EXPERIENCES AND PERCEPTIONS OF HEALTH LITERACY OF MONGOLIAN MOTHERS LIVING IN ULAANBAATAR, MONGOLIA

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Master of Science in International Health 2022

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A thesis submitted in partial fulfillment of the requirement for the degree of

Master of Science in International Health

by

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Declaration:
Where other people's work has been used (from either a printed or virtual source, or any other source), this has been carefully acknowledged and referenced in accordance with academic requirements.

The thesis .....**EXPERIENCES AND PERCEPTIONS OF HEALTH LITERACY OF MONGOLIAN MOTHERS LIVING IN ULAANBAATAR, MONGOLIA**.....is my own work.

Signature:.....

Master of International Health
KIT (Royal Tropical Institute)/Vrije Universiteit Amsterdam, The Netherlands

August 2022

Organized by:

KIT (Royal Tropical Institute)
Amsterdam, The Netherlands

In co-operation with:

Vrije Universiteit Amsterdam (VU)
Amsterdam, The Netherlands

Abstract

Background:

Health literacy was introduced, and its main concepts were translated for research purposes in Mongolia in 2020. Mothers are primary caretakers of their children, and the low health literacy of mothers is directly proportional to low pediatric health status. There is a gap in literature on Mongolian mothers' health literacy, their perception of health literacy in qualitative terms and available sources of health information, its significance on children's health and development.

Objective

To explore and describe experiences and perceptions of health literacy regarding pregnancy, childbirth, and childcare among Mongolian mothers living in Ulaanbaatar, Mongolia.

Methods

Nine Mongolian mothers living in Ulaanbaatar, Mongolia, were interviewed about their experiences and perceptions of health literacy during pregnancy, childbirth, and childcare. Semi-structured interviews based on the HLS-EU survey with open-ended questions were conducted in Mongolian or English. The interviews were recorded, translated, transcribed with participants' consent. Thematic analysis was done under the scope of the HLS-EU framework with an inductive approach using codes from the transcripts. The study did not intent to quantitatively measure health literacy level of participants.

Results and Conclusion

Communication between health professionals and patients is a significant factor influencing health literacy in mothers. Interventions are necessary to motivate medical professionals to inform patients, create educational programs targeting mothers to improve health literacy and improve mothers' skills related to HL in the population. Sources of health information on disease prevention and risk factors were mostly revolved around the internet, and there is a lack of reliable information on risk factors in Mongolian for mothers who did not speak a foreign language. Recommendations to NGOs of interest for interventions and possible research on improving health literacy in mothers and the general population are given.

Key words: health literacy, Mongolian mothers

Word count: 13021

Abbreviations

HL	Health Literacy
HLS-EU	The European Health Literacy Project
LMIC	Low-and Middle-Income Countries
NHMCH	National Center for Maternal and Child Health of Mongolia
OB/GYN	Obstetrics/Gynecologist
PHC	Primary Health Center
USD	United States Dollar
WHO	World Health Organization

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Background

Mongolia is a landlocked country in Central Asia with around 3 million inhabitants, being the world's most sparsely populated nation. Settlement patterns vastly differ between the capital city to rural areas. The capital city of Ulaanbaatar, rapidly grew in the past few years, hosting around two-fifths of the entire population (1). It is the largest city in Mongolia, whereas around half of the population lives in the countryside practicing a nomadic lifestyle (1). The literacy rate is around 98% in the total population, including males and females in Mongolia (2).

The Mongolian medical system formerly consisted of traditional and religious practices, until the Soviet Union introduced western medicine and built a new national system during the first half of 20th Century. The Soviet Union introduced the *Semashko* model healthcare system based on a centralized design with free services provided by government (3). Since the 1990s, the Mongolian government, with support from international organizations such as the Asian Development Bank and WHO, modified the system as part of a broader transition towards a more democratic and market-based structure (4).The transition to a new health care system was constrained by a lack of required financial resources, outdated infrastructure and equipment and a lack of available professionals with experience beyond the former centralized socialist system.

Health professionals around the world used to inform the population about health and well-being through patient education focusing on influencing behavior of the patient (5). Patient education needed to be efficient to relay the knowledge about health promotion and disease prevention alongside healthcare services provided by doctors and nurses at a healthcare facility (6). The term "health literacy" (HL) was introduced by Simonds in 1974, taking patient education up a notch to a social policy level (7). HL has had multiple definitions created by different researchers and organizations, leading to criticism it was competing with terms such as 'health promotion' and not having clear boundaries between the two concepts (8). Nutbeam described an outcome model where social determinants of health need to change through personal, social, and structural factors as an outcome of health promotion, where one of the intended outcomes was specified as HL (9). The World Health Organization (WHO) defines it in its 1998 glossary as "the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions (10).

The term rapidly drew attention from public health researchers and sociologists in the United States and Canada. The rest of the world has followed since. Efforts to understand and measure HL were initiated based on social determinants of health, technological advancements, and healthcare developments (8). The Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) were created to assess HL among the population by studying the verbal and written recognition of medical words and terms (11,12). Tests consisted of comprehension questions about the general knowledge of well-being and healthy lifestyles. The methodology did not reflect a more complex understanding of HL in healthcare and disease prevention (11,12). As healthcare developed, the field became enriched with innovative technologies and complex divisions of labor. Understanding basic medical terms is no longer sufficient to navigate effectively as a patient. An example of assessing HL through

questionnaires based on a conceptual model is The European Health Literacy Project (HLS-EU). Such methods generated evidence to determine the quantitative relationship between HL and low health status in the general population (13). Researchers had discussions and concluded a proper measuring tool of HL, covering multiple domains instead of few basic parameters is still lacking (14).

In 2020, HL was introduced, and its main concepts translated for research purposes in Mongolia. Terms such as patient education, health education and health knowledge were the most important concepts used to promote health and well-being for the general public (15). The scope of these terms was too broad to specifically target the population from a public health perspective with an organized framework. There is a lack of multidisciplinary understanding of health terms to discuss further public health knowledge in finance, education, and other fields. Although the term was introduced among medical workers, its usage has remained limited to professional circles.

