

ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF NURSING AND MIDWIFERY



VALIDATION OF THE AMHARIC VERSION OF THE MPOC-20 AMONG PARENTS OF CHILDREN WITH CHRONIC DISEASE IN TIKUR ANBESA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA, 2021. A VALIDATION STUDY

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A THESIS SUBMITTED TO ADDIS ABABA UNIVERSITY SCHOOL OF NURSING AND MIDWIFERY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN PEDIATRICS AND CHILD HEALTH NURSING.

MAY, 2021

ADDIS ABABA, ETHIOPIA

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COLLEGE OF HEALTH SCIENCES
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POSTGRADUATE PROGRAM

VALIDATION OF AMHARIC VERSION MPOC-20 AMONG PARENTS OF CHILDREN WITH CHRONIC DISEASE IN TASH, ADDIS ABABA, ETHIOPIA, 2021.

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ACKNOWLEDGMENT

First, I would like to give my warmest gratitude to Addis Ababa University, College of health science, School of nursing and midwifery for giving me a chance to do this thesis paper. Then, I would like to express my deepest gratitude to my advisors; Leul Deribe (MPH, Assistant professor, PhD fellow) and Mekonen Admasu (MSc) for their direct support, provision of relevant, timely comment and guidance for the overall work of this thesis.

LIST OF ACRONYMS AND ABBREVIATIONS

AAU- Addis Ababa University

ACCH- Association for the Care of Children's Health

Am- Amharic

AMOS- Analysis moment of structure

CFA- Confirmatory factor analysis

CFI- Comparative fit index

CI- Confidence interval

DF-Degree of freedom

FA- Factor Analysis

FCC- family-centered care

FCS- family-centered service

KMO- Kaiser-Meyer-Olkin

MPOC- Measure of Process of Care

MPOC-NL Measure of the process of care Netherland

NCRU- Neurodevelopmental Clinical Research Unit

OACRS- Association of Children's Rehabilitation Services

PA- Parallel analysis

PAF- Principal Axis Factoring

PCA- Principal Component Analysis

RMSEA- Root mean square error approximation

SRMR- Standardized root mean residual

SPSS- Statistical Package for Social Sciences

TASH- Tikur Anbesa Specialized Hospital

USA- United States of America

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SUMMARY

Background: Family-centered care is a fundamental approach to plan and deliver healthcare services for children and their families in collaboration with health professionals. Assessing the provision of family-centered care ensures the importance of family involvement evaluate the method of existing care. FCC has to be considered as best practice in pediatrics and used to clarify the parental misunderstanding about the care given for their children and helps to. A measure of Processes of Care (MPOC) is a crucial tool to evaluate family-centered care. Even if the concept was difficult to address; presence of reliable and valid MPOC tool was used to fill the gap related to the parental perception about the care.

Objectives: To examine validity and reliability of Amharic version of measure of the process of care-20.

Methods: Institution based cross-sectional study was conducted to measure the parental perception of the care they received using the MPOC-20 tool. Stratified sampling method was used to allocate sample to each unit proportionally, then consecutive sample was used to collect data. The instrument was translated to Amharic and back to English to comprehend and ensure readability of the questionnaire. Factor analysis was performed to assess the construct validity and reliability of MPOC-20. For each of the factors, Cronbach's alpha value was computed to determine the internal consistency of the Amharic version of MPOC-20. Data were entered via Epi data version 4.6. EFA was analyzed by using IBM SPSS version 25.0 and CFA by SPSS AMOS version 24.0.

Result: The factor structure of the Amharic version MPOC-20 was examined by using principal axis factoring with Varimax rotation to explore the factor structures. Five items were removed from the original MPOC 20 items, and 15 items were loaded into three factors. The three-factor model explained 47% of the total variance in the Amharic version MPOC-15. Cronbach's alpha was calculated to determine the internal consistency reliability of the factors in the Amharic version MPOC-15 and shows to had good overall internal consistency with Cronbach's alpha value of .88. CFA suggests that measuring indices of the three-factor structure of MPOC-15 had an acceptable fit model.

Conclusion: This study shows that the Amharic version MPOC-15 is valid and reliable with three-factor structure model to measure psychometric properties of the parents of children with chronic disease for evaluating family-centered care in the study population.

Key Words: family-centered Care, MPOC, Children, Chronic Disease, Parent, Validity, Reliability

1. INTRODUCTION

1.1. Background

Family-centered care (FCC) is a fundamental approach to plan and deliver healthcare services for children and their families in collaboration with health professionals (1). Family-centered service can be described as a holistic approach towards service delivery. Each child and its family's unique strengths, resources, and needs form the base for a highly individualized and good nature of care(2).

During the early 20th century, parents were not allowed to visit their children admitted to the hospital or allowed to visit only for hours. Ideas about family-centered practice originated in the 1940s with Carl Rogers' approach to working with families of children having a problem. In the mid-1960s, the Association for the Care of Children in Hospital (ACCH-now the Association for the Care of Children's Health) was founded and explored ideas about family-centered care. The term family-centered care seems to have been codified in 1992 by the USA's current Institute for Patient and Family-centered Care. It described the elements of family-centered care as primarily recognizing the family as a constant in the child's life and facilitating parent-professional collaboration at all levels of healthcare(3,4).

The philosophy and principles of FCC have to be considered as best practice in pediatrics hospitals in the developed world. The approach was born out of the recognition that the emotional needs of hospitalized children were unmet. Parents were not involved in the direct care of their children, children were often unprepared for procedures, and that visiting was severely controlled. In the developing world, because of scarce documentation on the management of hospitalized children, the implementation of family-centered care becomes difficult (5).

A family-centered care approach is essential to create suit environment in collaboration with health care teams and families to plan appropriate early interventions and decide on children's problems. The concept is also used to clarify the parental misunderstanding about the care given for their children and helps to evaluate the method of existing care. Assessing the provision of

family-centered care ensures the importance of family involvement to support health care professionals to improve the quality of care among the children(6).

The main goal of applying family-centered care is to promote and achieve better health outcomes and the patient's wellbeing. The concept should be assured by sharing updated information, providing support as needed. Inviting the family to participate in care delivery and decision-making, giving time to ask their question improves care quality (7).

MPOC was first introduced by clinicians and researchers of the multidisciplinary Neurodevelopmental Clinical Research Unit (NCRU) work in partnership with the Ontario Association of Children's Rehabilitation Services (OACRS) across Ontario, Canada. They aim to provide services to children with primarily long-term neurodevelopmental disabilities in the 1990s(1,7).

The MPOC used to measure and appreciate critical features of caregiving that parents want to receive and identifies the challenges of healthcare delivery system. The Measure of Processes of Care exists in 56-item and 20-item versions published in 1995 and in 2004 respectively (1,7).

The latest version of MPOC is a shorter and user-friendly version with 20 items. It was self-administered parent completed a questionnaire that refined from the original MPOC-56. It develops due to the disadvantage of the longer version, time-consuming, and having a high burden for participant response (1,7). It translated and evaluated in different countries language like China(9), Japan(10), Netherland(11), Norway(12), Slovenia(13), Sweden(14) and Korea(15).

1.2. Statement of problem

There are an overgrowing number of tools used under medical research and in a different clinical setting. The tools like Medical Home Family Index (MHFI), the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician and Group Survey, and Family-Centered Care Assessment (FCCA) are the most commonly used instruments to assess family-centered care. However, most don't address all principles that fulfill the family perspective on family-centered care, cannot assess parental perception and have a high participant burden due to many item(16).

The standardized care measurement tool is used to evaluate the technical quality and adequacy of health care providers and the problems related to standard procedures of diagnosis and treatment. Without such like assessment tools improving and providing of good quality of care becomes terrible. Without validating and testing the reliability of evaluation the process of care, parental perception about the care, bonding between health care provider and family, and necessity of the family for decision-making were challenging(17,18).

For the implementation of family centered care health professional's knowledge, attitude and skill on the benefit of involvement of parents during provision of care need special attention. For this health care program designers and researchers relies on investigating parents interest and health care providers experiences to monitor and evaluate the implementation of family-centered services and whether these fulfill their needs, preferences, and values. Validation and testing reliability of tools need methodological approaches that are mainly based on the families, clinicians, and researchers(5,18).

Non-use of a standardized instrument to measure the care provided in health care institution results in lack of trust in health professionals, difficulty to know parental perception about the care, inefficient use of the resource, and low quality of health care delivery. However, socio-cultural variation between the countries hinders the implementation of the concepts (19).

Socio-contextual and cultural differences among low and highly-resourced countries influence parental perception, expectation on care involvement, and health care provider's attitudes towards parental engagement. In most developing countries, parents are mainly involved in giving information about their sick child but not planning and implementing care(5,20). Besides

these parent educational level, communication skill (language), residential area, and severity of disease impact family-centered care application(20,21).

To achieve good quality family-centered care or service means meeting or exceeding the child's parental expectations beyond medical diagnosis and treatment. To perform and overcome challenges use of standardized tools gives a good response. The MPOC-20 assessment equips healthcare providers with information about how much the service is family-centered or not and contributes valuable insights into improving their family-centered practice(22).

The MPOC tool act as an aid or a checklist for overall assessment of care provision related to family-centered care. Assessing process of care to measure parental perceptions at children's treatment centers is not usual. It is essential to have a tool that clarifies and evaluates parental perception about the care they received(10,11,13,15,17,23,24).

Validation and testing of the reliability of this MPOC-20 tool among parents of children with chronic disease used to measures parents' perception about the care they received in the concrete situation. And also actions by health professionals on the aspects of caregiving, emotional wellbeing noted by parents during provision of care at treatment center. It will improve a child's health care under the consideration parent's socio-cultural context. It recognizes the family's role in the planning, delivering, and decision of care (17).

Overall, family-centered care in the pediatric unit becomes an essential concept; however, using instruments to evaluate family-centered care in our health care system is not usual. MPOC-20 is an internationally validated and reliable tool to evaluate the FCC due to its small number of items, time-consuming effect. Examining the validity and reliability of the Amharic version of MPOC-20 has valuable benefit and good to measure the psychometric properties of the family.

