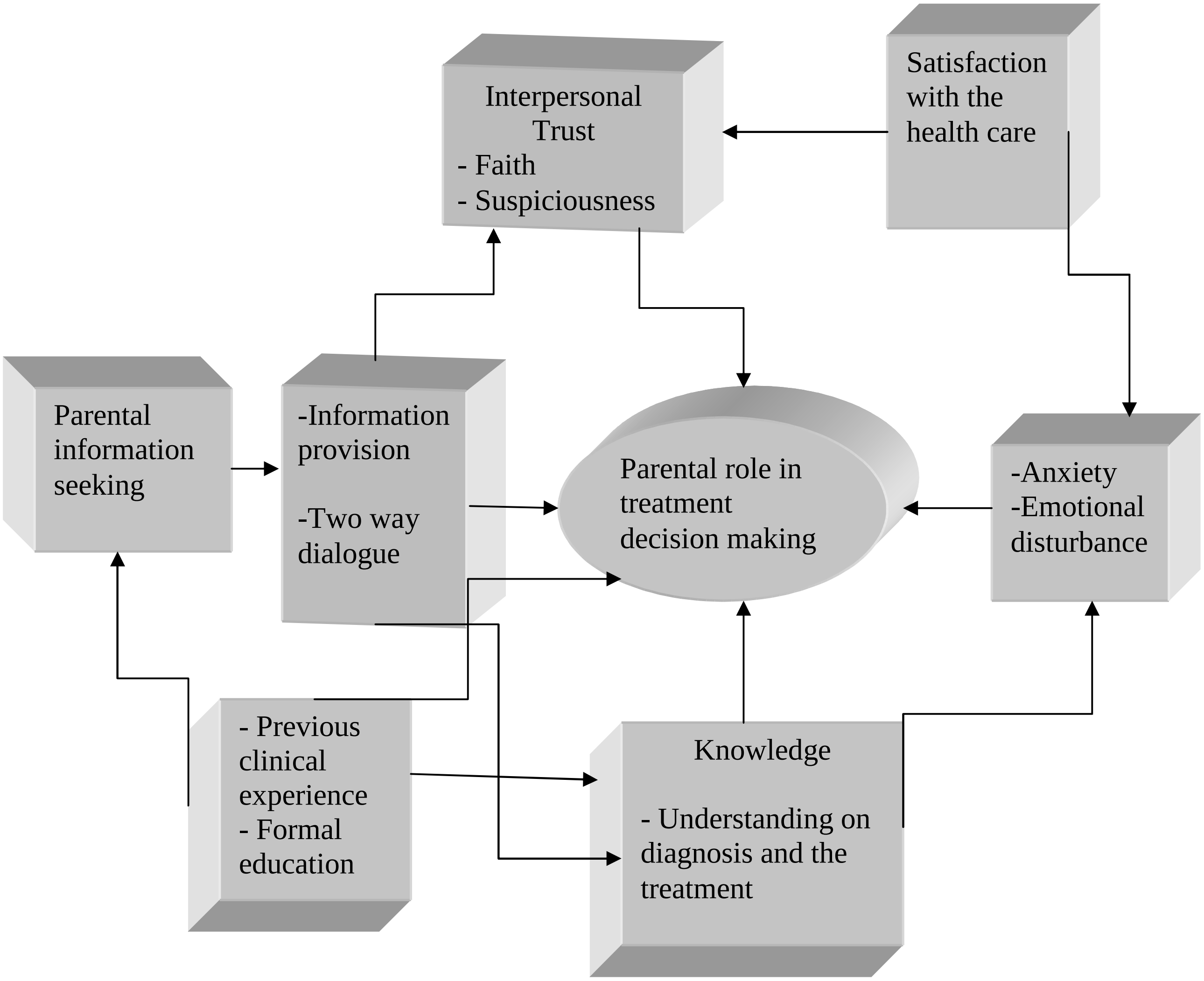

Figure 5: Data visualization on factors affecting parental role in treatment decision making among parents of children with cancer at TASH,2020

Theme 1: Parent health care provider relationship factors

Most of the respondents mentioned relationship they had with the health care provider, responsible in treating their ill child, was the main factor for their role during the treatment decision making. Two main aspects were stated in the relationship.

Communication

Through the process of treating a child with cancer the interaction a parent had with the health care provider was facilitated through the depth, extent and quality of communication they had and was found to be one of the main factors that affected the role they took in treatment decision. How well the information is provided by the heath providers, seeking of information by the parents and the two way dialogues in between the parent and the health providers were the main features in the communication process as stated by the parents.

Mrs. Alem (name changed) a 44 years old mother living in Addis Ababa and her child was diagnosed with Osteo-sarcoma reported to have an active role by stating she was the one who made the final decision whether or not to start chemotherapy for her child mentioned her reason to participate by saying " *They(health providers) provided me all the sufficient information's about my child's diagnosis which is a cancer on his bone and the possible treatments available*. *Not only that they also told me the importance of time in cancer treatment and they also gave me time to think over it.*"

On the other hand Mr. Belete (name changed) who is a farmer with a primary level educational background and had a passive role in the treatment decision making stated "*They (health providers) don't discuss with you what was the problem of the child, how it is know and how will it be in the future they just see the patient card and the result of the CBC then decide what should be next."*

Whereas Mr. Hagos (name changed) a 35 years old father who had interrupted his education due to the treatment process and became a full time guardian considered his passive role as it is due to the health providers were concerned for him." *I think the reason is due to they might felt I might get stressed out if they clearly discussed and involve me with the decision making*".

Two way dialogue among the parent of a sick child and the health provider who was taking care of the child treatment interventions was assumed to improve the parents role in engaging themselves in the process of decision making. Mrs. Semira (name changed) was living in a small town called Adama and her child was diagnosed with sarcoma. She said that "*Most of the health providers decide by themselves, they won't ask for your opinion. If they had listened my complains they would have made some changes before the complication had risen*". The experience of this mother indicated that lack of bilateral communication among parents and health provider made the mother to play more passive role in the decision-making process.

Mrs. Almaz (name changed) who was living in a rural area as a house wife also stated that the health providers were not willing to answer her questions appropriately. She said "*I ask them several times why did they gave her several medications but they were saying we are the physicians not you*". She also added "*I just accept their decision because as I told you they offended me, they warned me not to say anything or share my opinion. They even judged me as an arrogant person while I was trying to ask something. So, I just kept quit and respected their decisions*."

The information seeking behavior by some parents was also mentioned as a factor in taking one of the roles in decision making. Some parents may want to know detail information about the disease, its treatment modalities and side effect of the treatment. Getting information about those issues helped parents to make an informed decision. In line with Mrs. Fatima (name changed) a 45 years old mother whose child was admitted for more than two months with a diagnosis of Leukemia stated that " *Before starting the chemo if we didn't know all about the side effects of the drug like hair lose and skin lesions it would be very bad for us, but due to our request the doctors told us about it and we made a decision to take the chemo*".

Trust

One of the core aspects stated in the interviews which is related to the relationship between parents and health provider that influence perceiving some role in treatment decision making was the trust a parents had on the responsible health care taker. For some faith they had on health care providers made them to leave all the responsibilities to the care provider and expecting the outcome to be safe.

Parents prefer to play passive role because they have complete trust on decisions made by health providers. They mentioned as health care providers make decision for the good of their child and they prefer to accept their decisions.

A father named Tariku (name changed) who had a colleague level educational background and a retired former government employee with a child diagnosed with Leukemia said that " *From the Heaven to the Earth the one who manage everything is God but as to the first worshiper in the bible Peter mentioned health providers as 'drug owners' so even if the care taker is God, regarding science the one who will provide scientific help is the health provider so I believe in them.*" but still parents wanted to know about the treatment their child is receiving as of Mrs. Senke (name changed) who had been raising her child all by herself since her husband died six months ago and had no formal education mentioned that " *Its good if I know about the treatment but it's also fine if I didn't because I have a full trust on them, I just believed they will do what is good for my child*".

Whereas parents who lost trust became suspicious and preferred a more active role. Mrs. Almaz (name changed) who preferred a collaborative role mentioned that "*I consistently was asking them(Health providers) ... they just want me to continue the medication and were saying the acids secreted at the stomach was the cause for this so I don't have to be suspicious, ...*". Also Mrs. Fatima (name changed) who took an active role also said that "*Some of them said it's an ear infection others say some other things and that really makes me concerned and I became more involved in every procedures undertaken to my child*".

Theme 2: clinical factors

The other important factors mentioned was the child's illness condition and parents understanding of the health providers in the health system.

Child's illness condition

The emotional disturbance parents experience while hearing the diagnosis, the available treatment alternatives and the possible expected outcomes were discussed with a great number of parents in affecting their role in treatment decision making. Mrs. Semira (name changed) mentioned that " *I was telling them the disease was progressing and they were not helpful at all* *'she cried' then she stopped eating and sleeping and were suffering a very bad pain which made me worried so much. 'continuous crying'.* "

Lack of progress in the child's health status affected the role of parents. Some parents stated that they had given up on the health provision due to no progress on their child's health and made a decision to try their own alternatives by themselves. " *...I began to frustrate and decided not to bring her back to the hospital no more.*" said Mrs. Kemila (name changed) who discontinued the treatment once with angry voice. Also Mr. Tariku (name changed) who had been actively involved throughout the process of treatment stated " *The disease condition was one factor for me because the seriousness of the disease made me to be involved more and more...*".