To broaden the recognition and use of HL and its associated terminology, researchers conducted a literature review on the development of health literacy in different countries. This was complemented by limited research in Mongolia involving HL, mainly focusing on quantitative aspects of patient involvement and activation (16). Shining a spotlight on HL alone led to valuable insights. Low HL levels were aligned with higher levels of hospital and emergency department visits, low immunization rates and drug adherence (17). Additional literature suggests a possible communication gap between providers and patients and low attendance rates in follow-up appointments in patients with low HL rates (18). Analysis using a 'snowballing' technique revealed a significant relationship between mother's health literacy levels and child health (19–21). The findings generated significant attention, being a little explored topic in Mongolia.

Traditionally, mothers have played a vital role in Mongolian society. They were responsible for giving birth, raising children and acting as head of the family and tribe at the same time when men were away fighting wars (22). Mongolians respected women for their knowledge and experience in raising healthy children in harsh cold weather, following a nomadic lifestyle (22). Mongolia has always been a pronatalist country with a low population density. The government has since long promoted population growth (23). Since the Soviet times it has incentivized mothers to have four or more children by awarding a medal called "Order of Glorious Motherhood", complemented by monetary rewards (24). Due to the significant role of mothers in the family and society, the HL of mothers, availability of an accurate source of evidence-based health information for mothers is correlated to child health and future healthcare, economic development of the country. Similar qualitative studies were carried out in countries, such as Samoa and Hungary, to shed light on mothers' understanding of HL closely and their engagement, experiences during childcare related to HL where mothers are primary caretakers of their children and low HL of mothers, were directly proportional to low pediatric health status (25,26).

On top of being main family caretakers, Mongolian women's literacy rate is 96.4% and female gross enrollment ratio in tertiary education was 82% in 2019 (2,27). It is important to clarify the understanding of 'educated women' in Mongolia for the purpose of this study. Despite

the high tertiary education rate among Mongolian women, university and workplace dropout rate is high due to pregnancy and low percentage of women continue working after taking maternity leave (28,29). Traditional masculinity still exists among men and women are still responsible for household chores and babysitting full-time in most families (28). The country is facing increased rate of unemployment, wage gaps between genders, gender gaps and being educated does not elevate women to high socioeconomic status. Sometimes education even adds additional burden of breadwinning to women on top of regular household chores and childbearing responsibilities. Educated mothers living in the capital city are representative of Mongolian women who are aiming to improve their knowledge on child development, family health and it is worth studying their understanding of health literacy and experiences related to this topic.

Justification and Objectives

Brief background

Mongolians translated HL and introduced it in use among medical professionals only in 2020 (15). The public is still not familiar with the term, and the public's health knowledge is mainly referred to as patient knowledge, patient involvement, and activation (16). Research is available on relationships between HL and patient involvement in the care of patients with breast and cervical cancer. However, the HL aspect of the research seems to be focused more on comprehension of information and general literacy of patients in understanding health instructions and prescriptions (16). Instead, the term HL has developed into a complex understanding covering personal skills and knowledge, confidence to make changes in personal lifestyle, and community (10). Rapid urbanization in Mongolia from a traditional nomadic lifestyle has been a root cause for numerous factors affecting an increase in the burden of non-communicable and communicable diseases in recent years (30). Further research on patients' knowledge and attitudes on diabetes, hypertension, and other non-communicable diseases based on surveys concluded that the public has limited knowledge about the above-mentioned diseases (30). Some participants were utterly unfamiliar with specific diseases such as diabetes (30). HL of the population merits further investigation in the near future.

Mongolia has a young population with a large number of young people at fertility age, about 45% of the population and children of 0-14 years old taking up about 26% (31). These demographics underline the importance of targeted maternal and child health for the future healthcare development and public health of the country. However, there are limited studies done on this topic and researchers mainly focused on mother's health. Studies available show that women are relatively knowledgeable about factors that contribute to their own health, well-being and common diseases in Mongolia that affect women's health which is a significant part of HL (32). On the other hand, a large percentage of women are reluctant to have screening and monitoring of their health for due to lack of health education and this trend shows a somewhat lack of HL (32). Thus, improving women's HL by providing health information through primary health care visits, handbooks and other media is important. Number of researchers studied the maternal and child handbook utilization as an example of health information sources available in the country (33). Studies concluded that providing mothers with a handbook with health information has increased prenatal visits of pregnant mothers, decreased complications during pregnancy, and encouraged continuous care and health-seeking behavior in mothers (33). However, the positive results were achieved only if mothers were provided explanation on how to use the handbooks (33). These results illustrate how the distribution of health information for mothers, as part of HL, promotes healthier pregnancy by increasing treatment adherence, self-confidence in mothers, and continuous effort to seek information to raise healthy children.

There is a gap in literature on Mongolian mothers' HL, their perception of HL in quantitative and qualitative terms and its significance on children's health and development. Throughout history, mothers have been the primary decision-makers regarding childcare in Mongolian families (22). Low HL levels in the population indicated a high number of hospital and emergency department visits, a low immunization rate, and low medication adherence (17). Countries started assessing and developing policies, protocols to achieve HL as a public health

goal and to improve life quality in general since HL itself has become one of the determinants of public health over the years (13). Number of studies have been conducted in other countries, such as Samoa and Hungary, focusing on mothers' HL, their experience with health professionals and information sources available to them (25,26). The above-mentioned studies also reflect traditional practices and approaches unique to the country and the culture. The study done on Samoan mothers showed how important it is to provide health information through healthcare professionals and acknowledge mothers as experts when it comes to their child's health (25). Therefore, not only the availability of evidence-based information sources for Mongolian mothers, but their significance and contradictions with traditions and customs are worth studying in a country with urban, modern as well as traditional nomadic culture.

Such research can increase the availability of sources of knowledge that mothers find helpful, bring light on real-life examples and difficulties regarding lack of accurate sources of health literacy. Further work can be done to find ways to promote HL, bring awareness to the level of HL of mothers to improve recognition of the term for public use. The study thus can potentially impact health accessibility, health equity, and healthcare development significantly.