1.3. Significance of study

MPOC-20 is the tool used to measure the parental perception towards family centeredness of healthcare providers' care in a health care institution. Validated and tested (MPOC-20) tool among parents of children with a chronic disease condition can be used to know the degree of family centeredness of the care of the Amharic version of MPOC-20. To evaluate the existing and newly developed intervention aimed at improving family-centered care, used for health care providers and for researchers as an aid for evaluating family-centered care.

2. LITERATURE REVIEW

2.1. Introduction to validity and reliability

Reliability and validity are concepts used to evaluate the quality of research. They indicate how well strategy, technique, or test measures something.

2.1.2. Validity

Validity measures the accuracy or precision of what a researcher is supposed to measure by checking the usefulness and wellness of results correspond to developed theories and other measures of the same concept(26–28).

Validity has four main components: construct validity, face validity, content validity, and criterion validity. Construct validity has sub-components, discriminant and convergent, and criterion validity also has components; concurrent and divergent validity(26–28).

Construct validity refers to how well the tool was translated or transformed a concept, idea, or behavior that is a construct into a functioning and operating reality. Whenever a particular attribute has to be measured, construct validity is involved. It is the most usable form of validity to assess measurements and the basis for other types of validity(26–29).

Construct validity has two components; Discriminant validity and convergent validity. Discriminative validity is the extent to which one factor is explained by another factor than internal or external factors or other constructs within the entire factor. Discriminant validity test constructs that should have no relationship do, in fact, not have any relationship. And convergent validity refers to the degree to which two measures of constructs that theoretically should be related (26,28).

Face validity is a subjective view on the meaning of a construct and relevance of the measuring tools as to whether the items in the instrument appear to be applicable, sound, and clear. It evaluates the contents of the questionnaire's readability, understandability, practicability, and consistency of style and formatting. It clarifies that items are linguistically and analytically look like what is supposed to be measured(26,27).

Content validity assesses the extent to which the measurement covers whole parts of the concept being measured. It is recommended to apply content validity while the new instrument is developed. Content validity involves evaluating a new survey instrument to ensure that it includes all the essential items and eliminates unwanted items to a particular construct domain(26,27,29).

Criterion or concrete validity is how a measure is related to variables that one would expect to be correlated. It assesses the extent to which the result of a measure corresponds to other valid measures of the same concept. It is used to predict the performance and behavior of another situation(26,27).

2.1.2. Reliability

Reliability measures the extent of consistency and stability of the result of phenomena. Reliability is also concerned with repeatability. There are three types of reliability; test-retest reliability, internal consistency, and inter-rater reliability. Test-retest reliability measures the extent to which a construct that the researcher assumed to be consistent across time, then the scores they obtain should also be consistent across time and consider this is an actual problem. It requires using the measure on a group of individuals at the point of time, using it again on the same group of individuals later, and then comparing at test-retest correlation between the two sets of scores. Test-retest correlation of $+0.80$ or greater indicates good reliability(26,29).

Internal consistency measures the sameness of individuals' responses across the items in multiple-item measures. All the items on such measures are intended to show the same underlying construct, so people's scores on those items should be related to each other. The most common measure of internal consistency used by researchers is Cronbach's alpha, and a value of $+0.80$ indicates good internal consistency, and $+0.9$ shows excellent internal consistency(26,29).

Inter-rater reliability measures the extent to which different observers are consistent in their feeling and is often assessed by using Cronbach's α when the judgments are quantitative or an analogous statistic called Cohen's κ (the Greek letter kappa) when they are categorical(26,29).

Generally, reliability is expressed as correlation coefficient (r), with 1.00 indicating perfect reliability and 0.00 indicating no reliability. A reliability of .80 is considered the lowest acceptable coefficient for a well-developed measurement tool. For a research purpose instrument, reliability of .70 is considered acceptable(30,31).

Construct validity and internal consistency of measure of the process of care (MPOC-20) was conducted in this study. Examining construct validity was used to know the extent to which the concept or idea wanted to measure. The consistency of the items on its subscale among the participant was tested.

2.2. Overview of family-centered care

Family-centered care is the holistic clinical approach on the side of family related to the treatment of patients especially in pediatric setting. It encourages the planning, delivery, and evaluation of healthcare that considers the children and family as both care recipients and needs coordinated care. The main focus of family-centered care is to have a wholesome outcome for all of the concerned bodies in the treatment process. However, its main effect is on the outcomes of children's health(8).

Family-centered care gets widespread acceptance and support from numerous medical organizations, healthcare facilities, and communities. It is applied in many treatment settings and populations, which need the family to be best involved in response to child care and ease the challenges (8,32).

Family-centered care extends its use across several levels from the whole healthcare system to care providers, families, and children. Sometimes family-centered care defined in terms of its cost-effectiveness, service utilization, satisfaction, staff turnover rate minimization and job performance(8).

2.3. Review of articles on validity and reliability of MPOC-20

A measure of the process of care (MPOC) was applied to evaluate family-centered care in numerous pediatrics problems in many countries' health care settings. The MPOC-20 assesses family-centered care using five domains or underlying constructs of family-centered care as described by the MPOC developer.

A measure of the process of care (MPOC) tool was used to assess family centeredness in a different clinical setting with respective problems like children with chronic conditions(1,11,13), neurodevelopmental disorders(12,15), children with epilepsy(33), children with cerebral palsy(9), and on those who receive care at a rehabilitation center (10,12–14,22). The following articles review the validity and reliability of MPOC applied to assess family-centered care in different countries.

In a study conducted in Korea (2018), the correlation analysis of Korean version MPOC-20 was significantly correlated with their scale scores, ranging from 0.72 to 0.94. The respectful and supportive care domain rated the highest score of 5.45, whereas providing general information domain received the lowest rating of 4.25. Although two of the five scale scores, coordinated and comprehensive care and enabling and partnership, tended towards the higher end of the range 5.22 and 5.31, respectively. To measure internal consistency, the calculated Cronbach's alpha coefficient for each of the five scales lies between 0.85 and 0.95; these indicate to have good to excellent internal consistency(15).

Malay version MPOC-20 (2015) revealed that from the identified four factors, three of them have high internal consistency with Cronbach's alpha values of above 0.80. Cronbach's alpha for respectful and supportive care was 0.75, indicating a good internal consistency. The calculated Pearson's correlation coefficient to assess the correlation between the four factors of the MPOC-20 indicates all factors are correlated significantly with other factors ($p < 0.001$)(22).

A study conducted in Slovenia in 2015 to assess Validity, internal consistency reliability, and stability of Slovene version MPOC 20, from the parents who answer to what extent the processes of care had on all of the subscales distributed across the total items, the mean scores were greater than five on all the MPOC-20 subscales except for providing general information subscale which is 4.59. Providing General Information is also the only subscale not exhibiting negative asymmetry of the score distribution. Internal consistency and corrected item-total correlations for each of the five MPOC-20 subscales showed that to have high internal consistency of enabling and partnership (0.833), coordinated and comprehensive care (0.837), providing specific information about the child (0.842), respect and supportive care (0.886) and providing general information (0.906) and each item had greater than 0.3 of corrected item to total correlation value(13).

A study was done in China (2014) to evaluate the validity and reliability of the Chinese version of MPOC-20; the same five-factor solution confirmed the original MPOC-20 factor structure. All items of each scale of the Chinese MPOC-20 loaded on factor, the same as the original MPOC-20 distributed. The scale means of the MPOC-20 range from 4.62 to 5.26, in which respect and supportive care rated the highest scale score and providing general information rated the lowest. For internal consistency, the calculated Cronbach's alpha coefficient for each of the five scales has a high level of uniformity for each scale item, and alpha values were between 0.70 and 0.90(9).

A study was done in Japan (2013) revealed that the construct validity of the Japanese version of MPOC-20 scales was assessed and it becomes same acceptable five scales of the Japanese version of the MPOC. The correlation coefficient of items indicates to have high interrelationship with their scales, and the five scales also related to each other. The calculated Cronbach's alpha coefficient to measure internal consistency indicates the items in each scale have a high level of uniformity, ranging from 0.76 to 0.83(10).

A study conducted in Norway (2012) indicated good internal consistency, with four of the scales showing Cronbach's alpha above 0.80. For one of the scales (Providing specific information), Cronbach's alpha was 0.62, indicating moderate internal consistency. The value of the items within each five scale was grouped in statistical and clinically interpretable(12).

The study was done in Netherland (MPOC-NL) (2004) for assessing construct validity with confirmative analyses of the scale structure. The correlation of items with their respective scales correlated best, ranging from 0.64 to 0.86 and significantly ($P < 0.001$). Furthermore, the correlation between the scales of MPOC-NL and all scales correlated significantly with any other scales ($P < 0.001$), with r ranging from 0.50 to 0.92. The MPOC-NL becomes valid and reliable on each subscale item(11).

In a study conducted in South Africa (2009) to measure family-centered care using MPOC in disadvantaged South African settings, MPOC-20 becomes invalid and unreliable. The study increases the items to twenty-two. The additional two items were used to assess the positive correlation between the subscales and satisfactions. However, after doing the factor analysis, only eight items(MPOC-8 (SA)) were used to measure family centered care (34).

2.4. Subscales of MPOC

The measure of the process of care mainly evaluates the care given for children might be family-centered care. For providing better services for children with any health condition at health institutions, health professions should know more about the family's socioeconomic and cultural habits and inform the activity of care they receive.

Initially, the seven domains were used as the basis of item generation for the MPOC was identified to address the specific behavior of caregivers and evaluate parents' perception. The highest-ranked components, or 'domains', included parent involvement, education/information, treatment of disability, accessible and available care, continuity and consistency of care, coordination of care, and family-centered approach to care(1,7).

The study conducted in Malay, to assess Malay version MPOC-20 the original five factors items by combining and rearranging the questionnaire reduced the to four factors. Different from original MPOC version, Malay version combines factor 1 and 4 (enabling and partnership and coordinated comprehensive care) factors in one. Most of the rearranged items were loaded strongly ranged from 0.6-0.8, except for two items with an acceptable loading factor of 0.46 and 0.48 (22).

The calculated Cronbach's alpha for each of the MPOC-NL five scales reveals to have adequate internal consistency for each scale, ranging from 0.80 ('providing specific information about the child') to 0.95 ('Enabling and partnership' and 'Co-ordinated and comprehensive care for child and family'). The internal consistency analyses also supported the construct validity of the five scales (11).