In some parents the reason they had taken an active or collaborative role was to relive from anxiety they might develop due to lack of involvement they might have. Mr. Tarku (name changed) who had a collaborative role in the treatment decision making mentioned that " *Its good if you discuss about the treatment and take my opinion too because it really is helpful to alleviate your anxiety too and you will get some kind of comfort.*"

On the other hand the duration in the process of obtaining medical provisions had made some influence on the their role in treatment decision making. Mrs. Semira (name changed) said "*... then we took her to orthopedics, he saw the problem and ordered some syrup but the pain and the swelling was progressive. After that they (Health providers) want to conduct an operation and admit her but they didn't do the operation this is where I get frustrated and become dull and see how thing will go.*"

The other point raised was the urgency of the treatment needed. Some parents felt that there was no sufficient time to understood about the child’s health condition in order to involve in the decision making. They mentioned that as the child's disease condition had made it impossible to participate, there for all the decisions were made by health providers. "*I just wanted them to give him some sort of medication because he was extremity seek so I relied on them to save my child....*" said Mrs. Senke (name changed) in response for how the disease condition was. Also other participant mentioned *"...I need my child to start the treatment as soon as possible and get cured, that was my ultimate interest."*

Parents understanding of the health providers in the health system

After the parents understood about the health providers regarding what kind of role was dominant in the health care interaction through decision making parents was found to shape their role based on their observations. Parents previous experience and observation made them to think the acceptable way is to only receive health providers decisions and orders. Mr. Habtamu (name changed) a farmer whose child was 7 years old and diagnosed with Neuroblastoma finds himself as only a recipient and health providers as the sole decision makers because of the process he passed through. He said "*At first I was complaining that my child had no improvement so far but what I saw from the health providers was they just gave orders to me to give the drug until the completion. After that they just ordered me to take my child to Gonder Hospital so I just keep on receiving their orders only*."

On the other side Mrs. Fatima (name changed) mentioned that the friendly environment she confronted made her to be involved more and able her to take an active role. She said " *I can say all the health providers were cooperative and friendly, they gave me all the available alternatives so I were the one who made all the decisions about the treatments for my child, I even had tried spiritual alternatives.*"

Theme 3: Parental factors

The third main thematic area identified was parental factors which incorporate values parent gives for themselves, the knowledge level they had both the academic and previous clinical experience, level of satisfaction with the care recieved and their preferred level of involvement .

Parental values

Participants had mentioned that one of their reasons for taking apprehended role was they developed a personal feeling of comfort by being involved in the decision making process. As Mrs. Alem (name changed) stated her relief from regret as "*First it won't leave any regret on me, I am sure the right decision has been made. I had nothing to regret by saying I should have said that or this because I already made the decision myself.*"

Mrs. Kemila (name changed) said receiving adequate information and having collaborative decision making role helped her not to be sorrow about the decision made. She alleged that *" I will not regret if I get involved in the decision because as a human, we always review our past so it wouldn't be a what if question for me if I get enough information and make a decision*."

Another important issue they had raised was the value they gave for themselves; they raised their role as an advocate for their child as one factor that determines their role. Mr. Tariku (name changed) mentioned that " *As long as I am the father of the child, I need to take the responsibilities on behalf of my child and it also relieves them (Health providers) from conviction as long as I am the one who decided*."

The knowledge of the parents

Knowledge deficit was mentioned as one of the main factors for parents to be less involved on the treatment decision making. As the disease is unfamiliar to most of the parents the level of knowledge they had was poor. "*....you see it's hard to make a decision on something that you don't know*" said Mr. Hagos (name changed) when asked if he had a role in decision making.

For some parents to have adequate understanding about child health condition that enables them to be capable of making decision felt insufficient even after receiving information from health providers. Mrs. Kemila (name changed) had mentioned the knowledge gap as " *Even though they provided me information's about the diagnosis and the treatments I still luck sufficient knowledge to make a decision by myself*". Mrs. Bezunesh (name changed) who came from a small village called Eradodota, Arse, uneducated and a house wife said "… *It might be due to my luck of knowledge but they really provided me all the possible information… "*

On the other hand Mr. Tariku (name changed) mentioned his previous formal level of knowledge as one factor that helped him to actively involved in the decision making by saying "*As a person who had a science based educational background and working in the clinical area I did involve in every treatment decisions made to my child*".

Another subject raised was previous experience they had in the clinical area. This was explained in parents who mentioned their experience was associated with their increased level of involvement. Mr. Tariku (name changed) a nonprofessional who had been working as supporting staff and patient coordinator in a Hospital said *" ... I had been working as a cleaner in the operation room at Wolita Hospital plus I also had been working as a security personal for a white physicians working there and also I was a coordinator of patients so I knew the medical environment well so I was feet to make decisions for my child. I even had experienced many cases that the patient came in with a critical condition and thought the patient is going to die any sooner but finally got better and sometimes cured so, the experience I had in the hospital area made me to have an active role*." said a father who had made decisions about his child's treatment alternatives.

Level of satisfaction with the care givers

Parents level of satisfaction with the health providers was stated from two perspectives. Parents who were satisfied by the health provision were calm and let the health providers do their jobs and unsatisfied parents demanding more care and were actively watching all the treatment procedures.

Mrs. Fatuma (name changed) was worried and frustrated at the beginning of the treatment but became calm through the process, she said that "*I would really like to thank the health providers; they don't want any of their patients to die. My first impression when I came to this Hospital was it's a place of disaster but I found the health providers as my father and mother and there was no worries*."

where as a parents who felt their child's were mistreated had tried alternative treatments including spiritual healers. Mrs. Almaz (name changed) had a frustrating experience and said that *"...I get notified that noting will be made until the result comes. It was a very upsetting experience so I decided to quit and took my child to a Holy water for some time and traditional healers but neither of them worked finally...*".

Preferred level of involvement

The level of preference a parent had in taking a role in treatment decision making was another factor raised. When parents came to Hospitals in search for medical management for their child, they had some extent of interest in involving on decisions made and this interest was noted as affecting their actual role in the decisional process.

"*My mind didn't allow me to leave all the decision to the physician because if it's a major surgery or something I won't able them to do it*." said Mrs. Bezunesh (name changed) who took a collaborative role through the treatment decision making.

Mr. Tariku (name changed) also said that "*If you made a decision together and if appropriate treatment is given the outcome will be worthy, I think*."

Where as a parent who preferred a more passive role were found extrapolating all the responsibility to the health care provider. As Mrs. Senke (name changed) said "*Deciding by themselves is ok for me but what I want to give emphases is they should inform me what the alternatives are, what is better for my child and what they are planning to do."*

6. DISCUSSION

This study attempts to measure the role of parents in treatment decision making and factors affecting their roles at Tikur Anbessa Specialized Hospital Pediatric Oncology clinic, Addis Ababa, Ethiopia. As to the knowledge of the researcher it is the first of its kind in Ethiopia to assess parent‘s role in treatment decisions for parents of children with cancer.

The level of involvement parents uphold through the treatment decision making of their children with cancer varies among participants. At the beginning of this study parents were assumed to be more interested and eager to take a role on their child's treatment decision making but the reality was the reverse, parents were found to impose almost all their role to their health care providers and took a passive role.

Based on the CPS-P tool the preferred role in treatment decision making of parents was very high for passive, followed by collaborative and a insignificant active role. which was found to have a lower active role preference and a higher passive role preference compared to a study made at Mid-Western Canada University Hospital and Manitoba metropolitan university Hospital, Canada and Harvard medical center, USA (35–37). This might be due to a small sample size, educational and cultural variability among the parents.

The study also identified the actual role of parents in treatment decision making was primarily passive, followed by collaborative and finally active. which was found to have high passive and a very low active role compared to a study made at M.D. Anderson cancer center USA on cancer patients and their physician which had 13(17%) passive role , 49 [63%] shared role and 16(24%) active role (63). This might be due to socio-economic characteristic, cultural variability and level of literacy in between the two study participants.

While 138 (82.6%) of the participants reported having their preferred role and only 7(4.2%) had experienced extreme discordance in a sense of a shift from active role preference to actual passive role or vice versa. This finding was higher than a study in Manitoba, Canada, which 61% of them had their preferred role and 6% extreme discordance. The difference in having the preferred role might be due to, in this study almost all parents actual and preferred level of involvement was found to be passive where as in the Manitoba study variability was noticed in both preferred and actual role (64).

Regarding assessing factors that affected parental role in treatment decision making information preference and interpersonal trust was found as a statistically significant factors in the survey. Where a one point increase in parents information preference was found to decrease parental passive role by 40% [AOR (95%CI) = 0.6 **(**0.46-0.79)]. This findings was consistent with the finding at Harvard medical school, USA where KHOS scores were lowest among those with a passive role (mean=8.0), intermediate among those with a collaborative approach (mean=8.8), and highest among parents who had an active role in treatment decision-making (mean=10.7). A Spearman correlation captured the magnitude of the association between the measures (rho=0.29, p ¼ 0:001) (37).

The consistence was also reflected on a study made at Dana-Farber cancer institute, Boston, USA in which parents were less likely to hold a more passive role than desired when they also reported that information received had been of higher quality (OR, 0.41; P .001) (38).