Justification:

There is a lack of scientific studies that examine health literacy of Mongolian mothers, including their experiences and perceptions, during pregnancy, childbirth, and childcare living in Ulaanbaatar, and the area needs to be studied. In addition, HL is not publicly well understood term in the country that requires more baseline exploration to improve current population health. Overall objective of the research is to explore and describe experiences and perceptions of health literacy of Mongolian mothers living in Ulaanbaatar, Mongolia.

The study aims to understand the current HL understanding among mothers and enhance their HL by recommending necessary actions to improve for interested NGOs. Finding the right level of action based on mothers' perception of HL is crucial and this qualitative study attempts to achieve possible approach. The study does not intend to measure mothers' HL quantitatively.

Objectives of the study:

1. To explore perception of health literacy as an individual and as a member of a family among Mongolian mothers and their ability to access and understand medical and health-related information, information on risk factors;

A qualitative study involving interviews with open-ended questions is deemed suitable for exploring mothers' perceptions and understanding of health literacy as it allows them to tell their stories privately as an individual. Mothers ability to access and understand medical information, obtain information on risk factors and health-related issues regarding their health during pregnancy and child's health will be of interest. In many Asian cultures, including in Mongolia, mothers are the primary caretakers of their children, and their involvement in childcare is relatively high compared to their husbands (34). On the other hand, it should be noted that elderly and extended family members' influence and involvement in family matters including during pregnancy, and childcare are relatively high compared to many European countries (34).

Thus, it is important not to underestimate conflicting views of mothers, their family members and husbands on health literacy and to allow mothers openly talk about sources and processes of obtaining health information, information on risk factors using right questions and probes during the interview.

2. To examine medical, environmental, and traditional knowledge on pregnancy, childcare of Mongolian mothers with children up to 5 years of age and mothers' ability to judge and apply medical and health-related information, information on risk factors;

The study attempts to take a holistic approach to mothers' perceptions of HL by taking into account how environmental factors such as weather, family, environment of the mother affects daily decisions on health and well-being. A semi-structured interview focuses on mothers' experiences and perceptions, taking a broader view on multi-generational health knowledge rather than a narrow focus on individual HL. Mongolia has experienced a rapid transition from a nomadic lifestyle with traditional understanding of health to urbanized modern lifestyle with 'western' medicine, leading to a drastic difference between family members and generations (35). Therefore, the research aims to gain unique insight into Mongolian mothers' health knowledge considering above factors and their ability to judge and apply medical and health-related information, information on risk factors and their confidence and how it is reconciled with those of elderly family members.

3. To analyze experiences regarding health literacy in healthcare, disease prevention, health promotion domains during pregnancy and childcare for further interventions among educated Mongolian mothers with children under the age of 5

Interviews for the research is structured from the HLS-EU survey as a framework. The domains of the framework acts as a guide for further analysis. Mothers' detailed experiences within three domains looked into detail and possible interventions will be suggested based on results of mothers interpreting, understanding health issues in the scope of healthcare and public health. In addition, mothers' skills to access, understand, judge and apply relevant health information will be asked and organized within the HLS-EU framework sub-dimensions.

4. To recommend actions including policies and interventions for NGOs operating in Mongolia towards improving public health, maternity and child health;

The study attempts to analyze results and recommend interventions and policies on improving HL in general population based on findings. Multiple local and international NGOs are operating in Mongolia focusing on improving public health, maternity and child health, respected maternity care independent from government and public entities. This study will come up actions for NGOs to promote the understanding of HL in Mongolia and further incorporate the term in public health field to educate and empower general population.

Methods

Literature review

The literature review was done to look into studies done on HL to describe the term, compare the term from other similar understandings, develop tools for the research. Background information about Mongolia was collected from literature to get more understanding about current healthcare situation in the country. In addition, studies from other settings were looked into for further recommendations.

Search strategy	**Details**
Country	Mongolia and others
Language	Mongolian, English
Search engines	Google, Google Scholar, VU libraries, PubMed, WHO database, Mongolian National Database
Methods	Used key words are searching on search engines and online libraries using available access from the institute and other websites available to the public. Results were reviewed according to relevance, starting from results worldwide and narrowed them down to maternal and child health and health literacy-related works. Further results related to studies done in Mongolia were reviewed, and the 'snowballing' method was used to find other literature from systematic reviews, quantitative and qualitative studies. Website articles, peer-reviewed publishings, international and local project reports, local and other statistical reports were used. The Year of publication was not limited during the search.
Key words	Health literacy, patient education, health promotion, patient involvement, 'qualitative study' AND 'health literacy', 'health literacy' AND 'mothers', 'health literacy' AND 'pediatric health', 'health literacy' AND 'child health', Mongolian healthcare, Mongolian health promotion, Mongolian health policy, primary health care in Mongolia, 'Mongolia' AND 'healthcare indicators', qualitative study, qualitative research methods, 'qualitative studies' AND 'Mongolia', 'Mongolia' AND 'health literacy', 'Mongolia' AND 'child health', 'Mongolia' AND 'mothers', 'antenatal care' AND 'Mongolia', 'жирэмсний тэтгэмж', 'эмчийн цалин', 'doctor patient ratio' AND 'Mongolia', 'informed decision-making' AND 'healthcare', 'social media' AND 'health', 'husband's involvement' AND 'Mongolia', 'health literacy interventions'.

Table 1. Details on literature review

Research design

A qualitative design with a narrative approach was considered suitable for this research due to its organic nature, lack of quantitative and qualitative data available locally. Participants are encouraged to talk and bring in their experiences or social phenomena guided by questions asked by the researcher (36). The conversation proceeds naturally in a comfortable environment, not in a lab, allowing the researcher to observe participants' emotions, manners, and behaviors. Also, qualitative research has a flexible and holistic design that allows exploring and investigating the problem further amid the study without being bound by a set hypothesis or set area of perspective (37,38). The study does not intend to quantitatively measure HL.