The final factor solution resulted in 56 items being retained with five scale conceptual structures that reflect the essential features of family-centered service. Those five subscales are enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care, and respectful and supportive care. Finally, with the same five subscales, the MPOC items refined to 20 to avoid participant burden and for its non-time consuming benefit (1,7,23).

3. OBJECTIVES

3.1. General objective

- To validate and test the reliability of the Amharic version of the measure of the process of care (MPOC-20) for measuring parental perception among parents of children with chronic disease in TASH, Addis Ababa, Ethiopia, 2021.

3.2. Specific objectives were:

- To examine the validity of the Amharic version of the measure of the process of care (MPOC-20).
- To test the reliability of the Amharic version of the measure of the process of care (MPOC-20).

4. METHODS AND MATERIALS

4.1. Study area and period

The study was conducted in Tikur Anbesa specialized hospital pediatrics units for one month, from March 15 -April 15, 2021. Tikur Anbesa Specialized Hospital was one of the biggest university teaching and referral hospital established in 1972. Currently, it has 800 beds from these 58 beds in the pediatric ward. Totally 1240 clinical staffs were available; these 800 nurses were devoted to providing different health care services. Around 30 nurses are assigned to provide health service in the pediatric ward. It also has more than 950 administrative and contractual staff that supports the delivery of quality care. Annually 370000-400000 health customers were utilized from the health care service. The hospital gives rehabilitative, curative, and preventive services (Location and Ababa, 2016). Monthly HMIS report shows around 660 children were admitted in pediatric ward and 780 children visit pediatric follow up clinic for different childhood problems.

4.2. Study design

Institutional based cross-sectional study design was used since it was considered the most efficient way of testing and validating a measurement tool.

4.3. Source population

All parents of children with chronic disease in the pediatric ward and who had an appointment in a follow-up clinic were used as the source population.

4.4. Study population

Parents of the children with chronic disease who were admitted to the pediatric ward and visit the follow-up clinic during the data collection period were the study population.

4.5. Sample size determination

There was no general agreement among researchers to determine the sample size for factor analysis. Some authors recommend using the rule of thumb $N > 200$ were statistically enough for factor analysis(35). Others suggest 200 will be enough for measuring the scale having 40 items(36). According to Nunnaly's validating scale minimum of ten participants will be enough

to test the validity, or fewer than 300 samples will be sufficient(30,34). According to Hutcheson and Sofroniou, a sample size of 150 to 300 is sufficient for principal components analysis to perform factor analysis. Commonly participant to item ratio is recommended about 5:1 to 10:1. Despite these variations, Kahn suggests a minimum sample size of 300 to be confident of the results. A rough rating scale for adequate sample size in factor analysis has been offered in which 100=poor, 200=fair, 300=good, 500=very good, and 1000 or above =excellent(36). Based on the above suggestions, 300 participants were recruited and 20% dropout rate was considered because factor analysis highly depends on amount of sample size that increase in samples increase the reliability and validity of the tool to generalize for study population. So a total of 360 were recruited as study participants under consideration of time limitation and budget shortage.

4.6. Inclusion criteria and exclusion criteria

4.6.1. Inclusion criteria

- Those parents of children with chronic disease

4.6.2. Exclusion criteria

- Parents who had no willingness to participate
- Those parents who did not speak and listen to Amharic

4.7. Sampling technique

Study participants were selected using Stratified random sampling technique. Initially HMIS record sheet was reviewed for monthly patient flow and 1440 cases were reported, from which 660 children with chronic disease were registered in pediatric ward and 780 children were in follow up clinics. The total sample size was proportionally allocated in to each unit based on the monthly patient flow data that has been obtained from the HMIS registration book from each unit. After allocation, samples were taken consecutively to collect data.

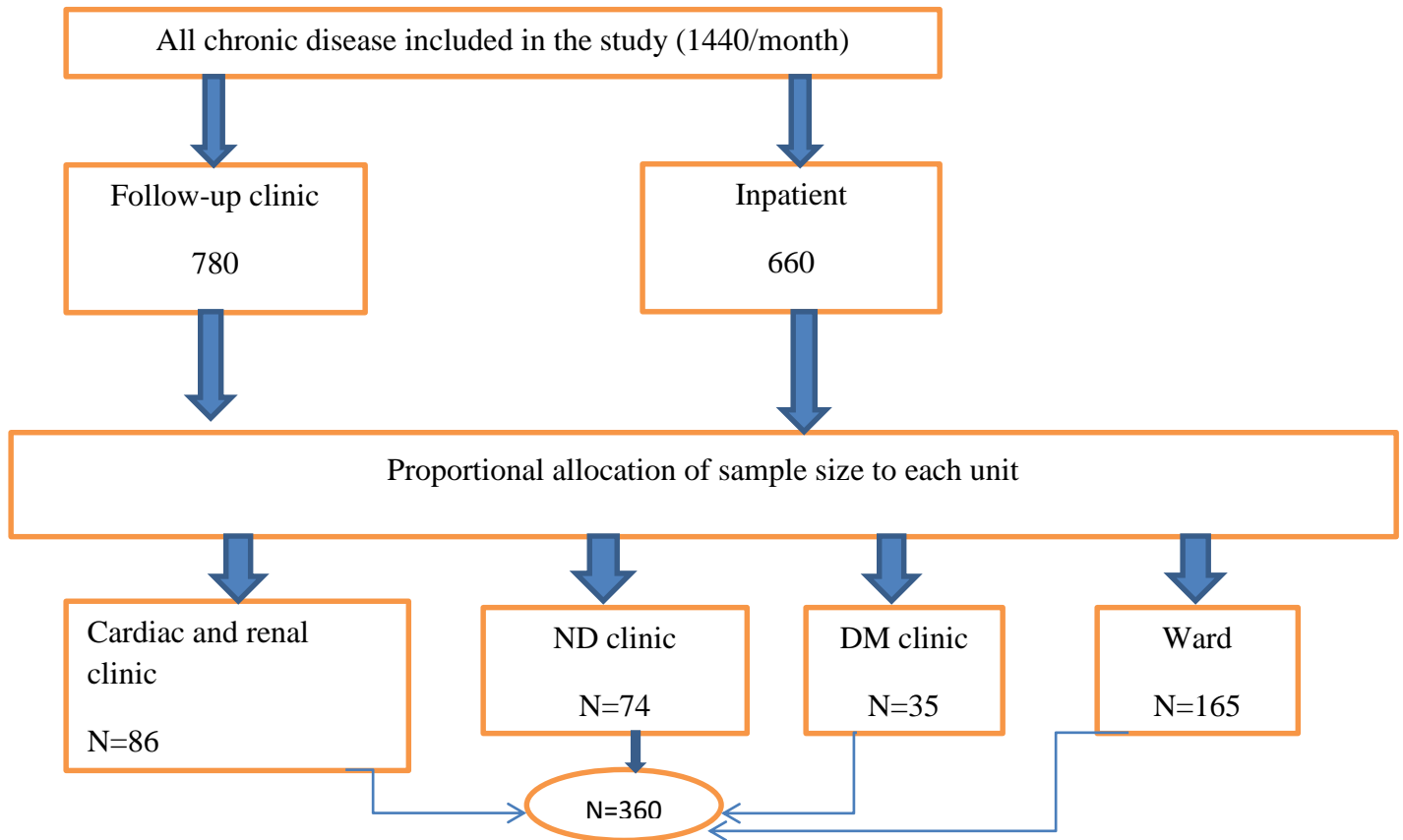


Figure 1 Schematic presentation of sampling procedure for measure of process of care among parents of children with chronic diseases at Tikure Anbessa Specialized Hospital Addis Ababa, Ethiopia, 2021

4.8. Instrument

The instrument was the Measure of Processes of Care questionnaire with 20-items, a shorter and improved version of the original 56-item MPOC questionnaire. The Can child Centre for Childhood Disability Research developed the questionnaire to assess the parental perception of care. The instrument was designed to assess the essential features of family-centered services. A 7-point Likert scale was used to capture the response; in which 1 is the lowest score which means 'not at all' to 7 is the highest score which indicates 'to a very great extent'. A score of 0 is to indicate 'non-applicable items'. The reliability of the MPOC-20 was assessed by calculating Cronbach's alpha for a minimum value of .70 for acceptability(30,31). For validity, the item loading under the factors should expect to the minimum value of 0.3. The original English version MPOC-20 was translated into the Amharic language by experts translating English to Amharic. The translated Amharic version of the questionnaire was then back-translated into English by individuals who use English as a second language and excellent Amharic speakers.

Then, these backward translations were cross-checked with the original English version. Those translators were individuals who know the health care system very well. Errors if any to the Amharic version of the MPOC-20 tool was corrected by discussing it with the translating team. Finally, the translated questionnaire was tested independently in a pilot sample of individuals who speaks Amharic to clarify and comprehend the contents.

4.9. Data collection process

A total of three BSC nurses and one supervisor have participated in data collection. Interview based data collection process was applied based on a structured questionnaire. The questionnaire was composed of socio-demographic characteristics and the MPOC tool questions. Two days of training were given for data collectors about the research objectives, data collection tool and techniques, ethical considerations, confidentiality, how to explain the purpose of the study, and take informed consent was before they proceed to data collection.

4.10. Data quality and control

Before determining the construct validity and internal consistency reliability, The English version of MPOC-20 was translated into the Amharic language. The pretest was conducted among 10% of the total sample size. The completeness, readability, and any error of the questionnaire were checked, and modification was made. Before data collection, codes for each questionnaire were given. After data collection, the supervisor and the principal investigator were checked the completeness of data and offer back to data collectors for incomplete data. The principal investigator checked the complete entry of data before analysis.

4.11. Operational definition

Acceptable tools- the tools are said to be acceptable if the response rate is more than 70%(37).

Communality - is a shared variance among the items. If all correlation coefficients between subscales and items of MPOC scales greater than 0.3 are considered acceptable(38).

Face validity- is supported if the questions are not confusing, upsetting, and do not contain complex vocabulary, and difficult to answer after the pretest(28).

Reliability- is assumed to be fulfilled if the calculated Cronbach's alpha coefficient is greater than 0.70(28,38).