In the qualitative session participants had also supported the idea that parents who seek a great extent of information showed an increased role in making a treatment decisions for their sick child. which was consistent with the finding of Mid-Western Canada university that many of the parents expressed the importance of keeping informed including the amount and regularity of information through their decisional role (36).

The other factor found to be associated was interpersonal trust among the parent on the health care provider. In which parents who had increased trust in their health care providers tended to have a more passive role [AOR (95%CI) =1.16 (1.02-1.22**)**]. The finding was controversial with a study made at Dana-Farber Cancer institute, Boston, USA. Where, even though there was association in between trust and parental role the association was the reverse of this study where parents who were less involved in decision making than they wished were less likely to trust their child’s physician’s judgment (OR, 0.46; 95% CI, 0.22 to 0.94; P .03) (38). This might be due to the cultural difference and the level of awareness in between the participants of the two studies.

In a study made at Mount Sinai School of Medicine, New York, NY, USA interpersonal trust was also found to have a statistically significant association among the responsibility of breast cancer patients on treatment decision making (P= <0.001). The finding indicated trust in physician was lowest among women with “not enough” responsibility (mean score=89±12) from a scale [1–100] and highest on “too much” responsibility for treatment decision-making (96.3±6.9) (65). The difference might be due to the educational level and socioeconomic differences among the two study participants.

The other result which was found to collide with this study was the study made at the University of Toronto how trust affected patients preference for participation in decision making, which stated a significant association existed in between trust and treatment decision making (P= < 0.0001) in which those with blind trust overwhelmingly tend to prefer a passive role (97.3% for chest pain, 81.1% for current health condition vignettes) and as the level of trust diminished the autonomous/consumerist role takes place and passive role was much lower (26.4% chest pain, 14.8% current health) (66).

The qualitative session of this study had also supported the finding as parents elaborated that when their trust gets better and better they become less involved and relinquished more role to the health providers in reverse to the ones who are suspicious and curious about everything. This finding was also similar with a qualitative study made at university-affiliated pediatric oncology facility in mid-western Canada that discussed parents who had confidence and relied all the roles to the health providers was found to have trust on them that they will act in their child's best interest. One parent expressed the depth of this trust as “I would still take their word for the gospel.”(36).

Communication a patient had in terms of the information the health provider supplies , the patient seeks and the two way interaction they had were also raised through the in-depth interview which were found to be the bold factors. It was also complied with the mid western Canada study in which most of the parents had stated that the importance of the physician keeping them informed, considering what they had to say and the two way nature of the dialogue they had as a main contributing factor for their enhanced role in treatment decision making (36).

The other important factor identified through the in-depth interview was the child's illness condition which was in terms of anxiety, disease progress and seriousness or urgency of the condition. parents stated that due to the exponential progress of the child's condition they were frustrated and were passive throughout the treatment period. This was also supported in a study made on mothers decision making process at Nebraska medical center, USA. Seriousness of the child’s condition and the fear that it produced in the mother's where named as most important in their decision for their child's care (56).

In case of anxiety the study participants used their participation as a tool in order to get rid of the tragic experience they were passing through. They mentioned that as they get more and more involved in the treatment process their level of anxiety had thoroughly diminished. In contrary Pediatric Oncology facility of mid western Canada had shown, parents identified the situational context as influenced their treatment decision making role, 22% of them described a feeling of shock, nervousness or of being overwhelmed which they stated impaired their ability to make decisions (36). This difference might be due to the cultural and response mechanism difference in between the two study participants.

Even though the knowledge level of parents was not found statistically significantly associated with parental role in treatment decision making parents expressed the importance of knowledge in terms of previous clinical experience, formal level of education and the knowledge they had regarding the treatment their child was having and the diagnosis through the in-depth interview.

Similar finding was noticed at University of California San Francisco and University of Pittsburgh School of Nursing USA, in which parents of children with cancer who had a higher education level expressed greater satisfaction with information received and a higher degree of autonomy in making decisions about their Childs treatment(42,43).

7. STRENGTH AND LIMITATION OF THE STUDY

7.1. Strength of the study

The study used both approaches, which were qualitative and quantitative to obtain an optimal findings and provide an explanation in different perspective, so it is more comprehensive than a single study.

To the knowledge of the investigator this study is a primary study in assessing parental role in pediatric cancer treatment decision making and factors associated in Ethiopia.

The study also used validated tools in assessing parental roles and different factors assumed to affect treatment decision making of parents and also open ended questions to further explore different additional factors.

7.2. Limitation of the study

Due to the current covid-19 pandemic patient flow to the Hospital was minimal this made the sample size to be small in the quantitative session.

Due to a cross sectional study design used it made the finding hard to construct a cause and effect relationship.

8. CONCLUSION AND RECOMMENDATIONS

8.1. Conclusion

In this mixed method study most of the parents of children with cancer at Tikur Anbessa Specialized Hospital, pediatric oncology clinic were found to have a passive preferred and actual role in pediatric cancer treatment decision making. The study also identified parental information preference sub scale (KHOS II) and interpersonal trust among parents and health care providers to be a statistically significant factors that affected parental roles in treatment decision making.

Moreover, the study also explored additional factors as child's illness condition, Patients understanding of the health providers in the health system, communication, previous clinical experience, educational level, level of satisfaction with the care given and preferred level of involvement through the in-depth interview.

8.2. Recommendation

Based on the findings of the study the following recommendations are forwarded to concerned bodies: -

To policy makers

Health planners and policy makers needs to develop a guideline for parental educational programs regarding their child's diagnosis and treatment.

They have to develop a rule that guides the parents and health care providers level of involvement in pediatric cancer treatment decision making.

To health facilities

Health facilities should organize educational sessions for parents focusing on the treatment their child is having all the possible alternatives and side effects if they have.

They also have to organize trainings for health providers focusing on ways to improving parental role on their child's medical care.

Health providers working in the facilities should motivate parents to enhance more decisional roles for parents of children with cancer for the better outcome of the child.

9. REFERENCE

1. Steliarova-Foucher E, Colombet M, Ries LAG, Moreno F, Dolya A, Bray F, et al. International incidence of childhood cancer, 2001–10: a population-based registry study. Lancet Oncol. 2017 Jun 1;18(6):719–31.

2. James G. Gurney, Richard K. Severson, Scott Davis. Incidence of cancer in children in the United States. Sex-, race-, and 1-year age-specific rates by histologic type - Gurney - 1995 - Cancer

3. Shad a. pediatric oncology in Ethiopia: an inter-USA and George town university Hospital twinning initiative with Tikur anbessa specialized hospital.2017.

4. Eggly S, Penner LA, Greene M, Harper FW, Ruckdeschel JC, Albrecht TL. Information seeking during “bad news” oncology interactions: Question asking by patients and their companions. Soc Sci Med. 2006;63(11):2974–2985.

5. Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WW, et al. Physician–patient–companion communication and decision-making: a systematic review of triadic medical consultations. Patient Educ Couns. 2013;91(1):3–13.

6. Gilbar R, Gilbar O. The Medical Decision-Making Process and the Family: The Case of Breast Cancer Patients and Their Husbands. Bioethics. 2009;23(3):183–92.

7. Family-provider relationships and well-being in families with preterm infants in the NICU. Heart Lung. 2001 Jan 1;30(1):74–84.

8. Dy SM. Instruments for Evaluating Shared Medical Decision Making: A Structured Literature Review. Med Care Res Rev. 2007 Dec 1;64(6):623–49.

9. Gilbar R, Gilbar O. The medical decision-making process and the family: the case of breast cancer patients and their husbands. Bioethics. 2009;23(3):183–192.

10. The Health Care Delivery System - The Future of the Public’s Health in the 21st Century - NCBI Bookshelf [Internet]. [cited 2019 Nov 18]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK221227/

11. Shin DW, Cho J, Roter DL, Kim SY, Yang HK, Park K, et al. Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists. Psychooncology. 2017;26(6):770–8.

12. Holm KE, Patterson JM, Gurney JG. Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer: Results from a Qualitative Study. J Pediatr Oncol Nurs. 2003 Nov 1;20(6):301–13.

13. Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Oncologists' and oncology nurses' attitudes and practices towards family involvement in cancer consultations. Eur J Cancer Care (Engl). 2017;26(1):e12470.

14. Laidsaar-Powell R, Butow P, Bu S, Charles C, Gafni A, Fisher A, et al. Family involvement in cancer treatment decision-making: A qualitative study of patient, family, and clinician attitudes and experiences. Patient Educ Couns. 2016;99(7):1146–1155.

15. Mckenna K, Collier J, Hewitt M, Blake H. Parental involvement in paediatric cancer treatment decisions. Eur J Cancer Care (Engl). 2010;19(5):621–30.

16. Gilbar R. Family involvement, independence, and patient autonomy in practice. Med Law Rev. 2011;19(2):192–234.

17. Breinholst S, Esbjørn BH, Reinholdt-Dunne ML, Stallard P. CBT for the treatment of child anxiety disorders: A review of why parental involvement has not enhanced outcomes. J Anxiety Disord. 2012 Apr 1;26(3):416–24.