Framework

The study is based on the HLS-EU conceptual framework objectives and its surveys within three domains – healthcare, disease prevention, and health promotion (39). The framework provides a systematic understanding of HL and relevant skills providing guidance throughout the planning, the execution of the research, and the analysis. As such, the above domains have provided guidance to interviewees/mothers to cover multiple health education and information aspects. The interview questions were created and explored experiences according to the HLS-EU model as the framework contains 12 sub-dimensions that cover and break down HL as a concept, as shown in Table 2 (13,39). The study incorporates findings with 12 sub-dimensions from the framework to emphasize mothers' abilities regarding HL in each domains. 12 sub-dimensions are called '12 skills' in findings and there are 4 skills within each domain (Table 2). HLS-EU framework originally used to quantitatively measure HL based on questionnaire model, however, this study uses domains and health literacy skills reflected in the framework as a qualitative model and does not aim to qualitatively measure HL. The holistic use of framework is further portrayed in sections below.

Sampling

Health Literacy	Access/obtain information relevant to health	Understand information relevant to health	Appraise/judge/evaluate information relevant to health	Apply / use information relevant to health
Health Care	1) Ability to access information on medical or clinical issues	2) Ability to understand medical information and derive meaning	3) Ability to interpret and evaluate medical information	4) Ability to make informed decisions on medical issues
Disease Prevention	5) Ability to access information on risk factors	6) Ability to understand information on risk factors and derive meaning	7) Ability to interpret and evaluate information on risk factors	8) Ability to judge the relevance of the information on risk factors
Health Promotion	9) Ability to update oneself on health issues	10) Ability to understand health related information and derive meaning	11) Ability to interpret and evaluate information on health related issues	12) Ability to form a reflected opinion on health issues

Sorensen et al. (2012)

Table 2. Matrix of Sub-Dimensions of Health Literacy Based On the HLS-EU Framework (39)

In the qualitative study design, the researcher chooses participants "who will best help them understand the research problem and questions" (38). Thus, the researcher used a maximum variation purposeful sampling strategy to find participants with various experiences to talk about for enough data to be collected for analysis. The attempt was made to recruit participants with diverse family structures and occupations. Participants were contacted and recruited until the study reached the data saturation point without new experiences or recorded information.

Inclusion criteria were created to examine as many experiences as possible about health literacy among Mongolian mothers. Participants were mothers who at the time of research (2021):

- Were a Mongolian citizen
- Resided in Ulaanbaatar, Mongolia
- Gave birth to a child in the past five years

Nine participants were recruited from the city of Ulaanbaatar, where the researcher was located. It proved more convenient to select mothers residing closer by, considering the limited possibility of traveling during COVID-19 restrictions. Mothers living in a city have better access to healthcare and tend to have more experience with healthcare professionals. The participant's age was not defined, but the participant had to have one or more children under the age of 5. These criteria narrowed the selection to mothers with relatively young children, those having been pregnant in the past five years. This was to benefit data accuracy by selecting mothers with a relatively fresh memory of their pregnancy and childcare experience. The study targeted mothers with various occupations and attempted to increase diversity among participants. Mothers varied in number of family members, family structure, education level and foreign language proficiency.

The researcher used a separate recruiter to contact participants to avoid the burden of agreeing to participate when the researcher contacts them directly. The recruiter was a non-academic individual who avoided putting participants under pressure to participate. The recruiter was given instructions on qualitative research methods and recruiting strategies to choose participants as diverse as possible limited to above criteria. The researcher and the recruiter discussed and agreed on the aim, goal, purpose, and objectives of the study to recruit participants with the variation of experiences for the study. Mothers were contacted and given brief information about the researcher, and objectives of the study and were invited to participate.

Semi-structured interviews

The interview questions were created based on the HLS-EU questionnaire with 16 questions. The questionnaire covered three domains of the framework and questions were summarized and converted to open-ended questions appropriate for qualitative study design since the original questionnaire aims to quantitatively measure level of HL. In addition, questions from HLS-EU questionnaire were replaced with alternative options and additional probes to meet study objectives and specific target group and culture of participants. The

researcher conducted both the interview and observation during the interview. The research aimed to take a narrative approach to hear experiences from mothers and relay it from participants' and researcher's views (38). The researcher conducted a semi-structured interview with additional probes in the preferred language of the participant, either Mongolian or English. Interviews were audiotaped with the consent of each participant.

The researcher asked mothers to choose the meeting time and location with the researcher upon their agreement to participate. Participation was voluntary and the researcher informed mothers they could skip answering any of the questions from the interview if they felt uncomfortable. The interviews were privately held, involving one participant and the researcher. The location was a comfortable and quiet environment for mothers with ensured privacy. Some mothers chose to have an online call through Zoom and Google meet due to the inconvenience of traveling from their summer place to the capital city and to avoid possible COVID-19 exposure. In that case, only audio was recorded during the interview with participants' content. The researcher explained the consent form and asked a participant to sign it before starting the interview. Also, the researcher answered questions from participants about the consent. Mothers were informed about the possibility of emotional distress during the interview when asked about childbirth or episodes of their child getting sick or hospitalized. The researcher then ensured mothers would be referred to a counselor located in Ulaanbaatar for further evaluation and consultation if they feel distressed from the interview.

Ethical clearance

Ethical clearance for this study as a thesis work for the researcher was sought and approved on July 12, 2021, by the Research Ethics Committee at KIT-Royal Tropical Institute located in Amsterdam, the Netherlands. Furthermore, local clearance was obtained by the Mongolian National University of Medical Sciences Ethics Committee Branch in Ulaanbaatar, Mongolia, on June 22, 2021.

Data analysis

The researcher used a narrative approach during the study. Interviews from individuals were translated into English, transcribed by the researcher after each interview. Transcriptions were analyzed using Creswell's step-by-step guide including line-by-line coding by hand, developing themes based on similarities and differences between codes, creating descriptions, finding interrelations in themes, and interpreting the meaning of the themes (38). Themes were created using an inductive approach based on the codes within the scope of the framework domains shown in the first vertical column of the framework (See Table 2). In addition, codes were analyzed and discussed within health literacy abilities from the first horizontal column of the framework (See Table 2). The analysis and results were reviewed and validated by the thesis advisor.