Chronic disease- is a disease that persists and lasts for three months or more. (*US. National Center for Health Statistics*)

CHD- is the defect in the structure of the heart great vessels that present at birth and have any evidence of heart lesion on Echo(39).

NDD- is a group of disorders that affect the development of the nervous system, leading to abnormal brain function, which may affect emotion, learning ability, speech, self-control, and memory(39).

CKD- kidney damage for \geq three months, as defined by structural or functional abnormality of the kidney, with or without decreased GFR manifested by an abnormality in the composition of the blood or urine and abnormality in an imaging test(39).

RHD- is the chronic heart disease that occurs after the immunologic reaction with sequelae of group A beta-hemolytic streptococcal infections of the upper respiratory tract and rheumatic involvement of valves and endocardium(39).

T1DM- is characterized by hyperglycemia and glycosuria is caused by autoimmune destruction of the insulin-producing beta cells (islets) of the pancreas leading to permanent insulin deficiency(39).

4.12.Data analysis

Factor analysis was used to assess whether the Amharic version of MPOC-20 items retain its structural validity or reduce number of the items in its scales among parents of children with chronic disease. Principal axis factoring was used to extract the number of factors. To clean the data multi-collinearity, singularity and corrected item to total correlation value were observed. To determine the factorability and adequacy of data for EFA, Kaiser-Meyer-Olkin (KMO), anti-image correlation (MSA), was used and a value of more than 0.50 has been accepted and Bartlett's sphericity test ($p < 0.001$) was performed to confirm patterns of the data(38). Factors with an eigenvalue > 1 and commonality > 0.30 have been extracted. A factor loading (FL) greater than 0.30 had valuable contribution for the factor(38). To determine the internal consistency of the MPOC-20, Cronbach's alpha values were computed for each factors. Descriptive statistics (text frequency tables, percentage, mean, SD) were used to report socio-

demographic characteristics and medical characteristics. Epi data V4.6 was used to enter data and exploratory factor analysis was done using SPSS version 25.0. SPSS AMOS V24 did confirmatory factor analysis.

4.13. Ethical considerations

Ethical clearance and approval letter were obtained from the Institutional Review Board (IRB) of the College of Health Sciences of Addis Ababa University. A formal letter from the Department of Nursing and Midwifery was submitted to TASH research and community service office to obtain their co-operation. A formal letter from the pediatrics and child health department of TASH was distributed for each of the pediatric units. Informed consent was taken from the participants in written form/orally for those who cannot read or write after the aim and significance of the study explained fully to each parent before collecting the data. If the parent agrees to participate, informed consent was taken. The rights to refuse to be interviewed, to ask any unclear question, or withdraw at any particular point during the data collection process without frustration were explained for study participants. Those who had not willing to participate were given the right to do so.

5. RESULT

5.1. Socio-demographic characteristics related to the families

From the total of 360 eligible samples, about 334 (93%) parents of children have participated in this study. Most of them were mothers, which account for 250(74.9%), followed by fathers 75(22.5%). The age of parents who participated in this study ranged from 20-65, with a mean (\pm SD) of 31 (\pm 5) years. The educational level of most of the parents was the secondary school which accounts for 153 (45.8%) followed by higher education 98(29.3%). Related to the parents' marital status, around 320(95.8%) were married, followed by divorced parents 5(1.5%). The majority of respondents were housewives mothers, which constitute 182(54.5%), followed by merchants 76(22.8%). Most parents had two children at home, which accounts for 164(49%) (Table1).

Table 1 Socio-demographic characteristics of study participants (N=334), family variables

Variables	Category	Frequency	Percent
Parental relationship to the child	Mother	250	74.9
	Father	75	22.5
	Others	9	2.7
Occupation	Housewife	182	54.5
	Farmer	10	2
	Merchant	76	22.8
	Government employee	52	15.6
	Others	14	4.2
Marital status	Married	320	95.8
	Unmarried	3	.9
	Others	11	3.3
Educational level	Illiterate	1	.3
	Read and write	10	3
	Primary school	72	21.6
	Secondary school	153	45.8

	Higher education	98	29.3
Number of children at home	1	164	49.1
	2	92	27.5
	3	56	16.8
	>4	22	6.6

5.2. Socio-demographic characteristics related to the children

The age of children whose parents participated in this study was ranged from 1 to 17 years, with the mean (\pm SD) of 4(\pm 3) years. The majority of parent's children who have the chronic disease were 177(53%) and 157(47%) for females and males, respectively. Lots of chronic diseases including congenital heart defect 102(30.5%), neurodevelopmental disorder 44(13.2%), chronic kidney disease 27(8.1%), were diagnosed (Table 2).

Table 2 Summarized clinical characteristics of children with chronic disease in TASH, 2021 (N=334)

Confirmed diagnosis	Frequency	Percent
CHD	102	30.5
neurodevelopmental disorder	44	13.2
CKD	27	8.1
Cerebral palsy	26	7.8
Seizure disorder	23	6.9
HSD	18	5.4
Typy1DM	17	5.1
Down's syndrome	14	4.1
Others	63	18.9
Total	334	100

For these diseases, most parents admit their children to receive care for second visit 81(24.3%) followed by third visit 53(16%) visit chronic pediatrics disease follow up clinic four round 59(17.7%), followed by more than four round 42(12.5%).

Hospital stay time		Frequency	Percentage
Follow up clinic	Second visit	81	24.3
	Third visit	53	16
	fourth visit	37	11
	>4 th visit	10	3
Pediatrics ward	Two weeks	41	12.3
	Three weeks	59	17.7
	Four weeks	11	3.3
	>4weeks	42	12.5
	Total	334	100

5.3. Reliability

Cronbach's alpha coefficient was calculated to determine the internal consistency of the Amharic version MPOC-20. The overall reliability of the Amharic version of MPOC-20 was 0.853. Based on reliability item statistics, five items had low corrected item to total correlation value and eliminated before extraction. Those items were; item 2 "Provide you with written information about what your child is doing in therapy?"(0.05), item 14 "Provide you with written information about your child's progress?"(0.79), item 15 "Tell you about the results from the assessment?" (0.135), item 19 "Have information available to you in various forms, such as a booklet, kit, video, etc?" (0.79) and item 20 "Provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?" had negative correlation value (-0.67).

However, after removal of the above five items (2, 14, 15, 19 and 20), the reliability shows a slight increment. About 88.5% of the Amharic version of the MPOC-15 items among children with chronic disease was highly reliable or internally consistent.

Reliability for each subscale was computed, and all of the subscales have a good to high Cronbach's alpha value which ranges from 0.75 to 0.84. Each of the items has a high Cronbach's alpha if the item is deleted.

Table 3 Reliability of MPOC among parents of children with chronic disease in Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2021 (number of items=15)

No. of items	of Items	Cronbach's alpha if item deleted
1	Help you to feel competent as a parent?	.882
2	Provide a caring atmosphere rather than just give you information?	.871
3	Let you choose when to receive information and the type of information you want?	.870
4	Look at the needs of your “whole” child (e.g., at mental, emotional and social needs) instead of just at physical needs?	.889
5	Make sure that at least one team member is someone who works with you and your family over a long period?	.876
6	Fully explain treatment choices to you?	.880
7	Provide opportunities for you to make decisions about treatment?	.879
8	Provide enough time to talk so you don't feel rushed?	.876
9	Plan together so they are all working in the same direction?	.873
10	Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as “Mom” or “Dad”)?	.876
11	Give you information about your child that is consistent from person to person?	.876
12	Treat you as an individual rather than as a “typical” parent of a child with a disability?	.882
13	Give you information about the types of services offered at the organization or in your community?	.877
14	Have information available about your child's disability (e.g., its causes, how it progresses, and future outlook)?	.881
15	Provide opportunities for the entire family to obtain information?	.871

Table 4 shows the reliability of each subscale Amharic version MPOC-15 items among children with chronic disease in TASH, 2021 (N=334)

Factor	Number of items	Mean±SD	Cronbach's alpha
Enabling, partnership, coordinated and comprehensive care	7	38.69 ±5.32	.84
Providing information and respective care	6	31.39 ±5.27	.75
Supportive care	2	9.14 ±1.84	.78

5.4. Exploratory factor analysis

a. Construct validity

Construct validity of Amharic version measure of the process of care (MPOC-Am) was determined by using exploratory factor analysis and CFA. Twenty items of the MPOC were subjected to do factoring analysis by using IBM SPSS statistics version 25. An EFA was performed with principal axis factoring. The suitability of data for factor analysis was assessed by referring to the communality, KMO of the overall and individual items for sample adequacy, and Bartlett's test of sphericity before undergoing PAF for factor extraction. Items were cleaned by using KMO, multi-collinearity, singularity and on reliability of corrected item to total correlation value and Cronbach's alpha if item deleted value.

The communality of the scale, which indicates the amount of shared variance with other items with a value greater than 0.3 were accepted for factor extraction. Kaiser Meyer-Olkin (KMO) of the data was assessed to measure the sample adequacy, and it should be above the recommended value of KMO >0.5(37,38). This study has a good KMO value of 0.88. This value indicates that the sample was adequate to perform factor analysis. Bartlett's test of sphericity was observed to measure the overall correlation among the items within the correlation matrix; statistically, the p-value should be <0.05(37). The data has a significant value with ($\chi^2=2766.583$, $df= 190$, $p <0.001$). This value indicates that doing factor analysis was appropriate.

Individual items KMO value was checked by observing the diagonal anti-image correlation matrix to measure sample adequacy. For the individual items, on the anti-image correlation matrix, item 2 (“Provide you with written information about what your child is doing in therapy?”) has a value less than the recommended value of 0.5(38), which was 0.4. Reproduced correlations were computed between the observed and reduced correlation to assess the model fitness for EFA. Only 26(13%) non-redundant residuals were with absolute values greater than 0.05. This value indicates good according to the minimum acceptable percentage for residual value (50%) (38). From the initial EFA, item2 (“Provide you with written information about what your child is doing in therapy?”) has the poor corrected item to total correlation value and low individual item anti-image KMO value. Due to this reason item was eliminated before the following analysis.