18. Barrera M. Brief Clinical Report: Procedural Pain and Anxiety Management With Mother and Sibling as Co-therapists. J Pediatr Psychol. 2000 Mar 1;25(2):117–21.

19. The problem of treatment abandonment in children from developing countries with cancer - Arora - 2007 - Pediatric Blood & Cancer - Wiley Online Library [Internet]. [cited 2020 Jan 27]. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/pbc.21127

20. Mansell R, Purssell E. Treatment abandonment in children with cancer in Sub-Saharan Africa: Systematic literature review and meta-analysis. J Adv Nurs. 2018;74(4):800–8.

21. Dy SM. Instruments for Evaluating Shared Medical Decision Making: A Structured Literature Review. Med Care Res Rev. 2007 Dec 1;64(6):623–49.

22. Sloper P. Predictors of Distress in Parents of Children With Cancer: A Prospective Study. J Pediatr Psychol. 2000 Mar 1;25(2):79–91.

23. Kerr LMJ, Harrison MB, Medves J, Tranmer JE, Fitch MI. Understanding the Supportive Care Needs of Parents of Children With Cancer: An Approach to Local Needs Assessment. J Pediatr Oncol Nurs. 2007 Sep 1;24(5):279–93.

24. Mary D-W, Bridget Y, David H. Rethinking Experiences Of Childhood Cancer: A Multidisciplinary Approach To Chronic Childhood Illness: A Multidisciplinary Approach to Chronic Childhood Illness. McGraw-Hill Education (UK); 2005. 219 p.

25. Levi RB, Marsick R, Drotar D, Kodish ED. Diagnosis, Disclosure, and Informed Consent: Learning From Parents of Children With Cancer. J Pediatr Hematol Oncol. 2000 Feb;22(1):3.

26. Dixon-Woods M, Findlay M, Young B, Cox H, Heney D. Parents' accounts of obtaining a diagnosis of childhood cancer. The Lancet. 2001 Mar 3;357(9257):670–4.

27. Hinds PS, Birenbaum LK, Clarke-Steffen L, Quargnenti A, Kreissman S, Kazak A, et al. Coming to Terms: Parents' Response to a First Cancer Recurrence in Their Child. Nurs Res. 1996 Jun;45(3):148–153.

28. Kristensson-Hallstrom I, Elander G. Parents' experience of hospitalization: different strategies for feeling secure. Pediatr Nurs. 1997 Jul 1;23(4):361–8.

29. Hallström I, Runeson I, Elander G. An Observational Study of the Level at Which Parents Participate in Decisions During Their Child's Hospitalization. Nurs Ethics. 2002 Mar 1;9(2):203–14.

30. Lipstein EA, Brinkman WB, Britto MT. What Is Known about Parents' Treatment Decisions? A Narrative Review of Pediatric Decision Making. Med Decis Making. 2012 Mar 1;32(2):246–58.

31. Hallström I, Elander G. Decision-making during hospitalization: parents' and children's involvement. J Clin Nurs. 2004;13(3):367–75.

32. Simons J, Franck L, Roberson E. Parent involvement in children's pain care: views of parents and nurses. J Adv Nurs. 2001;36(4):591–9.

33. Whitney SN, Ethier AM, Frugé E, Berg S, McCullough LB, Hockenberry M. Decision making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model. J Clin Oncol. 2006;24(1):160–165.

34. Degner LF, Sloan JA. Decision making during serious illness: What role do patients really want to play? J Clin Epidemiol. 1992 Sep 1;45(9):941–50.

35. Pyke-Grimm KA, Degner L, Small A, Mueller B. Preferences for Participation in Treatment Decision Making and Information Needs of Parents of Children With Cancer: A Pilot Study. J Pediatr Oncol Nurs. 1999 Jan 1;16(1):13–24.

36. Pyke-Grimm KA, Stewart JL, Kelly KP, Degner LF. Parents of Children With Cancer: Factors Influencing Their Treatment Decision Making Roles. J Pediatr Nurs. 2006 Oct 1;21(5):350–61.

37. Gagnon EM, Recklitis CJ. Parents' decision-making preferences in pediatric oncology: The relationship to health care involvement and complementary therapy use. Psycho-Oncol J Psychol Soc Behav Dimens Cancer. 2003;12(5):442–452.

38. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Parents' Roles in Decision Making for Children With Cancer in the First Year of Cancer Treatment. J Clin Oncol. 2011 May 20;29(15):2085–90.

39. Tarini BA, Christakis DA, Lozano P. Toward Family-Centered Inpatient Medical Care: The Role of Parents as Participants in Medical Decisions. J Pediatr. 2007 Dec 1;151(6):690-695.e1.

40. Hyde M, Punch R, Komesaroff L. Coming to a Decision About Cochlear Implantation: Parents Making Choices for their Deaf Children. J Deaf Stud Deaf Educ. 2010 Mar 1;15(2):162–78.

41. Cox ED, Smith MA, Brown RL. Evaluating Deliberation in Pediatric Primary Care. Pediatrics. 2007 Jul 1;120(1):e68–77.

42. Stewart JL, Pyke-Grimm KA, Kelly KP. Parental Treatment Decision Making in Pediatric Oncology. Semin Oncol Nurs. 2005 May 1;21(2):89–97.

43. Ruccione K, Kramer RF, Moore IK, Perin G. Informed Consent for Treatment of Childhood Cancer: Factors Affecting Parents' Decision Making. J Pediatr Oncol Nurs. 1991 Jul 1;8(3):112–21.

44. Butow PN, Maclean M, Dunn SM, Tattersall MHN, Boyer MJ. The dynamics of change: Cancer patients' preferences for information, involvement and support. Ann Oncol. 1997 Aug 1;8(9):857–63.

45. Renner LA, McGill D. Exploring factors influencing health-seeking decisions and retention in childhood cancer treatment programmes: perspectives of parents in Ghana. Ghana Med J. 2016;50(3):149–156.

46. Kon AA. The shared decision-making continuum. Jama. 2010;304(8):903–904.

47. Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med. 1999 Sep 1;49(5):651–61.

48. The promise of shared decision-making in paediatrics - Fiks - 2010 - Acta Paediatrica - Wiley Online Library [Internet]. [cited 2020 Jan 4]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1651-2227.2010.01978.x

49. Calnan MW, Sanford E. Public trust in health care: the system or the doctor? BMJ Qual Saf. 2004 Apr 1;13(2):92–7.

50. Kirschbaum MS, Knafl KA. Major Themes in Parent-Provider Relationships: A Comparison of Life-Threatening and Chronic Illness Experiences. J Fam Nurs. 1996 May 1;2(2):195–216.

51. Kilicarslan-Toruner E, Akgun-Citak E. Information-seeking behaviours and decision-making process of parents of children with cancer. Eur J Oncol Nurs. 2013 Apr 1;17(2):176–83.

52. Miles MS, Frauman AC. Nurses' and parents' negotiation for caregiving roles for medically fragile infants: Barriers and bridges. Key Asp Caring Chronically Ill. 1993;239–249.

53. Angst DB, Deatrick JA. Involvement in Health Care Decisions: Parents and Children with Chronic Illness. J Fam Nurs. 1996 May 1;2(2):174–94.

54. Avis M. Choice cuts: an exploratory study of patients’ views about participation in decision-making in a day surgery unit. Int J Nurs Stud. 1994 Jun 1;31(3):289–98.

55. Alamanou GD, Balokas AS, Fotos VN, Patiraki E, Brokalaki H. Information needs of cancer patients: Validation of the Greek Cassileth’s Information Styles Questionnaire. Eur J Oncol Nurs. 2016 Feb 1;20:49–57.

56. Gross GJ, Howard M. Mothers’ decision-making processes regarding health care for their children. Public Health Nurs. 2001;18(3):157–168.

57. Njuguna FM. Adherence with Childhood Cancer Treatment in Kenya. :210.

58. Gupta S, Yeh S, Martiniuk A, Lam CG, Chen H-Y, Liu Y-L, et al. The magnitude and predictors of abandonment of therapy in paediatric acute leukaemia in middle-income countries: a systematic review and meta-analysis. Eur J Cancer. 2013;49(11):2555–2564.

59. Background of Tikur Anbessa Hospital | College of Health Sciences [Internet]. [cited 2020 Jan 4]. Available from: http://www.aau.edu.et/chs/tikur-anbessa-specialized-hospital/background-of-tikur-anbessa-hospital/

60. Krantz DS, Baum A, Wideman M v. Assessment of preferences for self-treatment and information in health care. J Pers Soc Psychol. 1980;39(5):977.

61. Anderson LA, Dedrick RF. Development of the Trust in Physician Scale: A Measure to Assess Interpersonal Trust in Patient-Physician Relationships. Psychol Rep. 1990 Dec 1;67(3_suppl):1091–100.

62. Hays RD, Shaul JA, Williams VSL, Lubalin JS, Harris-Kojetin LD, Sweeny SF, et al. Psychometric Properties of the CAHPS^{TM} 1.0 Survey Measures. Med Care. 1999;37(3):MS22–31.

63. Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S. Patient Preferences Versus Physician Perceptions of Treatment Decisions in Cancer Care. J Clin Oncol. 2001 Jun 1;19(11):2883–5.

64. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O’Neil J, et al. Information Needs and Decisional Preferences in Women With Breast Cancer. JAMA. 1997 May 14;277(18):1485–92.