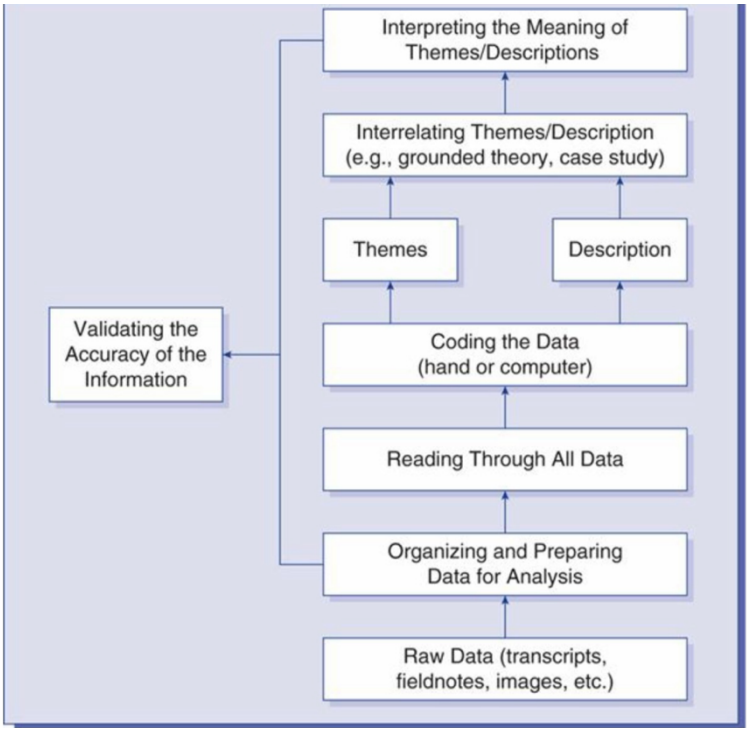

Figure 1. Data Analysis in Qualitative Research (38)

Limitations

The interviewees were located only in one city, Ulaanbaatar. Due to the small sample size, it is evident the results will not reflect the health literacy status of all Mongolian mothers. Also, limited to the inclusive criteria, participants are small group of mothers who have access to healthcare and other sources of information on childcare and they are not representative of all Mongolian mothers who have limited access to healthcare. There is a possibility of selection bias due to the purposeful sampling method.

The study was limited by the national and KIT guidelines due to COVID-19 pandemic worldwide to prevent further spreading of the infection due to the study. KIT Guidelines on on Data Collection Procedures During COVID-19 and national and local government guidelines were closely followed throughout the research.

Results

Participants' interviews were transcribed and analyzed for thematic analysis according to the objectives of the research. Thematic analysis was done after line-by-line coding nine interview transcripts. An inductive approach was used to create themes based on codes. Experiences and perceptions of HL in Mongolian mothers emerged as themes which are divided in three domains of the HLS-EU framework: healthcare, disease prevention, and health promotion (39). 12 sub-dimensions from the framework were included withing domains to emphasize mothers' abilities related to HL. The framework served as a guide to categorize and organize themes under the scope of HL.

Participants' general information was included in Table 3, and participants were referred to as Participant # for privacy purposes. It is important to note that Participants 2 and 6 chose not to disclose their occupation during the interview.

Table 3. General information of participants.

Participant Number	Marital Status	Number of Children	Children's age, gender	Whom they live with	Education level	Occupation	English language proficiency
1	Separated	1	5 y.o., girl	Mother	Undergraduate	1st year medical student	Intermediate
2	Married	2	2 y.o., boy; 10 y.o., girl	Husband, mother-in-law	Undergraduate	Unknown	Intermediate
3	Married	2	5 y.o., boy, 6 y.o, boy	Husband	Undergraduate	Yoga instructor (medical degree on hold due to maternity leave)	Beginner
4	Married	1	4 y.o., boy	Husband	Secondary	Housewife	None
5	Married	1	20 days old, boy	Husband, mother, younger sibling	Undergraduate	Majored in architecture, currently a housewife	Advanced
6	Married	1	4 y.o., girl	Husband	Undergraduate	Unknown	Beginner
7	Married	2	10 months old twin girls	Husband, mother-in-law	Undergraduate	Majored in political science, currently a housewife	Advanced
8	Engaged	1	5 months old, boy	Husband	Graduate	Worked in environme	Advanced

						ntal sector, currently a housewife	
9	Married	2	4 y.o girl, boy in 3rd grade, boy in 5th grade	Husband	Secondary	Housewife	None

Healthcare

Emerging themes were divided into the first of three domains of the HLS-EU framework: healthcare. Themes were included in this domain as it related to healthcare experience and perceptions of mothers. 4 skills analyzed from Table 2 for this domain are 1) Ability to access information on medical or clinical issues, 2) Ability to understand medical information and derive meaning, 3) Ability to interpret and evaluate medical information, 4) Ability to make informed decisions on medical issues (Table 2). Interview questions focused on mothers' experiences, self-confidence in their knowledge, information sources, stories about healthcare facilities, as well as healthcare professionals they have visited and encountered during pregnancy, childbirth, and childcare. Participants started with antenatal care, monitoring during pregnancy, and proceeded to a public and private hospital experience during childbirth and hospital visits post-birth, when their children got sick.

"Doctor's advice is my first choice"

Doctors, medical facility and hospitals are the first choices of care for mothers when it comes to pregnancy and severe illness of their children to seek and obtain health information. Medical knowledge is sometimes much more sophisticated and requires professional training to find accurate, peer-reviewed information. Participants have all visited their primary care doctor at the primary health center (PHC) for an antenatal check-up during their pregnancy. They explained such a visit at the local primary health center is compulsory in order to be able to receive maternity allowance from the government.

Primary care doctors are the first information point for pregnant mothers, and mothers trusted their doctors for basic understanding and further directions. All participants visited their local, public PHC, got their initial instructions, followed doctors' directions, and had their routine check-ups. Despite their monitoring and PHCs, not all participants chose to give birth in public maternity hospitals. One of the participants had a different case, and she had to receive her antenatal care and monitoring at the National Center for Maternal and Child Health of Mongolia (NCMCH) because she had twins. Another mother who has two children said:

"When I first got pregnant with my older child, I used to get routine information from my primary care doctor, but for my second pregnancy, I had more knowledge myself rather than having to visit the primary care center all the time." [Participant 2]

Participants did not provide much information about their relationship with their OB/GYN (obstetrics/gynecologist) during childbirth and how much they trusted their doctors

throughout the labor and delivery, especially mothers who gave birth in public maternity hospitals. Participant, who gave birth in a private hospital, chose her OB/GYN and provided her antenatal care, and delivered her baby. She described her OB/GYN as a "lot calmer, relaxed" and "had more western/up-to-date education".