The second EFA was performed with 19 items; KMO for the individual item for sample adequacy was checked. As a rule, all individual item KMO values must be greater than 0.5 before factor rotation(37). The result shows item 15, "Tell you about the results from the assessment?" has a KMO of 0.48 (38). When all 20 items factor rotation was done, the item retained as a single item for the factor and had negative Cronbach’s alpha value with its grouped item. This item was also eliminated before factor extraction.

For retaining the number of factors, Kaiser’s criteria (eigenvalue >1) and scree plot test diagram were checked. Based on Kaiser's criterion of retaining factors, eigenvalues that are greater than one considered a factor (29,35,37). The PAF extracted value shows three factors eigenvalue above one, explaining 47% of the total variance. The first factor explains the highest value (37%) of variance, followed by 6%, and 3.5%, of the variance for each factor. The Scree plot test was ambiguous; however, it seems to recommend two or three factors to retain as shown below (Figure 1).

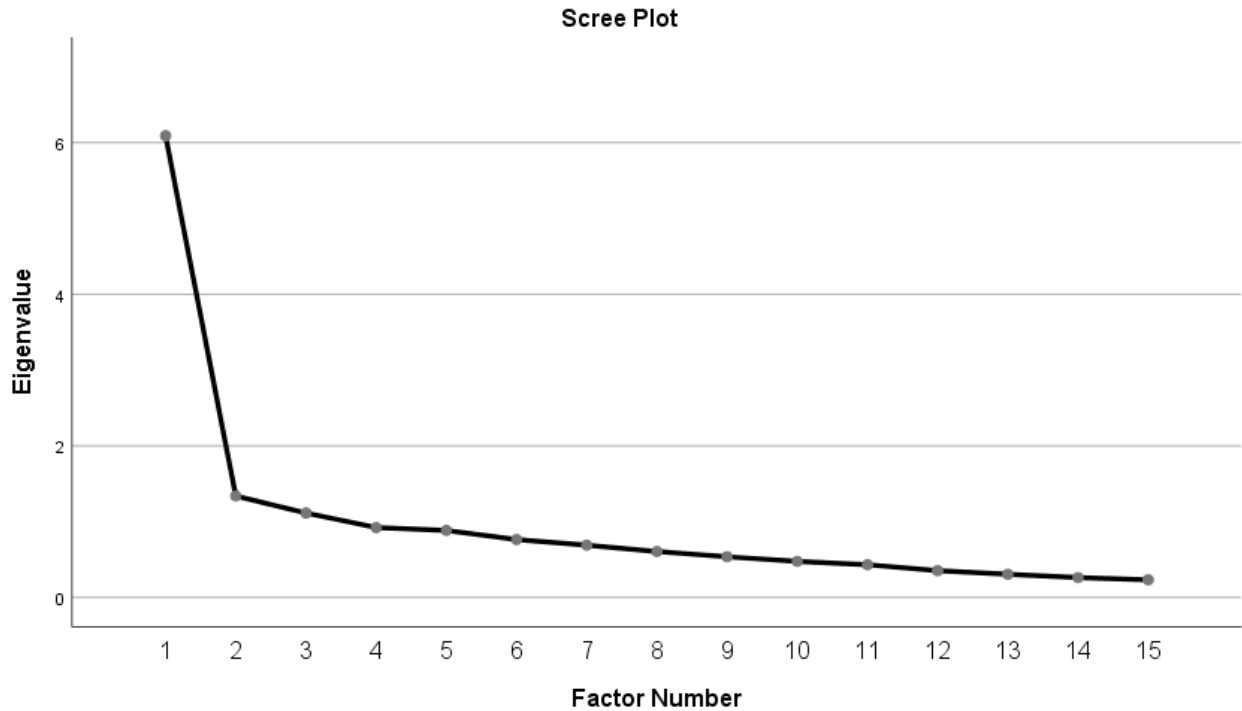


Figure 2 Diagrammatic illustration of the number of the extracted factor

Factor rotation was performed to optimize the factor structure and ease its interpretability. When oblique rotation (direct oblimin) was requested, the correlation between the factor becomes lower (<0.3), and many items were loaded under the first factor. Then orthogonal rotation method (varimax) was used to minimize the number of items with extreme loading(37). Each of the items was significantly loaded under the corresponding factors. The items were settled at each factor with a significant loading, ranging from 0.32 and 0.76. Seven from the 15 items have cross-loading among the factor. During such cases, items were counted under having the more loaded value within the factor. Exploratory factor analysis with varimax rotation revealed three significant factors accounting for 47% of the total variance.

Before rotation, the first factor explains more variance than the remaining five factors, 37% of the total variance, compared to 6%, and 3.5% of the variance for each consecutive factor. This variation indicates, most of the items were loaded under the first factor. Interpretation for a suchlike arrangement of items under a single factor was difficult(37,38,40). After rotation, only 21% of the variance for the first factor compared to 13%, and 13%, of the second and third factors. Here items were loaded and have a suitable rearrangement under each factor and easy for interpretation.

Table 5 Exploratory factor analysis factor loading of MPOC-15 item among children with chronic disease in TASH, 2021 (N=334)

Variables	FACTORS		
	EPCCC	PIR	SC
Fully explain treatment choices to you?	.610	.237	-.030
Plan together so they are all working in the same direction?	.610	.174	.491
Provide opportunities for the entire family to obtain information?	.60	.443	.220
Provide opportunities for you to make decisions about treatment?	.594	.287	.093
Provide enough time to talk so you don't feel rushed?	.579	.180	.350
Give you information about your child that is consistent from person to person?	.548	.324	.222
Make sure that at least one team member is someone who works with you and your family over a long period?	.544	.358	.202
Give you information about the types of services offered at the organization or in your community?	.267	.619	.148
Provide a caring atmosphere rather than just give you information?	.288	.552	.397
Look at the needs of your "whole" child (e.g., at mental, emotional and social needs) instead of just at physical needs?	.107	.525	.051
Let you choose when to receive information and the type of information you want?	.394	.454	.432
Have information available about your child's disability (e.g., its causes, how it progresses, and future outlook)?	.200	.385	.155
Help you to feel competent as a parent?	.263	.321	.157
Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	.180	.295	.760
Treat you as an individual rather than as a typical parent of a child with a disability?	.088	.155	.752

NB: - EPCCC (enabling, partnership, coordinated and comprehensive care); PIR (providing information and respective care); SC (supportive care)

Items were ordered and sorted by the size of loading to ease the interpretation. Loading value below 0.3 has no substantive significance for the factor. As table 3 shows, seven items were significantly loaded in the first factor, six items loaded in the second factor, two items under the third, and three items were significantly loaded in the fourth factor. Loading of each item on a factor reflects the homogeneity of items on MPOC.

In all, the four factors of MPOC were named for this study population. The names of the factors were adopted from the original MPOC factor names and previous literature. The combined name was given based on the highly loaded items under the factor compared to the original MPOC-20 items to factor combination for this study. For instance, the first factor was named enabling, partnership, coordinated, and comprehensive care; because most of enabling and coordinated care items from original MPOC factor were loaded significantly under factor one (0.544-0.611).

Factor two named providing information and respect; in which the six items have substantive loading value (0.321-0.619). Two items were loaded under factor three named supportive care (0.760, 0.752).

5.5. CFA model fitness

Confirmatory factor analysis was done for four factors with 15 items. SPSS Amos V24 was used for confirmatory factor analysis (CFA) to decide model fitness of the three-factor structure MPOC-15 for the study population. Fundamental statistics values; chi-square to the degree of freedom (χ^2/d_f), root means square error of approximation (RMSEA), comparative fit index (CFA), standardized root mean squared residual (SRMR), and p-value indices (37) were determined to evaluate the goodness of fitness model for the four-factor structure of MPOC-15 for 334 sample size. Based on the value of model fitness measuring indices, all suggests MPOC-15 has an acceptable CFA model fit (Table 6).

Table 6 shows the value of goodness fit indices of three-factor structures model of the Amharic version MPOC-15 among children with chronic disease in TASH, 2021 (N=334)

Measurement indices	Three-factor model	Remark
X ² /df (CMIN/DF)	367.855/124=3.05 (between 1&3	Acceptable
CFI	0.915	Acceptable
SRMR	0.057 (<0.08)	Excellent
RMSEA	0.079 (>0.06) 90%CI (0.068-0.086)	Acceptable
P-value	0.000	Not estimated

Correlation between the factor score of each construct has a positive relationship to one another. Every item to the construct was correlated significantly at ≥ 0.5 except for three items (shown in the diagram below). In this study, removing those items cannot improve the fitness and kept due to its theoretical significance. Each of the item shows to had a good construct correlation with its factor and indicates a validity of the Amharic version of MPOC-15 for the study population. Each factor had best positive relationship with other factor, correlation coefficient value of 0.58, 0.68 and 0.79.. (Figure 3)