65. Schlembach PJ. Breast cancer treatment decision-making: Are we asking too much of patients. Breast Dis. 2014 Jan 1;25(3):212–4.

66. Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? Health Expect. 2004;7(4):317–26.

10. APPENDIX

Annex A:Information sheet and consent form

Research Project: Parental role in Pediatric Cancer treatment decision making at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia/2020.

Name of Principal Investigator: Daniel Betemariem

Introduction: This information sheet and consent form is prepared by the investigator whose main aim is to explore the Parental role in pediatric cancer treatment decision making in Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia/2020 .The investigator is a graduating MSC Oncology student from Addis Ababa University School of Nursing and Midwifery, Department of Nursing.

Purpose: This research is mainly tries to evaluate the Parental role in treatment phase of child cancer and will explore different factors that affect the parents involvement from the parents and health providers perspective. This will enable the working Professionals where the current parental participation is at and if there is a gap it will help in reasoning.

Procedures: you are kindly invited to take part in our research because we believe you can provide the necessary information for the research. Participation into the study is on voluntary basis. If you are willing to participate in our project, you need to understand and sign the consent form. Then, you will be asked to give your response by the data collectors. All the responses given by the participants and the results obtained will be kept anonymous and confidential. No one outside the research team will have access to your responses.

Risk and/or Discomfort: you will not face any risk in participating in this research but it might take a bit of your time and this might be uncomfortable.

Benefits: Even though there are no immediate benefits for participants this research will defiantly benefits in the future, because the result will show where parents participation status is and will give their perspectives as a standing point to see the reasons for the current status and be used as a tool to see if there is a need to make changes for the future.

Incentives: This is totally a voluntary participation.

Confidentiality and Anonymity: The information that we will collect from this research project will be kept confidential. The audio recordings of the interview made during this research will be used only for analysis. No other use will be made of them without your written permission.

Right to Refuse or withdraw: you have the full right to refuse from participating in this research (you can choose not to respond some or all of the questions) if you do not wish to participate; and this will not affect you. You have also the full right to withdraw from this study at any time you wish to, without losing any of your rights which will not influence the way you are treated in the health institution or in the community as a recipient of this site.

Persons to contact for further information: If you have any question you can contact the principal investigator in the following address:

Name: Daniel Betemariem

Tel: +251-912-76-84-52

Email:danielbetemariem@gmail.com

Contact information for complaint: If you have any concern that the research team is conducting their activities unethically or inappropriately please contact my advisor Mr. LeulDeribe.

Tel: 251-911-97-39-83

Email: leul.deribe@gmail.com

If you agree to participate in this study, I appreciate your truthfulness, and after having this consent form read to you, please put a sign below to show if you are willing to participate (No need of writing your name).

Are you willing to participate in this study?

Yes [ ] No [ ] ***Thank you for taking part in this study.***

Annex B:English version of the Quantitative Questionnaire on parental role in pediatric cancer treatment decision making.

Serial number_____________ Date:_____________

Section1: Socio Demographic Data of the Parents

1. Age (Years) _______________

2. Sex: Father [ ] Mother [ ]

3. Marital Status: A. Living alone [ ] B. Living with a partner [ ]

4. Residence: A. Urban [ ] B. Rural [ ]

5. Educational level: A. No education[ ] B. Can read and write [ ]
C. Primary school[ ] D. Secondary school[ ] E. More than secondary[ ]

6. Occupation: A. Employed [ ] B. Unemployed [ ]

section 2 : Socio Demographic Data of the Children

1. Age (months)__________________

2. Sex: Male [ ] Female [ ]

3. Time since diagnosis :_______________

4. Diagnosis:____________

5. Disease severity: A. Low risk [ ] B. Intermediate risk [ ] C. High risk [ ]

6. Treatment: A. Surgery[ ] B. Radiation therapy[ ] C. Chemotherapy[ ]

section 3: Treatment decisional role preference of Parents Using Control Preference Scale For Pediatrics.

1. Select one among the following which you prefer to take role in treatment decision making for your child with cancer?

A. I prefer to make the final decision about which treatment my child will receive.

B. I prefer to make the final selection of my Childs treatment after seriously considering my Doctors opinion.

C. I prefer that my Childs Doctor and I share responsibility for deciding which treatment is best for my child.

D. I prefer that my Doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E. I prefer to leave all decisions regarding my childes treatment to my Doctor.

Figure 6: Control Preference Scale for Pediatric (CPS-P) statements for Parental involvement in Pediatric Cancer treatment decision making at Tekur Anbesa Specialized Hospital, Addis Ababa, Ethiopia, 2020.

2. Select one from the above five alternatives which you believe is your actual role?

section 4: Items for the Krantz Health Opinion Survey on information preference and behavioral involvement.

Information subscale

1. I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam. A. Agree B. Disagree

2. I'd rather have doctors and nurses make the decisions about what's best than for them to give me a whole lot of choices. A. Agree B. Disagree

3. Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health. A. Agree B. Disagree

4. I usually ask the doctor or nurse lots of questions about the procedures during a medical exam A. Agree B. Disagree

5. It is better to trust the doctor or nurse in charge of a medical procedure than to question what they are doing. A. Agree B. Disagree

6. I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately. A. Agree B. Disagree

7. I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me. A. Agree B. Disagree

Behavioral Involvement subscale

1. Except for serious illness, it's generally better to take care of your own health than to seek professional help. A. Agree B. Disagree

2. It is better to rely on the judgments of doctors (who are the experts) than to rely on "common sense" in taking care of your own body. A. Agree B. Disagree

3. Clinics and hospitals are good places to go for help since it's best for medical experts to take responsibility for health care. A. Agree B. Disagree

4. Learning how to cure some of your own illness without contacting a physician is a good idea. A. Agree B. Disagree

5. It's almost always better to seek professional help than to try to treat yourself. A. Agree B. Disagree

6. Learning how to cure some of your illness without contacting a physician may create more harm than good. A. Agree B. Disagree

7. Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves. A. Agree B. Disagree

8. If it costs the same, I'd rather have a doctor or nurse give me treatments than to do the same treatments myself. A. Agree B. Disagree

9. It is better to rely less on physicians and more on your own common sense when it comes to caring for your body. A. Agree B. Disagree

Section 5: Trust on the health care provider

Questions	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1. I doubt that my doctor really cares about me as a person.					
2. My doctor is usually considerate of my needs and puts them first.					
3. I trust my doctor so much I always try to follow his/her advice.					
4. If my doctor tells me something is so, then it must be true.					
5. I sometimes distrust my doctor's opinion and would like a second one.					
6.I trust my doctor's judgments about my medical care.					
7. I feel my doctor does not do everything he/she should for my medical care.					
8. I trust my doctor to put my medical needs above all other considerations when treating my medical problems.					
9. My doctor is a real expert in taking care of medical problems like mine.					
10. I trust my doctor to tell me if a mistake was made about my treatment.					
11. 1 sometimes worry that my doctor may not keep the information we discuss totally private.					

Section 6 : questions assessing the quality of communication

Questions	Always	Sometimes	usually	Never
1. The physician took time to answer my questions.				
2. The health care provider provided me as much medical information as I wanted.				
3. They provided me information without my intended need to ask.				
4. They made me feel listened to.				
5. We had communicated in a sensitive manner				
6. They provided me understandable answer.				

Annex C:English version of the Qualitative Questionnaire

Section 1: For parents of children with cancer

1. Age:__________ 3. Marital Status:______________

2. Sex:____________ 4. Residence:________________

5. Childs diagnosis:_____________

5. Can you tell me about how decisions were made about your child's treatments? and what was your role at the time? (probe for whether the participation is Active or collaborative or passive and ask what they mean when they say Active or collaborative or passive)

6. why do you choose your role in treatment decision making?

7. Do you think you should be involved in decisions regarding treatment for your child?

- If yes, how often and in what extent? (probe for whether the participation is Active or collaborative or passive and ask what they mean when they say Active or collaborative or passive)
- If no, why?

8. Is there a difference between your actual role and preferred role?

9. If so why do you think is the difference existed between the two roles (actual and preferred) ?

10. Can you mention some factors that affect your role? (Probe for the effect of their language/culture, educational status, religion, etc.)

11. After the decisional outcome what is your impression due to your decisional role? (Probe for depression, satisfaction or regret)and why?