Mothers explained that their most trusted source of childcare information is a doctor/pediatrician and they understood health information provided to them which shows the 1st skill in the healthcare domain (Table 2). Some participants mentioned they have a pediatrician that they regularly visit to seek advice on fundamental health issues of their children or contact a specific pediatrician when their child gets sick. They visited their pediatrician's office as soon as children had symptoms and followed doctors' instructions and prescriptions. Participants would trust a doctor more than any other sources of information, even though some of them do not have a pediatrician/doctor they visit regularly. The most frequently repeated reason for trusting a doctor was that doctors had scientific knowledge and evidence-based information versus the traditional approach and hearsay information. Their trust in professional care and medical facility is reflected in participants' choices when they talked about times when their children got sick. Three participants had situations when their children had severe episodes such as seizures, burn, and they immediately called an ambulance. Doctors who came in the ambulance gave instructions and were helpful except when the child had a communicable disease and had to wait for a specific diagnosis to get transported. One mother speaks fluent English and her frequently used source of information is the internet via Google search, but she was sure that she would go to a doctor right away with severe symptoms without even Googling. These mothers are able to evaluate whether their children are critically ill based on the information they have obtained from various sources in line to 3rd skill (Table 2).

It is common for doctors to advise inpatient care for multiple days, and mothers mostly agreed to a treatment and hospitalization. However, one participant did not want her child to stay in the hospital and got the prescription for home from the ambulance doctor. She gave medications to her son, and her mother-in-law, a retired doctor, gave injections at home. Two mothers talked about a time when they were young and inexperienced and did not know what to do when their child got sick. One of them mentioned a time when child got chickenpox and she didn't obtain updated health information and used old methods which were not effective. In both cases, mothers admit that they misjudged a right time to get seen by a medical professional. They had lack of 1st, 2nd, 3rd, 4th skills of healthcare domain at that time (Table 2). However, they had positive experience with doctor's prescribed treatment when they decided to see a doctor, and claim it is better to call a doctor as soon as possible. They agree that they were young first-time mothers at that time and since then they have obtained and applied up-to-date medical information when their children got sick and learned skills that lacked before.

"When my daughter was 2 months old, she caught a cold. Since I was a new mother at the time, I was crying with her….. A pediatrician at the local hospital prescribed her two pills, and it went away in the next couple of days….. When she got sick, my family and husband all agreed to call a doctor and seek medical attention….. I think I should have called a doctor sooner, probably right away when my daughter started feeling unwell." [Participant 6]

"If you don't have any questions, they will not tell you anything"

Mothers trust doctors and seek their help when needed for their children's health and well-being. However, participants emphasize how difficult it is to extract information from doctors other than diagnosis and treatment. Even though doctors are knowledgeable and trustworthy, doctor visits usually end up being a uni-directional communication from doctor to a patient. Despite mothers' age and previous experience with pregnancy and childbirth, there was a noticeable trend of not receiving enough information during their check-ups. Thus, it affected 3rd and 4th skills from the domain to interpret and evaluate medical information and further ability make informed decisions (Table 2).

Few mothers who became pregnant relatively young did not know what to do or what to ask during check-ups. Young mothers were usually students and mentioned they had a heavy academic load and had limited time to search for information from other sources and compare, evaluate and apply them in a critical manner with 3rd and 4th skill (Table 2). They did not get enough information from their antenatal visits and had negative consequences during childbirth due to a lack of basic information. After years have passed since they gave birth, these mothers found more helpful information and often wondered why primary care doctors did not tell them. Participants pointed out that breathing exercises were not advised at all during their pregnancy to prepare for childbirth. Mothers had difficulty breathing during labor and thought they did not push right because they were not prepared. One participant told in detail how difficult it was to push without knowing how to breathe, and it was dangerous for her and her baby. She experienced a vaginal tear during birth and thought it was because she could not push 'right'. Doctors and nurses did not tell her how to breathe or push during labor. Even though, they might have heard about the breathing before, they did not evaluate the useful nature of this technique with 3rd skill and made decision to apply the technique to ease their experience with 4th skill (Table 2).

"I had to be the nicest person begging everyone to get seen or get treated. I had to go and ask if there is anything wrong with me, if I was doing fine. If you don't have any questions, they (doctors) will not tell you anything". [Participant 7]

Some participants went to PHCs and hospitals with many questions about pregnancy and their baby's health. Mothers were curious about their well-being and wanted to know more. One of the participants chose one of the most expensive private hospitals to receive her antenatal care, but she also had to go to compulsory PHC visits. She compared private and public clinics and said PHC doctors did not provide mothers with helpful information to prepare for birth and prevent possible complications. Doctors at PHCs often were 'too cautious' about mothers' health and frequently highlighted the risk of miscarriage without much explanation. On the other hand, the doctor at the private hospital was helpful and was willing to talk about all the details. However, even this doctor did not provide information beyond what was asked by mothers. The participant understood that doctors prefer patients not to ask too many questions and did not know how to interpret these differences and compare which one is better or worse to make further health decisions with 3rd and 4th skills (Table 2).

Mothers described similar experiences of not being able to get information from doctors when their children were sick. One of the participants stayed at the NCMCH for three months with her baby. One of her twin daughters was diagnosed with bacterial meningitis and developed hydrocephalus. Her baby had to undergo a shunt surgery, and she shared her experience of her stay. She felt the need of patients' mothers wanting answers but doctors not providing them. The participant felt that doctors' job is not informing but only prescribing medicine and performing surgeries. It was a common understanding among patients in the hospital and their families. She researched online and prepared two pages worth of questions for the surgeon who was going to perform surgery on her baby. She said she might have been the first person with that many questions for the doctor. Unfortunately, the doctor said, "You know everything already. Why are you wasting my time?". The participant was able to change her doctor and challenge to get answers to her questions.