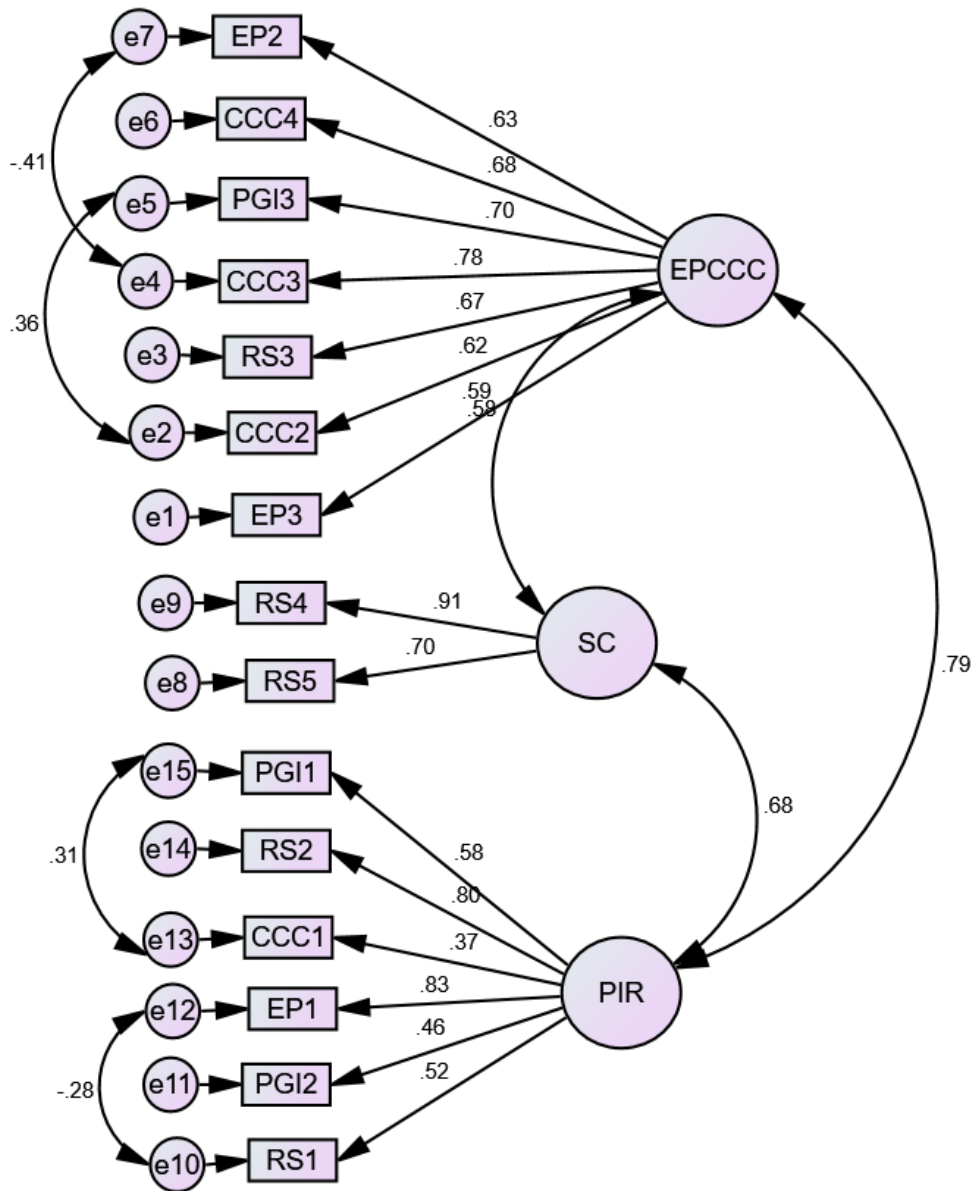


Figure 3 CFA diagrammatic illustration of three-factor structure of the Amharic version MPOC-15 among children with chronic disease in TASH, 2021.

6. DISCUSSION

MPOC was used to assess family-centered care in children with different disease conditions. The validity and the reliability of the original MPOC were developed to measure the family-centeredness of health care services among children with neurodevelopmental disabilities. It is essential to demonstrate validity and reliability of the tool among different languages, culture and disease conditions with the expectation of a similar outcome. In this study, the validity and reliability of the Amharic version of MPOC-20 among parents of children with different chronic diseases were investigated.

Although the original MPOC-20 was psychometrically good for Canadian, Netherlands, Japanese, Malay, Slovene, Korean versions, the Amharic version MPOC-20 was modified to the new MPOC-15 (Am) version. Having different factor structure may use to summarize the consistency of instrument in different new situations(41). Items eliminated from the MPOC (Am) were based on statistical evidence and theoretical background. The finding of this study was reliable and explored a four-factor matrix for this study population.

Removed items were related to providing specific information about the children in the original MPOC-20. The parents did not get information about the assessment result and have no written information about the therapy given for their children. Providing information about the assessment result for the parent and therapy given for their children is not common in Ethiopia. Due to this reason, parents may not expect this from health providers. According to family centered care principle, information from health professional had valuable benefit to maximize the quality of care(3,21,32). Similar finding(24,41), indicates health professional should focus on providing both general and specific information and parents need written information to decide on treatment choices effectively. Residential area and educational status the parent also have impact to communicate openly and receive information from health professional as well, the idea also discussed in related study done from other countries(1,21,24,34).

Family-centered care measuring factors of MPOC-15, the first domain reveals that the health care professionals give information and engage them to plan together about treatment. Health care workers were collaborative and encouraged them to decide on the treatment modalities. The second domain mainly indicates that the health professionals were good to give directions for additional available information related to the disease beyond the care they received in hospital.

Though age of children was challenging to know the emotional and mental needs, parents ensure health workers provide good mental, emotional and social needs for this study population. They provide holistic care that includes information related the disease's progress and look for the child's psychological needs. Similarly, studies (1,24)suggest that professional should give attention on needs based on the age of the children. This implies that if there were coordinated care and enabling the parent to have a role on their children, the mutual respect between the users would be maintained.

The supportive care domain claims that health professionals look at parents as equal to their children. They treat as individuals and give support for their unique needs. This indicates a good motivation among the professionals to support and respect the parent. This study result had similar description to the study done in Canada to assess structural validity of MPOC among epileptic children(33).

The reliability (Cronbach's alpha) of 15 items Amharic version MPOC was found to be 0.88, which was high and shows that the Amharic version MPOC is reliable for assessing family-centered care among children with chronic disease. Each subscale of MPOC has good internal consistency, ranging from .75 for providing general information subscale to .84 enabling, partnership, coordinated, and comprehensive care subscale. This result has similarity to the four-factor Malay version MPOC-20, which has Cronbach's alpha ranges from 0.75 to 0.9(22) for four-factor structure and better consistency related to five scale Norweigan MPOC-20, which range from 0.62- 0.93(12) and less consistent as compared to Slovene translation MPOC-20 (.83-.90)(13). Each item has a similar Cronbach's alpha to the overall internal consistency value, ranging from .85 to .87. This value statistically supports the construct validity of MPOC-15.

In this study, the exploratory factor analysis suggests selected items for factor rotation were loaded with three factors. The number of retained factor for Amharic version MPOC-20 were similar to the Malay version of MPOC-20 but had differences in the number of items and their distribution. In most studies, the use of MPOC-20 was to measure family-centered care among the children with neurodevelopmental disabilities that need a long time regular therapy at a rehabilitation center(10–14,22). However, for this study, childhood chronic disease was used, in which parents come to the hospital periodically or when the children experience some unusual health conditions. For these neither progressive nor curative diseases, parents spend a short time to receive care. These suggest having a difference in the provision of care and perception about the care among parents.

EFA construct validity of the Amharic version of MPOC-15 was acceptable for three-factor scales. Each scale has a good to high correlation coefficient; this indicates items were highly related to its scale. Even though, there was a difference in the number of items and factor structure from the original MPOC-20, confirmatory factor analysis was done to ensure whether the EFA three-factor measurement is appropriate for the study population. CFA reveals that each item has acceptable loading with its factor. All factors had a good inter-factor correlation and measured similar concepts, except providing general information domains had a poor correlation with other factors. This correlation indicates that still provision of information from the health professional and parent-professional communication needs improvement.

7. CONCLUSION

As other studies extreme caution has to be taken for examining validity of the Amharic version MPOC (20). This study shows that 15 items of MPOC was valid and reliable. This modified version MPOC-15 had good psychometric measure to evaluate family-centered care in the Amharic language among parents of children with chronic disease.

8. RECOMMENDATION

Efforts need to be made from program managers to have more measurement tools in health facilities for measuring family-centered care. Since MPOC items were used to measure parental perception about the care, other tools also need to be validated to measure parental satisfaction.

The original MPOC was used for children with neurodevelopmental disorders in rehabilitation center, other studies test MPOC validity among children with chronic disease, and also some studies use specific disease like epilepsy, cerebral palsy. In this study, parents of children with any of chronic diseases including neurodevelopmental disorders were used to collect data. This might have an effect to differ the responses of parents. For further study it's better to use modified MPOC-15 for specific diseases to have similar response and better psychometric measure of parental perception about the care.

MPOC-15 was an easy instrument, however; researcher should take caution while asking the questions and words used to capture information from caregivers for further study and it's better to test stability of the tool over a while. And also health professional should give attention to use MPOC-15 for evaluating family centered care.

9. LIMITATION

MPOC was only tool used to measure the perception of the parent towards to care; information related to the parental satisfaction was not collected. Using of many diseases for this may affect the overall opinion of the parent, in which parents have different expectation along with the diseases. Test retest reliability was not conducted because most of parents were not available/visit follow up clinic for more than once within one month. Socio-demographic characteristics of this study were not discussed with the MPOC items. It's because of time limitation.

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APPENDICES

APPENDIX I: PARTICIPANT INFORMATION SHEET

Greeting: Good morning/afternoon my name is _____ I am working on behalf of research conducted by Abdulsemed Shafi student of Addis Ababa University, College of health science, school of nursing and midwifery. I would like to ask a few questions which take around 15-20 minutes. The genuine responses that you are going to give are very important to evaluate the care provided by health professionals is family centered or not. You are selected to be a participant of this study if you give me consent after you have understood the following information sheet:

The title of the study is validation of Amharic version of measure of process of care-20 (MPOC (AM)-20) among parents of children with chronic disease in Tikur Anbesa specialized hospital, Addis Ababa, Ethiopia, 2021.

The objective of the study is to examine the validity and reliability of the Amharic version of measure of process of care-20 (MPOC-20).

Benefit of the study: If you participate in this research, there may not be direct benefit to you and your child, but your participation is likely to help us in assessing the validity and reliability of the process of care among childhood health problems. Ultimately this will help us to identify the gap and take the appropriate intervention by the authorized stakeholder .you will not be provided any incentive or payment to take part in this study.

Risk of the study: If you participate in this research it has no risk for the participants, and the interview will be private to make safe participants from any fear.

Rights of participants: In this study, the participants have full rights to refuse the participation, and can ask any question which is not clear to you. You have right to unanswered any questions that you do not want to answer, and you may end this interview at any time you want to.

Confidentiality: Any information forwarded will be kept private and your name will not be specified.

APPENDIX II: CONSENT FORM

I have read this form, or it has been read to me in the language I comprehend and understand all conditions stated above.

Do you have any question? If, no

Are you willing to participate in this study?

1. No (Say Thank you)

2. Yes participant's signature _____

Continue your interview I certify that the nature and purpose, the potential benefits and possible risks associated with participating in this study have been explained to the volunteer.