12. Is there anything additional point you need to add?

Annex D:የመረጃ፡እና፡ስምምነት፡ቅጽ፡የአማርኛ፡ትርጉም

የምርምር፡ፕሮጄክት-በልጆች፡ካንሰር፡ህክምና፡ውሳኔ፡አሰጣጥ፡የወላጅ፡ተሳትፎ፡በጥቁር፡አንባሳ፡ስፔሻላይዝድ፡ሆስፒታል፣ አዲስ፡አበባ፡ኢትዮጵያ/2020 ፡፡

የዋና፡አጥኚዉ፡ስም-ዳንኤል፡ቤተማርያም

መግቢያ

ይህ፡የመረጃ፡ወረቀት፡እና፡የስምምነት፡ቅጽ፡የተዘጋጀው፡ዋና፡ዓላማው፡በልጆች፡ካንሰር፡ህክምና፡ውሳኔ፡አሰጣጥ፡የወላጅ፡፡ተሳትፎ፡በጥቁር፡አንባሳ፡ስፔሻላይዝድ፡ሆስፒታል፡በአዲስ፡አበባ፤ኢትዩጵያ፡በ2020፡ማጥናት፡ነው፡፡ዋና፡አጥኚዉ፡በአዲስ፡አበባ፡ዩኒቨርስቲ፡በነርሲንግ፡ትምህርት፡ቤት፡አንኮሎጂ፡ዲፓርትመንት፡ውስጥ፡የማስተርስ፡ተማሪ፡ነዉ፡፡

ዓላማው-ይህ፡ምርምር፡በዋነኝነት፡በልጆች፡ካንሰር፡ህክምና፡ደረጃ፡ላይ፡የወላጅ፡ድርሻውን፡ለመገምገም፡እና፡ከወላጆች፡እይታ፡አንፃር፡የወላጅ፡ተሳትፎን፡የሚነኩ፡የተለያዩ፡ጉዳዮችን፡ለመመርመር፡ይሞክራል፡ይህ፡የወቅቱ፡የወላጅ፡ተሳትፎ፡የሚገኝበት፡እና፡ክፍተት፡ካለ፡ማስተካከያዎች፡ለማድረግ፡ይረዳል፡፡

ሂደት፡-ለምርምር፡ሂደቱ፡አስፈላጊውን፡መረጃ፡መስጠት፡ይችላሉ፡የሚል፡እምነት፡ስላለን፡በምርምራችን፡ውስጥ፡እንዲሳተፉ፡በአክብሮት፡ተጋብዘዋል።በጥናቱ፡ውስጥ፡መሳተፍ፡በፈቃደኝነት፡ላይ፡የተመሠረተ፡ነው።በመጠይቁ፡ውስጥ፡ለመሳተፍ፡ፈቃደኛ፡ከሆኑ፡የስምምነት፡ቅጹን፡መረዳት፡እና፡መፈረም፡ያስፈልግዎታል፡፡ከዚያ፣ምላሽዎን፡በሚሰበስቡት፡ሰብሳቢዎች፡እንዲሰጡ፡ይጠየቃሉ።በተሳታፊዎች፡የተሰጠው፡ምላሾች፡እና፡የተገኙት፡ውጤቶች፡ሁሉ፡በሚስጥር፡ይያዛሉ፡፡ከአጥኝዎች፡ውጭ፡ማንም፡የእርሶን፡ማንነት፡ማወቅ፡አይችልም፡፡

ስጋት፡ወይም፡ምቾት፡የሚነሳ፡ነገር፡-በዚህ፡ጥናት፡ውስጥ፡በሚሳተፍበት፡ወቅት፡ምንም፡ዓይነት፡ችግር፡አያጋጥምዎትም፡ነገር፡ግን፡ትንሽ፡ጊዜዎን፡ሊወስድ፡ይችላል፡እና፡ይህ፡ደግሞ፡ምቾት፡ላይኖረው፡ይችላል፡፡.

ጥቅማጥቅሞች-ይህ፡ምርምር፡ይጠቅምዎታል፡ምክንያቱም፡ውጤቱ፡የእርስዎ፡የተሳትፎ፡ሁኔታዎ፡የት፡እንደደረሰ፡ያሳያል፡እና፡ምክንያቶች፡ለመመልከት፡እይታዎችን፡ይሰጠዎታል፡እንዲሁም፡አስፈላጊ፡ከሆነ፡ለማሻሻል፡እንደመሳሪያ፡ያገለግላሉ፡፡

ማበረታቻዎች-በግልፅ፡የበጎ፡ፈቃድ፡ተሳትፎ፡ነው፡፡

ምስጢራዊነት፡እና፡ማንነትን፡መደበቅ፡-ከዚህ፡ምርምር፡ፕሮጀክት፡የምንሰበስበው፡መረጃ፡በሚስጥር፡ይጠበቃል፡፡ከጥናቱ፡የሚሰበሰበው፡መረጃዎ፡በፋይሉ፡ውስጥ፡ይከማቻል፣እና፡ስም፡አይኖረውም፣ከዋና፡መርማሪው፡በስተቀር፡ለማንም፡አይገለጥም።

የመቃወም፡ወይም፡የማስወገድ፡መብት፡-በዚህ፡ጥናት፡ውስጥ፡ላለመሳተፍ፡ሙሉ፡መብት፡አለዎት፡(ለመሳተፍ፡ካልፈለጉ፡የተወሰኑ፡ወይም፡ሁሉንም፡ጥያቄዎች፡ላለመመለስ፡መምረጥ፡ይችላሉ)እና፡ይሄ፡እርስዎን፡አይጎዳዎትም።እንዲሁም፡የዚህ፡ሆስፒታል፡ተገልጋይ፡እንደመሆኖ፡ምንም፡አይነት፡መብቶችን፡ሳያጡ፡ከዚህ፡ጥናት፡የመገለል፡ሙሉ፡መብት፡አልዎት፡፡

ለበለጠ፡መረጃ፡-ማንኛውም፡ጥያቄ፡ካለዎት፡በሚከተለው፡አድራሻ፡ዋና፡አጥኚዉን፡ማነጋገር፡ይችላሉ::

ስም:-ዳንኤል፡ቤተማርያም

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ለቅሬታ፡የመገኛ፡አድራሻ፡-የምርምር፡ቡድኑ፡ተግባሮቻቸውን፡በትክክል፡ባልተሠራ፡ወይም፡አግባብ፡ባልሆነ፡መንገድ፡የሚያከናውን፡ስለመሆኑ፡የሚያሳስብዎት፡ነገር፡ካለ፡እባክዎን፡የእኔን፡አማካሪ፡አቶ፡ልኡል፡ደርቤን፡ያናግሩ፡፡

ስልክ፡ 251-911-97-39-83

ኢሜይል:leul.deribe@gmail.com

በዚህ፡ጥናት፡ውስጥ፡ለመሳተፍ፡ከተስማሙ፡እውነተኛነትዎ፡አደንቃለሁ፡፡ይህ፡የስምምነት፡ቅጽ፡ለእርስዎ፡ከተነበበልዎት፡በኋላ፡ ፡ለመሳተፍ፡ፈቃደኛ፡መሆንዎን፡ለማሳየት፡ከዚህ፡በታች፡ፊርማዎን፡ያኑሩ(ስምዎን፡መጻፍ፡አያስፈልግም)፡፡

በዚህ፡ጥናት፡ለመሳተፍ፡ፈቃደኛ፡ነዎት?

አዎ[ ]   አይደለሁም[ ]

ስለተሳተፍእናመሰግናለን፡፡

AnnexE:በሕፃናት፡ካንሰር፡ሕክምና፡ውሳኔ፡አሰጣጥ፡ላይ፡የወላጅ፡ተሳትፎን፡በተመለከተ፡የመጠን፡መለኪያ፡መጠይቅ፡የአማርኛ፡ትርጉም፡፡

መለያ፡ቁጥር_______________ ቀን: _______________

ክፍል:1-የወላጆቹ፡የስነ-ህዝብ፡መረጃ

1.ዕድሜ(በዓመት):__________________

2.ጾታ: ሀ.አባት [ ] ለ.እናት [ ]

3.የጋብቻ፡ሁኔታ፡- ሀ.በትዳር፡የሚኖር [ ] ለ. ለብቻዉ፡የሚኖር [ ]

4.የመኖሪያ፡ቦታ ሀ. ከተማ [ ] ለ. ገጠር [ ]

5.የትምህርት፡ደረጃ

ሀ.ያልተማረ/ች [ ] ለ. ማንበብ፡እና፡መጻፍ፡የሚችል/የምትችል [] ሐ.የመጀመሪያ፡ደረጃ፡ትምህርት[]

መ. ሁለተኛ፡ደረጃ፡ት/ቤት [ ] ሠ. ከሁለተኛ፡ደረጃ፡በላይ []

6.የስራ፡ሁኔታ፡-ሀ.ስራ፡ያለዉ [ ] ለ.ስራ፡የሌለዉ

7. የመኖርያአድራሻ፡- ሀ. ከተማ ለ. ገጠር

ክፍል 2-የህፃናት:የስነ-ህዝብ፡መረጃዎች

1.ዕድሜ፡(በዓመት):_______________

2.ጾታ- ሀ.ወንድ [] ለ.ሴት []

3.የካንሰሩ፡አይነት፡-__________________

4.የሕፃኑ፡ህመም፡ከታወቀ፡ጊዜ፡አንስቶ:- ____________________

5.የበሽታው፡ከባድነት- ሀ.ዝቅተኛ፡አደጋ [] ለ. መካከለኛ፡አደጋ [] ሐ. ከፍተኛ፡ስጋት []

6. የተሰጠዉ፡ሕክምና: ሀ. የቀዶ፡ጥገና[ ] ለ. የጨረር፡ሕክምና[ ] ሐ.ኬሞ፡ቴራፒ[ ]

ክፍል፡3-ለሕፃናት፡ሕክምና፡የወላጆች፡የውሳኔ፡አሰጣጥ፡ሚና፡ምርጫ፡፡

1. ካንሰር፡ላለበት፡ልጅዎ፡የህክምና፡አሰጣጥ፡ውሳኔ፡ላይ፡እርሶ፡እንዲሳተፉ፡ከሚመርጡት፡መካከል፡አንዱን፡ይምረጡ?