Mothers described doctors as not being responsible for informing patients and mothers. Patients had to resort to other information sources such as the internet, social media, and family members who had similar experiences for answers to their questions. Different doctors and nurses worked in shifts, and mothers were not informed what the treatments were and who would continue the treatment the next day. There are contradictions among doctors between different hospitals and within the same hospital as well. These conflicts confuse mothers even if they have 1st and 2nd skills to find health information from other sources. When professional medical providers give out conflicting information, it affects 3rd and 4th skills which includes clear judgement and evaluation of the mother (Table 2). Another participant mentioned that she is always skeptical about expensive medications prescribed by doctors because the reason and purpose of medications are never explained in detail. Thus, she resorts to interpreting the prescription in her own and buy medications based on her past experiences and information from friends and family.

"I always had to ask and fight for information, asking 'Why?' questions, 'This doctor told me this, but you are telling something different, 'Why are you doing this when that doctor told me that. I had to show doctors that I did my homework, and I'm prepared, I know something." [Participant 7]

A possible reason for doctors withholding information from patients is explained by a mother who went to medical school. She said:

"…doctors and medical professionals know but do not spread that information to the public. I do not blame them, and I know they don't have enough time, and they are not provided a decent working environment. Doctors are doing nurses' work, and nurses are responsible for nursing/patient assistants' duties in Mongolia… I think 50-60% of them are not satisfied with their profession and work. They just do what they should, and they don't do anything extra. Thus, they don't explain anything further". [Participant 3]

Disease prevention

Themes in this domain focus on HL experiences and perceptions of mothers related to health risk factors and disease prevention. Interview questions focused on exploring sources of traditional and modern medical health practices during pregnancy and childcare as it related to the research objectives. Mothers have various sources for health information to prevent diseases and the interviews provided an opportunity to explore how Mongolian mothers made medical decisions, considering traditional practices and modern medical practices. The domain focuses on skills: 5) Ability to access information on risk factors, 6) Ability to understand information on risk factors and derive meaning, 7) Ability to interpret and evaluate information on risk factors, 8) Ability to judge the relevance of the information on risk factors (See Table 2).

"Mothers on the internet actively give directions which are very helpful…"

Compared to the previous theme in "Healthcare" domains, sources of information on 'disease prevention and risk factors' are considered easier to find and understand. Thus, mothers researched this topic on their own or asked around from various sources which involves 5th skill (Table 2). During the interview, the most frequently repeated sources were related to the 'online world' such as social media, websites, and search platforms.

As soon as mothers became pregnant, they started to do research online. Many of them joined Facebook groups consisting of pregnant mothers whose due dates were closer to theirs and obtained information. Mothers who speak English tend to search and find information on Google in English. However, mothers note that search results and books/materials in English have their shortcomings. Information from different countries has been difficult to adapt in Mongolia due to the unavailability of resources. Participants struggled to find the right ingredients including fresh vegetables to make baby food for their children with recipes in English. Some vegetables were not available, or the quality was not reliable. At times, mothers had to order preventative medicine and tools from abroad. Thus, they preferred Google searches to be place specific, as it is important to consider the availability of services and other preventative tools. Mothers mostly are able to access information and understand information within their ability that are 5th and 6th skill (Table 2).

"It was hard to get information on pregnancy, childcare, and infant's health issues in the Mongolian language through Google search. It was usually the same information over and over again copied from the same article. On the other hand, Facebook was much more informative because it allowed people to share their own experiences." [Participant 5]

The quote from above illustrates the fact that some participants preferred social media such as Facebook and Instagram over a Google search. It has emerged that searching information through Google (or any other search engine) in Mongolian is not common among participants as there are not enough reliable sources. Many mothers prefer content in Mongolian due to language barriers. Mothers mentioned several popular Facebook groups and Instagram accounts that have many mothers as members and all contents are in Mongolian which arms them with 6th skill of understanding information (Table 2). Some of these accounts provide information on children's food and nutrition, including recipes and information on macro, micronutrients, ways

to prevent disease through nutrition. Furthermore, Facebook groups are considered trendy among mothers, people post their questions and share information freely. One of the participants mentioned that almost everyone has smartphones these days, which is more convenient, and people spend a lot of time scrolling through Facebook. A participant joined a Facebook group in another country to find more specific information on her child's condition as well.

"I stopped following 'useless' friends and started following accounts of mothers who post about childcare. I usually don't read academic research, and I feel it is better to learn from other mothers' experiences, and some of those mothers are doctors or health professionals." [Participant 2]

As noted by some participants, Facebook has a wealth of information on risk factors and disease prevention, however, it is challenging to validate the accuracy of those posts and answers written by mothers on social media. Some participants noticed that information on social media varies significantly in terms of accuracy and reliability. One of the participants explained how Facebook groups had a large amount of hearsay information from unknown sources, information that contradicted science, evidence-based medicine, and other sources that this mother trusted. She thinks the information was wrong and superstitious but observed that many mothers believed and advised each other. Participants are able to find the information on social media and evaluate the accuracy based on their prior experience and risk factors most of the time within 7th skill (Table 2). Mothers do not blindly believe everything and apply to their lives.

7 out of 9 participants mentioned Facebook at least once during their interview, which shows that Facebook is a widespread source of information for pregnancy, childcare, disease prevention, and risk factors. Since they noticed the size of the audience on those Facebook groups and how mothers rely on information there, a couple of participants who speak English started to translate in their opinion accurate, evidence-based information from English to Mongolian and shared it on Facebook.

"When many other mothers would have questions on Facebook, I often answered them by Googling it or looking it up from my book, and others disagreed. Some others were curious that I had that information. Obviously, it was harder for mothers who didn't know English to look it up as quickly." [Participant 8]

The participant whose daughter had hydrocephalus started her own Facebook group called "Children with Hydrocephalus and Shunt in Mongolia" and continued to receive messages from her group members during the interview. She said mothers have many questions about their children and their condition, but they cannot do searches online because they do not speak English. Mothers research information that are relevant to their situation or their condition and apply to their children within 7th and 8th skills (Table 2).