Date _____ Starting time _____

end _____ Signature of the interviewer _____

Result of the interview:

1. Completed
2. Respondent not available
3. Refused
4. Partially completed

Checked by supervisor, name _____ Signature _____ Date _____

APPENDIX III: ENGLISH VERSION QUESTIONNAIRE

MEASURE OF PROCESSES OF CARE QUESTIONNAIRE (MPOC-20)

We want to understand and measure the feelings and experiences of parents who have a child with chronic disease, like diabetes mellitus. We are especially interested in knowing about your perceptions and your view of the care and service you have received during your hospital stay.

There are questions we would like to ask you. These questions are based on what parents, like you have told us about the way that the care and service is given. We are interested in your own personal thoughts and would be thankful if you would answer these questions. There is no right or wrong answer. It is important that you feel free to answer the questions as honestly as possible.

For each question, you need to tell us to what extent you have experienced the events or the situations described. A score of 7 means that you have experienced this aspect to a very great extent, or most of the time. A score of 1 means that you have not experienced this aspect at all. In other words, the higher the score, the more you have experienced this situation or this aspect of the service. A score of 0 means that the question does not apply to you.

In the questions, the word people mean those persons who work directly with you or with your child when you come for therapy. It may include the physiotherapists, the occupational therapists, speech therapists, social workers, doctors, nurses, etc.

The following sentence is an example of the kinds of questions you will be asked. This example also shows what your answer could mean.

To what extent did the person who gave you this questionnaire ...

..... explain to you why they want you to take part in this study To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
7	6	5	4	3	2	1	0

A score of 7 means that the person who gave you this questionnaire explained everything very clearly and very well and you understand exactly why you are taking part in the study

A score of 4 means that person who gave you this questionnaire explained some things clearly, but there are some things you are not clear about. A score of 1 means that the person did not explain anything to you at all and you know nothing at all about this study. A score of 0 means that you never received any questionnaire and so you cannot answer the question. The question does not apply to you.

During your hospital stay, to what extent do the people who work with your child	Indicate how much this aspect or situation happens to you							
Help you to feel competent as a parent?	7	6	5	4	3	2	1	0
Provide you with written information about what your child is doing in therapy?	7	6	5	4	3	2	1	0
Provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0
Let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
Look at the needs of your “whole” child (e.g., at mental, emotional and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
Make sure that at least one team member is someone who works with you and your family over a long period?	7	6	5	4	3	2	1	0
Fully explain treatment choices to you?	7	6	5	4	3	2	1	0
Provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
Provide enough time to talk so you don’t feel rushed?	7	6	5	4	3	2	1	0
Plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you a ‘Mom’ or ‘Dad’)	7	6	5	4	3	2	1	0
Give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0

Treat you as an individual rather than as a “typical” parent of a child with a disability?	7	6	5	4	3	2	1	0
Provide you with written information about your child’s progress?	7	6	5	4	3	2	1	0
Tell you about the results from the assessment?	7	6	5	4	3	2	1	0
Give you information about the types of services offered at the organization or in your community?	7	6	5	4	3	2	1	0
Have information available about your child’s disability (e.g., its causes, how it progresses, and future outlook)?	7	6	5	4	3	2	1	0
Provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
Have information available to you in various forms, such as a booklet, kit, video, etc?	7	6	5	4	3	2	1	0
Provide advice on how to get information or to contact other parents (e.g., organization’s parent resource library)?	7	6	5	4	3	2	1	0

SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. Child-related variables

1.	Age in month	
2.	Sex	Male
		Female
3.	Length of stay in pediatric ward	Two week
		Three week
		More_____
4.	No visit in pediatric follow up clinic	Two
		Three
		Four
		≥Five
5.	Diagnosis	Congenital heart disease
		Renal disorder (CKD)

		NDD
		DM
		If other, specify_____

2. Family-related variables

1.	Relationship to the child	Mother
		Father
		Sibling
		If other, specify_____
2.	Age of care giver	
3.	Marital status	Married
		Divorced
		Widowed
4.	Occupation	Housewife
		Merchant
		Farmer
		Gov. employee
		If other, specify_____
5.	Residential area	Addis Ababa
		Oromiya
		Amhara
		SNNPR
		Other, specify_____
6.	Level of education	No formal education
		Read and write
		Primary school
		Secondary school
		Higher education
7.	Number of children at home	

APPEDIX IV: AMHARIC TRANSLATED PARTICIPANT INFORMATION SHEET AND CONSENT FORM

የተሳታፊዎች መረጃ ቅጽ

መግቢያ

ጤና ይስጥልኝ ስሜእባላለሁ ዛሬ እዚህ የተገኘሁት በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ የነርቲንግ ናሚድዎዎደፈረ ት/ቤት ተማሪ የሆነው **አብድልሰሙድ ሻፊ** እያደረገ ያለውን ጥናት እሱን በመወከል ልጠይቅዎ ነው። መጠይቁም ከ15-20 ደቂቃ ይፈጃል። የጥናቱ ርዕስ MPOC-20 የሚባል የአማርኛ ትርጓሜው የህክምና አገልግሎት አሰጣጥ ሂደትን መለካት ሲሆን ቤተሰብን ያማከለ የአገልግሎት አሰጣጥን ለመገምገም የሚጠቅም መለኪያ/መጠይቅ ነው። ይህም በህፃናት ወላጆች ተግባራዊ የሚደረግ መጠይቅ ሲሆን እርሶም በጥናቱ ተሳታፊ ለመሆን ከተመረጡት መካከል በመሆንዎ የእርሶ ተሳትፎ አገልግሎቱን ለመለካትና ተማሪውንም የሁለተኛ (ማስትረስ) ዲግሪ ለማግኘት የሚያስች ልጥናት ነው።

የጥናቱ አላማ:- የ MPOC-20 የአማርኛ ትርጓሜ ተገቢነት እና ተአማኒነት በጥቁርነት በሳስቴሽናላይዝድ ሆስፒታል አዝጋሚ/ዘውታሪ የሆነ በሽታ ባለባቸው ህፃናት ወላጆች ማጥናት

ለተጠያቂው የሚሰጠው ጥቅም:- እርስዎ ቀጥታ የሚያገኙት የክፍያም ሆነ ሌላ ጥቅማጥቅም አይኖርም ነገርግን ተአማኒነት ያለው መጠይቅ ለማግኘት እና ክፍተቶችን በመለየት ከሚመለከተው አካል እርምጃ ለመውሰድ ይረዳል።

የሚያስከትለው ጉዳት:- መረጃ ሰብሳቢው ሲጠይቅ ምቹት ላይሰማዎ ይችላል ግን የርሶ ተሳትፎ በጣም ይጠቅመናል፤ የግልዎ ሚስጥር የተጠበቀ በመሆኑ ፍርሃት እንዳይሰማዎት።

የተሳትፎ ፈቃደኝነት:- ለመሳተፍም ሆነ ላለመሳተፍ ሙሉ መብት አሎት፣ መጠየቁን ጀምረው ከመሀል የማቆምም ሆነ ያልፈለጉትን ጥያቄ ያለመመለስ ሙሉ መብት አሎት።

ሚስጥራዊነቱ:- ይህ የሚሰጡን ግላዊ መረጃ ሚስጥራዊነቱ የተጠበቀ ነው። ይህ መረጃ በኮምፒውተር በሚስጥር የሚመዘገብ ሲሆን ስምዎት አይጠቀስም እና በምንም አይነት መንገድ ሊታወቅ አይችልም።

በኮምፒውተር ውስጥ ያለው መረጃ በሚስጥር ኮድ ታስሮ ይቀመጣል። የሚሰጡን ሁሉም መረጃ ከተባለለት ዓላማ ውጪ አይውልም።

ጥያቄ አለዎት? የሌላም ከሆነ

በጥናቱ ለመሳተፍ ዝግጁ ነዎት?

1. አይደለሁም (አመሰግናለሁ)
2. አዎአሳተፋለሁ (ፊርማ_____)

ሰለምርምሩ ተጨማሪ መረጃ ከፈለጉ ከታች የተጠቀሰውን ሰጪ ማናገር ይችላሉ።

የጥናት አድራጊው ስም፡- አብድልሰመድ ሻፊ

ስልክ ቁጥር፡- +2519167956873/+251921350005

የኢሜይል አድራሻ፡- shafiabdulsemed@gmail.com

የስምምነት ቅፅ

ከላይ የጥናቱ አላማ፣ ጥቅሙ፣ ጉዳቱ፣ እንዲሁም ሚስጥራዊነቱ በሚገባኝ እና በምረዳው ቋንቋ ተብራርቶልኛል። የጥናቱ ዓላማ ተረድቻለሁ። በጥናቱ ላይ ያለመሳተፍም ሆነ ከጀመርኩ በኋላ በፈለኩት ጊዜ አቋርጬ የመሄድ ሙሉ መብት እንዳለኝ አውቃለሁ። የጠየኩት ጥያቄ ሁሉ ተመልሶልኛል። በዚህ ጥናት ላይ ተሳትፎዬ ፈፅሞ በፍላጎት ላይ የተመሰረተ ነው።

የምላሽ ሰጪ

ፊርማ _____ ቀን _____

የጠያቂ

ስም _____ ቀን _____

የመጠይቅ መለያ ቁጥር _____

የጠየቁበት ቀን _____ የተጀመረበት ሰዓት _____ ያለቀበት ሰዓት _____

APPENDIX V: AMHARIC TRANSLATED QUESTIONNAIRE

1. የህክምና አገልግሎት አሰጣጥ ሂደት መለኪያ መጠይቅ

ዘውታሪ ወይም አዝጋሚ በሽታ ያለባቸው ህፃናት ወላጆች ያላቸውን ስሜት እና ልምድ መረዳትና መለካት እንፈልጋለን። ይህ መጠይቅ በተለይ ሆስፒታል በቆዩበት ጊዜ ስለተደረገልዎት እንክብካቤ እና አገልግሎት ያለዎትን ግንዛቤ እና ምልክታ ለማወቅ የተዘጋጀ መጠይቅ ነው። ልንጠይቅዎ የምንፈልጋቸው የተወሰኑ ጥያቄዎች አሉ። እነዚህ ጥያቄዎች እንደእርስዎ ያሉ ወላጆች እንክብካቤ እና አገልግሎት ስለሚሰጥበት መንገድ በሚነግሩን ላይ የተመሠረተ ነው። እርሶም የግልዎን ሀሳብ እንዲያካፍሉን እንፈልጋለን። ትክክለኛ ወይም የተሳሳተ መልስ የለም። በተቻለ መጠን ጥያቄዎቹን በሐቀኝነትና በነጻነት ይመልሱ። ለጥያቄዎች መልስ ስለሰጡ እናመሰግናለን።