ሀ.የልጆቼን፡ህክምና፡የመጨረሻ፡ምርጫ፡ማድረግ፡እመርጣለሁ፡፡

ለ.የዶክተሮች፡አስተያየት፡በጥሞና፡ካሰብኩ፡በኋላ፡የልጆቼን፡ህክምና፡የመጨረሻ፡ምርጫ፡ማድረግ፡እመርጣለሁ፡፡

ሐ.የልጄ፡ዶክተር፡እና፡እኔ፡ለልጄ፡የትኛው፡ህክምና፡የተሻለ፡እንደሆነ፡የመወሰን፡ሀላፊነት፡እንጋራለን፡፡

መ.ዶክተሬ፡የትኛው፡ሕክምና፡ጥቅም፡ላይ፡እንደሚውል፡የመጨረሻውን፡ውሳኔ፡መስጠቱን፡እመርጣለሁ፣ግን፡የእኔን፡አስተያየት፡በቁምነገር፡ይመለከታቸዋል፡፡

ሠ.የልጆቼን፡አያያዝ፡በተመለከተ፡ሁሉንም፡ውሳኔዎች፡ለዶክተሬ፡መተው፡እመርጣለሁ፡፡

2.የእርስዎ፡ትክክለኛ፡የሥራድርሻ፡ነው፡የሚሉትን፡ከላይ፡ከተጠቀሱት፡አምስት፡አማራጮች፡ውስጥ፡አንዱን፡ይምረጡ?

ክፍል፡4-በመረጃ፡ፍላጎት፡እና፡በባህሪ፡ማካተት፡ላይ፡ያተኮሩ፡ጥያቄዎች

የመረጃ፡ፍላጎት

1.በሕክምና፡ምርመራ፡ወቅት፡ሐኪሙን፡ወይም፡ነርስን፡ምን፡እያደረጉ፡እንደሆነ፡ብዙ፡ጊዜ፡አልጠይቅም፡፡

ሀ. እስማማለሁ ለ.አልስማማም

2.ብዙ፡የህክምና፡ምርጫዎችን፡ለኔ፡ከሚሰጡኝ፡ይልቅ፡ሀኪሞች፡እና፡ነርሶች፡የተሻለዉን፡ቢወስኑ፡እመርጣለሁ፡፡

ሀ. እስማማለሁ ለ.አልስማማም

3.እስኪነግሩኝ፡ከመጠበቅ፡ይልቅ፡ብዙውን፡ጊዜ፡ሐኪሙን፡ወይም፡ነርሷን፡ከምርመራ፡በሃላ፡ወዲያውኑ፡እጠይቃለሁ፡፡

ሀ. እስማማለሁ ለ.አልስማማም

4.ብዙውን፡ጊዜ፡በሕክምና፡ምርመራ፡ወቅት፡ሐኪሙ፡ወይም፡ነርሷን፡ስለጤና፡ምርመራዉ፡በተመለከተ፡ብዙ፡ጥያቄዎችን፡እጠይቃለሁ፡፡

ሀ. እስማማለሁ ለ.አልስማማም

5.የሚሰሩትን፡ከመጠየቅ፡ይልቅ፡በሕክምና፡ሂደት፡ኃላፊነቱን፡የሚወስዱ፡ሀኪም፡ወይም፡ነርስ፡ማመን፡ይሻላል ፡፡

ሀ. እስማማለሁ ለ.አልስማማም

6.ብዙውን፡ጊዜ፡ወዲያውኑ፡ከመጠየቅ፡ይልቅ፡የህክምና፡ምርመራ፡ውጤትን፡እስኪነግሩኝ፡ድረስ፡ዶክተር፡ወይም፡ነርስ፡እጠብቃለሁ ፡፡

ሀ. እስማማለሁ ለ.አልስማማም

7.ዶክተር፡ወይም፡ነርስ፡ለእኔ፡ዉሳኔ፡ከሚሰጡ፡ይልቅ፡ለጤንነቴ፡የተሻለው፡ነገር፡ብዙ፡ምርጫዎች፡ቢሰጡኝ፡እመርጣለሁ

ሀ. እስማማለሁ ለ.አልስማማም

የስነምግባርተሳትፎንዑስ

1.ከከባድ፡ህመም፡በስተቀር፡በአጠቃላይ፡የባለሙያ፡እገዛን፡ከመፈለግ፡ይልቅ፡የራስዎን፡ጤና፡መንከባከቡ፡የተሻለ፡ነው፡፡

ሀ. እስማማለሁ ለ.አልስማማም

2.የራስዎን፡ሰውነት፡ለመንከባከብ፡የጋራ፡መግባባት፡ላይ፡ከመተማመን፡ይልቅ፡በሀኪሞች፡(ባለሙያዎች)፡ውሳኔ፡መተማመን፡ይሻላል፡፡

ሀ. እስማማለሁ ለ.አልስማማም

3.ክሊኒኮች፡እና፡ሆስፒታሎች፡እርዳታ፡ለማግኘት፡ጥሩ፡ቦታዎች፡ናቸው፡ምክንያቱም፡የሕክምና፡ባለሙያዎች፡ለጤና፡እንክብካቤ፡ሀላፊነት፡መውሰድ፡ስለሚችል፡፡ ሀ. እስማማለሁ ለ.አልስማማም

4.ከሐኪም፡ጋር፡ሳይገናኙ፡አንዳንድ፡የራስዎን፡ህመም፡እንዴት፡ማዳን፡እንደሚችሉ፡መማር፡ጥሩ፡ሀሳብ፡ነው፡፡

ሀ. እስማማለሁ ለ.አልስማማም

5.ራስዎን፡ለማከም፡ከመሞከር፡ይልቅ፡የባለሙያ፡እርዳታ፡መጠየቅ፡ሁልጊዜም፡የተሻለ፡ነው፡፡

ሀ. እስማማለሁ ለ.አልስማማም

6.ከሐኪም፡ጋር፡ሳይገናኙ፡የተወሰኑ፡ህመሞትን፡እንዴት፡መፍታት፡መማር፡ከጥቅሙ፡ይልቅ፡ጉዳቱ፡ሊያመዝን፡ይችላል፡፡

ሀ. እስማማለሁ ለ. አልስማማም

7.ህመምተኞች፡እራሳቸውን፡ከመንከባከብ፡ይልቅ፡ብዙውን፡ጊዜ፡በዶክተሩ፡ወይም፡በነርስ፡ጥበቃ፡ስር፡በጣም፡በተሻለ፡ማገገም፡ይችላሉ፡፡

ሀ. እስማማለሁ ለ. አልስማማም

8.ወጪዉ፡ተመሳሳይ፡ከሆነ፡እራሴን፡ከማከም፡ይልቅ፡በጤና፡ባለሙያ፡መታከም፡እመርጣለሁ፡፡

ሀ. እስማማለሁ ለ. አልስማማም

9.የህክምና፡ባለሙያ፡ላይ፡ጥገኛ፡ከመሆን፡ይልቅ፡በግል፡እምነት፡እራስን፡መንከባከብ፡የተሻለ፡ነዉ፡፡

ሀ. እስማማለሁ ለ. አልስማማም

ክፍል:5:በጤና፡ባለሙያዉ፡ላይ፡ስላለ፡እምነት

ጥያቄዎች	በጥብቅ፡ እስማማለሁ	እስማማለሁ	ገለልተኛ	አልስማማም	በጥብቅ፡ አልስማማም
1.ሐኪሜ፡እንደግለሰብ፡ለእኔ፡እንደሚያስብልኝ፡ እጠራጠራለሁ፡፡					
2.ሐኪሜ፡ብዙውን፡ጊዜ፡የኔን፡ፍላጎት፡ከግምት፡ውስጥ፡ ያስገባል፡እንዲሁም፡ቅድሚያ፡ይሰጣቸዋል ፡፡					
3.ሀኪሜን፡በጣም፡አምናለሁ፡ሁልጊዜ፡የእሱን/ሷን፡ ምክር፡ለመከተል፡እሞክራለሁ።					
4.ሐኪሜ፡አንድ፡ነገር፡ከነገረኝ፡መረጃዉ፡ሁሌም፡ እውነትነት፡ይኖረዋል፡፡					
5.አንዳንድ፡ጊዜ፡የዶክተሩን፡አስተያየት፡እጠራጠራለሁ፡ እና፡ሌላ፡አማራጭ፡እፈልጋለሁ።					
6.ሐኪሜን፡ስለ፡ሕክምና፡እንክብካቤዬ፡በሚወሰኑ፡ ውሳኔዎች፡አምናለሁ፡፡					
7.ሐኪሜ፡ለህክምና፡እንክብካቤዬ፡የሚፈለገውን፡ሁሉ፡ እንደማያደርግ፡ይሰማኛል፡፡					
8.የሕክምና፡ችግሮቼን፡በምታስተናግድበት፡ጊዜ፡ የሕክምና፡ፍላጎቶቼን፡ሁሉ፡ከምንም፡በላይ፡ እንደሚያስቀድምልኝ፡ሀኪሜን፡አምነዋለሁ/ናታለሁ፡፡					
9.ሀኪሜ፡እንደኔ፡ያሉ፡የጤና፡ችግሮችን፡ለመንከባከብ፡ እውነተኛ፡ባለሙያ፡ነው፡፡					
10.በሕክምናዬ፡ላይ፡ስሕተት፡ከተደረገ፡ሐኪሙ፡ እንደሚነግረኝ፡አምናለሁ፡፡					
11.አንዳንድ፡ጊዜ፡ሐኪሜ፡የምናወራውን፡የግል፡መረጃ፡ ሙሉ፡በሙሉ፡ሚስጥራዊ፡ላያረገዉ፡ይችላል፡የሚል፡ ስጋት፡ያድርብኛል፡፡					