ለእያንዳንዱ ጥያቄ እርስዎ ላይ የተከሰቱትን ክስተቶች ወይም ሁኔታዎች የተሰጡትን አገልግሎት በምን ያህል እንደተረዱ ይግለጹ። መጠይቁ ከ1-7 ያሉ የወጤት ደረጃዎችን የያዘ ሲሆን፤ 7 ማለት በጣም ብዙ በሆነ ጊዜ ወይም ብዙ ጊዜ ተደርጎሎታል እንደማለት ነው። 1 ማለት በጭራሽ አልተደረገሎትም እንደማለት ነው። በሌላ አገላለጽ ውጤቱ ከፍ ባለ መጠን አገልግሎቱን በበለጠ ሁኔታ አግኝተዋል ማለት ነው። 0 (ዜሮ) ማለት ጥያቄው እርስዎን አይመለከትም ማለት ነው።

በጥያቄዎቹ ውስጥ **ሰዎች** የሚለው ቃል ማለት ለህክምና ሲመጡ በቀጥታ ከእርስዎ ወይም ከልጅዎ ጋር አብረው የሚሰሩትን ሰዎች ማለት ነው። ከነዚህም ውስጥ ሐኪሞችን፣ ነርሶችን፣ እንዲሁም ሌሎች ድጋፍ ሰጪ ሰራተኞችን ሊያካትት ይችላል።

የሚከተለው ዓረፍተ ነገር ለሚጠየቁት ጥያቄዎች ምሳሌ ነው። ይህ ምሳሌ የእርስዎ መልስ ምን ማለት ሊሆን እንደሚችል ያሳያል።

ይህንን መጠይቅ የሰጠዎት ሰው እስከምን ድረስ

በዚህ ጥናት ውስጥ ለምን እንድትሳተፉ እንደተፈለገ አብራርቶሎታ?

በጣም ትልቅ በሆነ መጠን	በከፍተኛ ደረጃ	በጥሩ ደረጃ	በመጠኑ	በትንሽ መጠን	በጣም ትንሽ በሆነ መጠን	በፍፁም	ተፈጻሚ የማይሆን
7	6	5	4	3	2	1	0

የ 7 ውጤት ማለት ይህንን መጠይቅ የሰጠዎት ሰው ሁሉንም ነገር በደንብ እና በጥሩ ሁኔታ አስረድቷል እናም በጥናቱ ውስጥ ለምን እንደምትሰተፉ በትክክል ተረድተዋል ማለት ነው።

የ 4 ውጤት ማለት ይህ መጠይቅ የሰጠዎት ሰው አንዳንድ ነገሮችን በግልፅ አስረድቷል ነገርግን አንዳንድ ለእርስዎ ግልፅ ይሆኑ ነገሮች አሉ እንደማለት ነው።

የ 1 ውጤት ማለት ግለሰቡ በጭራሽ ምንም ነገር አልገልጽልዎትም እናም ስለዚህ ጥናት በጭራሽ ምንም አያውቁም እንደማለት ነው።

የ 0 ውጤት ማለት ምንም ዓይነት መጠይቅ በጭራሽ አላገኙም ማለት ነው ። ስለሆነም ጥያቄውን መመለስ አይችሉም። ጥያቄው ለእርስዎ አይመለከትም።

2. ማህበራዊናቤተሰባዊጥያቄዎች

2.1. ህፃኑን የሚመለከት

1.	ዕድሜ	
2.	ፆታ	ወንድ
		ሴት
3.	ልጅዎ ሆስፒታል ተኝቶ የቆየበት ጊዜ	ሁለት ሳምንት
		ሶስት ሳምንት ከዚያ በላይ _____
	በዙር	ለሁለተኛ
		ለሶስተኛ

		ለአራተኛ
		ለአምስተኛ ና ከዛ በላይ
4.	የተረጋገጠው በሽታ ዓይነት	የልብበሽታ
		የኩላሊት ህመም
		የስኳር
		የአዕምሮ ህመም
		ሌላ ከሆነ ይለዩ_____

2.2. ቤተሰብ-ነክ ጥያቄዎች

1.	ከልጅዎ ጋር ያለዎት ግንኙነት	እናት
		አባት
		እህት
		ወንድም
		ሌላክ ሆነ ይለዩ-----
2.	እድሜ	
3.	ስራ	የቤት እመቤት
		ገበሬ
		ነጋዴ
		የመ/ሰራተኛ
		ሌላ ከሆነ ይለዩ-----
4.	የጋብቻ ሁኔታ	ያገባ/ች
		የተፋታ/ች
		የሞተበት/ባት

5.	የትምህርት ደረጃ	አልተማርኩም
		ማንበብና መጻፍ እችላለሁ
		የመጀመሪያ ደረጃ
		ሁለተኛ ደረጃ
		ከፍተኛ ት/ት
6.	የመኖሪያ ቦታ	አዲስ አበባ
		አሮሚያ
		አማራ
		ደቡብ
		ሌላ ከሆነ ይለዩ-----
7.	ቤት ውስጥ ያሉ ልጆች ብዛት	

3. የህክምና አገልግሎት አሰጣጥ ሂደት መለኪያ መጠይቅ

በሆስፒታል ቆይታ ለልጅ ጤና ጋር የሚሰሩ ሰዎች እስከምንድረስ ይሰራሉ		ይህንን አገልግሎት ወይም ሁኔታ ምን ያህል እንደሚያገኙ ወይም በእርስዎ ላይ እንደሚከሰት ያመልክቱ							
		በጣም ትልቅ በሆነ መጠን	በከፍተኛ ደረጃ	በጥሩ ደረጃ	በመጠኑ	በትንሽ መጠን	በጣም ትንሽ በሆነ መጠን	በፍጹም	ተፈጻሚ የማይሆን
01	እንደ ወላጅ ወይም ቤተሰብ እችላለሁ የሚል ስሜት እንዲሰማዎት ያደርገታል?	7	6	5	4	3	2	1	0
02	ለልጅዎ ስለሚደረግለት ህክምና በጽሑፍ መረጃ ይሰጥዎታል?	7	6	5	4	3	2	1	0
03	ስለበሽታዎ መረጃ መስጠት ብቻ ሳይሆን አንክብካቤን ይሰጣሉ	7	6	5	4	3	2	1	0
04	መረጃ መቼ እንደሚቀበሉ እና የሚፈልጉትን የመረጃ አይነት እንዲመርጡ ያስችልዎታል?	7	6	5	4	3	2	1	0
05	የልጅዎን አካላዊ ፍላጎት ብቻ ሳይሆን የልጅን 'አጠቃላይ' ፍላጎት (ለምሳሌ፣ አእምሮ፣ ስሜታዊ እና ማህበራዊ ፍላጎቶችን) ያገናኘዋል?	7	6	5	4	3	2	1	0

06	ቢያንስ አንድ ሰው ለረጅም ጊዜ ከእርስዎ እና ከቤተሰብዎ ጋር አብሮ ይሰራል?	7	6	5	4	3	2	1	0
07	የሕክምና ምርጫዎች ሙሉ በሙሉ ይብራሩልዎታል?	7	6	5	4	3	2	1	0
08	ስለህክምና ምርጫ ውሳኔ እንዲወስኑ ለማድረግ እድሎች ይሰጡዎታል?	7	6	5	4	3	2	1	0
09	ችኮላ እንዳይሰማዎትና የመወያያ በቂ ጊዜ ይሰጥዎታል?	7	6	5	4	3	2	1	0
10	ሁሉም ባለሙያዎች ከእርስዎ ጋር አብሮ በማቀድ በአንድ አቅጣጫ ይሰራሉ?	7	6	5	4	3	2	1	0
11	እንደአንድ የሕመምተኛ ወላጅ ሳይሆን እኩል እንደህመምተኛው ይንከባከብዎታል?	7	6	5	4	3	2	1	0
12	ባለሙያው ለሌሎች ሰዎች እንደሚያደረገው ሁሉ ለርሶም ስለልጅዎ ተከታታይ የሆነ መረጃ ይሰጥዎታል?	7	6	5	4	3	2	1	0
13	እርስዎን እንደህመምተኛው ወላጅ ሳይሆን እንደግለሰብ ይንከባከብዎታል?	7	6	5	4	3	2	1	0
14	ስለልጅዎ ጤንነት ሁኔታ የጽሑፍ መረጃ ይሰጥዎታል?	7	6	5	4	3	2	1	0

15	ስለልጅዎ ህክምና ምርመራ ውጤት ይነገርዎታል?	7	6	5	4	3	2	1	0
16	በሆስፒታል ወይም በአካባቢዎ ውስጥ ስለሚሰጡ የህክምና አገልግሎቶች መረጃ ይሰጥዎታል?	7	6	5	4	3	2	1	0
17	ስለልጅዎ የበሽታሁኔታ (ለምሳሌ፣ መንስኤዎቹ፣ ስለለውጥሂደቱ፣ ወደፊት ሊሆን ስለሚችለው ሁኔታ) መረጃ ይሰጣሉ?	7	6	5	4	3	2	1	0
18	መላው ቤተሰብ መረጃ እንዲያገኝ እድሎችን ያመቻቻሉ?	7	6	5	4	3	2	1	0
19	በተለያዩ መልኩ ለምሳሌ በበራሪ ወረቀት፣ በስዕል፣ በቪዲዮ፣ ወዘተ ባሉነገሮች መረጃ ይቀርብልዎታል?	7	6	5	4	3	2	1	0
20	መረጃን እንዴት ማግኘት እንደሚችሉ (ለምሳሌ የሆስፒታሉን የወላጅቤተ-መፃህፍት) ወይም ሌሎች ወላጆችን እንዴት ማግኘት እንዳለብዎት ምክር ይሰጥዎታል?	7	6	5	4	3	2	1	0