ክፍል፡6-የዉይይት፡ጥራት፡የሚገመግሙ፡ጥያቄዎች

ጥያቄዎች	ሁሌም	አንዳንድ፡ጊዜ	አብዛኛውን ጊዜ	በጭራሽ
1.ሐኪሙ፡ለጥያቄዎቼ፡መልስ፡ለመስጠት፡ጊዜ፡ይሰጣል፡፡				
2.የጤና፡ባለሙያዉ፡እንደፈለግኩት፡ብዙ፡የህክምና፡መረጃዎች፡ ይሰጠኛል።				
3.እኔ፡ጥያቄ፡ሳላቀርብ፡ባለሙያዎቹ፡መለጃ፡ይሰጡኛል፡፡				
4.አስተያየቴ፡ተሰሚነት፡እንዳለዉ፡እንዲሰማኝ፡አርገዉኛል፡፡				
5.ዉይይቶች፡ስናረግ፡ለእያንዳንዱ፡ነገር፡ትኩረት፡ሰተን፡ነዉ፡፡				
6.ለመረዳት፡የሚያስችለኝን፡መልስ፡ሰተዉኛል፡፡				

Annex F:የካሊታቲቭ፡መጠይቅ፡የአማርኛ፡ትርጉም

ክፍል:1:-ለቤተሰቦች፡የተዘጋጀ፡መጠይቅ፡የአማርኛ፡ትርጉም

መግቢያ፡-የቤተሰብ፡ተሳትፎ፡በህክምና፡ዉሳኔ፡አሰጣጥ፡ላይ፡ሊኖር፡ይችላል፡፡በልጆች፡ህክምና፡ሁኔታ፡ላይ፡ዉሳኔ፡ሊሰጡ፡የሚችሉት፡ቤተሰቦችና፡ጤና፡ባለሙያዎች፡በተናጠል፡ወይም፡በጋራ፡ሊሆኑ፡ይችላል፡፡

1.እድሜ፡_______________

2.ጾታ፡_________________

3.የጋብቻ፡ሁኔታ፡______________

4.የመኖርያ፡አካባቢ፡_______________

5.የልጅ፡ህመም፡_________________

6.ልጅን፡በማሳከም፡ሂደት፡ዉስጥ፡ለልጅ፡ስለሚሰጡ፡የህክምና፡መድሃኒቶች፡ዉሳኔዎች፡እንዴት፡ይሰጡ፡ነበር?በዉሳኔ፡አሰጣጡ፡የርሶ፡ሚና፡እንዴት፡ነበር? (ተሳታፊው፡በንቃት፤በትብብር፡ወይም፡ገለልተኛ፡በመሆን፡እንደሆነ፡ይጠይቁ፡እና፡መቼ፡ንቁ፡ወይም፡የትብብር፡ወይም፡ገለልተኛ፡በመሆን፡ለነሱ፡ምን፡ማለት፡እንደሆኑ፡ይጠይቁ)

7.ለታመመው:ልጅዎ:ሕክምና:በሚሰጡ:ውሳኔዎች:ውስጥ:መሳተፍ:አለብኝ:ብለው፡ያስባሉ?

- አዎ፡ከሆነ፡በምን፡ደረጃ?(ተሳታፊው፡በንቃት፤በትብብር፡ወይም፡ገለልተኛ፡በመሆን፡እንደሆነ፡ይጠይቁ፡እና፡መቼ፡ንቁ፡ወይም፡የትብብር፡ወይም፡ገለልተኛ፡በመሆን፡ለነሱ፡ምን፡ማለት፡እንደሆኑ፡ይጠይቁ)

- የለብኝም፡ከሆነ፣ለምን?

8.ለምን፡የህክምና፡ውሳኔ፡አሰጣጥ፡ላይ፡ሚናዎን፡መርጡ?

9.አሁን፡ባሎት፡ሚና፡እና፡በህክምና፡አሰጣጥ፡ዉሳኔ፡ዉስጥ፡ለመሳተፍ፡ባሎት፡ፍላጎት፡መካከል፡ልዩነት፡አለ?

10.ከላይ፡ለተጠየቀዉ፡ጥያቄ፡መልሶ፡አዎ፡ከሆነ፡ምክንያቱ፡ለምን፡ይመስሎታል?

11.ለያዙት፡ሚና፡አስተዋጽኦ፡ያላቸውን፡አንዳንድ፡ምክንያቶች፡መጥቀስ፡ይችላሉ?(የቋንቋ/ባህላቸው፣የትምህርት፡ሁኔታቸው፣የሃይማኖታቸው፣ወዘተ...)

12.ከህክምና፡ዉሳኔዉ፡በሁዋላ፡ከተፈጠረዉ፡ነገር፡በመነሳት፡በሰአቱ፡በነበሮት፡ተሳትፎ፡አሁን፡ምን፡ይሰማዎታል?

13.ማከል:የሚፈልጉት፡ተጨማሪ፡ነጥብ:አለ?

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Families: List of Code Families and their Members

Code Family	Codes
Anxiety	• anxiety due to lack of conversation • Parent might be anxious • stress relieve • stressful at the beginning • strong personality • to alleviate stress • to relieve anxiety • won't get anxious due to lack of knowledge
Faith on the HP	• faith on the health care due to previous clinical experience • full trust on the physicians • hp have wisdom • hp made unintentional faults • parents trust built up through time • the trust will rise • trust the physicians words
False perception	• considers cancer as a sin • disease is from above • false belief make the disease worse • tried alternative treatments
Feels comfortable	• deciding together have personal benefits. • free of regret • parent losing hope • parental fear • to give my impression • uncomfortable with Drs decision
formal education	• having some formal education • science based educational background
health provider informing patient	• advise to start medical treatment • discussed about z medication • discussed about z side effects • educated on adverse effect delay • educated on the value of time for treatment • exemplary teaching • exchange information well • false hope due to misinformation • high information provision • HP comforted the parents • HP inform the parent • HP the informant role

	• HP willing to respond • inform the parents • information for planning a head • information on the consequence of the disease • lack of information exchange • notified • physicians answers parental questions • provide sufficient information • share all information • take a lesson regarding time
outrageous view on the health provider	• recognizes hp knowledge • respect their decisions
Parents considered recipient	• command from the health provider • dawn play parents opinion • ignorance
Parents look on the decisional role	• accept their decision • active role • agreed decision making • parent considering sharing of decision • parents perceives collaboration as worthy • partnership • passive role preference
Parents seeking information	• ask a lot • consistent complaining for progress • continuous nagging the health providers • don't ask questions • information for financial planning • information for planning a head • information gap • interested in detailed information • lack of information exchange • listens the doctors advise • not eager to get information • parent constantly seeking information • parent needs detailed information • parental consistent information request • parents level of information
parents understanding of the interaction	• a feeling of undermined • avoiding the parents questions • considered as an arrogant • cooperative hp • felt listened • health providers are not friendly • health providers offend parents for involving • hp considers my interest

	• parent will be intimidated if tried to be involved
personal worth	• advocate for the child • confident • parent considers own authority • pooling responsibility to one's self • taking responsibility
previous clinical experience	• an experience from others influenced decision • have bad experience • learned from other dalliance • parents lack of clinical experience • previous clinical exposure • previous unsuccessful treatments • trust through experience • upsetting experience
Progress of the disease	• discharging with no improvement • disease condition • disease progression • focused on getting cured • HP were very concerned • seriousness of the disease
Satsfaction with the health care	• health providers are committed • hp have empathy • hp very supportive • in search for alternative medication • mistreatment • not committed • satisfied with the hp • satisfied with the treatment
Shocked with the Dx	• frustration • gave up on health provides • misinformation • shocked with unexpected news • unprepared for the bad news
suspicion	• contradictory decision from the health providers • curious • curiosity due to contradictory opinions from HP • parent was suspicious
treatment process	• duration of tx • elevated stress due to no management • exostive experience • insufficient medical supply • misdiagnosis • no improvement post medication

	no solution parent got confused due to contradictory decisions previous unsuccessful treatments prolonged lab appointment quit the treatment due to lacking improvement
Two way dialoge	aggressive behavior decide and start the medication together discussed about z medication discussed about z side effects discussed together felt listened health providers self centrism hp disregards patients opinions hp not willing to discuss not willing to listen one way communication resistant to listen others
Understanding of the Tx and Dx	fear of deciding due to knowledge deficient got lesson about the side effects after seeing the change internationalizing the health problem lack of knowledge about the disease lack of knowledge about the tx parent recognizes own knowledge deficient parent recognizing own knowledge about the child parents knowledge improvement recognizes own knowledge deficient
urgency	HP were urgent parental hunger for medical management for the child patients sense of urgency urgency to save Childs life