"I learn traditional practices from elders in my family…"

Participants were asked questions about traditional practices and rituals related to the health and well-being of their children. Mothers shared practices that they do or do not do to prevent their children from diseases and sources of traditional information. All participants

agreed that they get updated on traditional practices from elders, including grandparents, parents, and parents-in-law, older neighbors. Participants were mothers who gave birth in the past five years, and their ages ranged from 24 to 37. Older family members had more knowledge about traditional Mongolian practices and often advised mothers to try those approaches. A couple of the participants mentioned that the traditional ways are what their parents practiced when they were children and encouraged them to do the same. This theme is the most relevant with 7th and 8th skills of interpreting and evaluating traditional information on risk factors and whether mothers are able to judge the relevance of the information to modern world and their situation (Table 2).

"People above the age of 35 always use traditional practices and constantly advise them to others because they have experienced positive results themselves." [Participant 3]

Participants use certain traditional practices related to childcare, and some estimated that 10-30% of their preventative methods are based on traditions. Mothers explained those practices as significant to health and unique to Mongolia. For example, some participants used sheep tail oil to massage their babies' bodies and feet to improve circulation and boost their immunity, while some others observed their babies had rash from the oil and stopped using it. Mothers considered it to be important that their children eat meat and not become vegan, even when some of their children do not like to eat meat. A Mongolian traditional diet is dominated of fatty meat of grass-fed cattle and sheep as well as dairy products which many Mongolians consider to be key in surviving the country's harsh continental weather.

Some mothers refer to some practices as 'superstitious' and perform rituals for their peace of mind. Many mothers agreed that if they would be desperate with a sick child and 'western' medicine does not help, they might try out traditional rituals as their last resort. They consider such practices are more of a psychological treatment and comfort rather than a scientific practice. It shows mothers are able to evaluate the differences within 7th skill, however, performing them for peace of mind shows that 8th skill of judgement of relevance to prevent diseases is somewhat limited (Table 2).

There were multiple examples of contradictions noticed during the interview between traditional beliefs and 'western' medicine. Mothers had to judge and decide if they wanted to follow elders' advice or doctor's instructions using 8th skill (Table 2). As mentioned in previous themes, almost all participants trusted doctors with their child's health and preventative information. Mothers noted that some traditional practices could even be dangerous for babies. They judge and compare scientific findings with traditional methods and all participants mentioned they avoid going extreme in both ways. For example, many people believe it is good for babies to suck on fatty sheep tail that has been dipped in boiling water for few seconds. This is believed to boost immunity and form a protective layer in the stomach as a preparation for introducing solid food. However, one participant points out that it could be unhygienic and might contain bacteria harmful to babies. Such practices are referred to as 'outdated' and evidence-based sources are preferred for preventative purposes. Participants agree that traditional practices may have been historically practical based on diseases that children suffered at that time, however, science and technology have developed in the meantime, producing advice better suited to raise healthy children and address environmental risk factors. It shows mothers' good

ability to understand, evaluate the differences in the face of conflict under 5th and 7th skill and further ability to see the relevance to the present situation their children are facing (Table 2).

"Old traditions and practices were appropriate during that time, in that environment, it is not suitable now. Our working hours, air, food, and diet are very different now. Before people had healthy soil right outside of their homes, did not have air pollution, did not use soiled food, but now we have air pollution, foods with chemical fertilizers, stored meat. Also, science has been coming up with innovative technology all the time." [Participant 3]

Health promotion

Semi-structured interviews contained questions that aimed to study sources of health information of mothers and how mothers inform themselves to understand health issues. Numerous factors influence mothers' ability to understand and form opinions on health issues. Themes on essential factors affecting mothers' opinions on health issues emerged from repetitive codes in transcripts. The research objective to explore mothers' perceptions of HL as a member of a family was mainly focused on this domain. Women surrounding Mongolian mothers seem to have the greatest influence in building mothers' perception of health issues. In addition, as a family member, husbands' understanding and involvement in health issues were analyzed, which affects mothers' health decisions as well. Themes were based on 9) Ability to update oneself on health issues, 10) Ability to understand health related information and derive meaning, 11) Ability to interpret and evaluate information on health related issues, 12) Ability to form a reflected opinion on health related issues skills within the the domain (See Table 2).

"Women's natural instinct"

Mothers frequently repeated their mother and mother-in-law, women around them, as a source of health information. Participants' mothers played an essential role in the formation of health understanding and influenced health related decisions as well. Half of the participants currently lived with their mothers along with husband/fiancé and children. Especially, working mothers rely more on their mothers or mothers-in-law on day-to-day decisions regarding their children's health and well-being. When asked about family members' involvement in their children's health decisions, 'mothers' was the code that was mentioned in almost all interviews during the research.

Participants were asked when and how often they talked about health issues at home. They mentioned that they talk to their mothers daily regarding their children's health. Since many participants lived with their mothers, they can make observations of their children together and frequently discussed health issues based on symptoms. For example, if the child has a runny nose or dry lips, they had conversations that the child might have caught cold and decide to take preventative measures. They offer medical or traditional advice to mothers from a perspective of an elderly family member based on their own experience in raising children in the past. The mother or the mother-in-law are often the primary caregivers for instance using home remedies while parents are away at work. Participants mostly enjoy talking to their mothers about health

issues, but one of the participants mentioned that the conversation might turn into a criticism. They worry about their children's health and see symptoms as a problem that needs to be solved. Offering solutions or providing suggestions on preventative measures that could have been taken before the child got sick can turn into a sensitive issue to talk about. Nevertheless, mothers and mother-in-laws are one of the closest sources at home to obtain health information and updates mothers on their children's health and relevant points as in 9th skill (Table 2).

The involvement of mothers and mothers-in-law in health decisions can cause disagreements as well. One of the participants was 18 years old when she became pregnant and often relied on her mother-in-law during pregnancy and childbirth. She shared about contradictions between information from doctors and her mother-in-law. For example, when she experienced tonus during pregnancy, her mother-in-law did not have much knowledge on that matter. She suggested that she walk more and mop the floor while squatting, but the doctor advised her to be calm and have bed rest. The primary care doctor told her to prepare her breast for nursing before giving birth, but her mother-in-law was against the idea of touching her nipples. The mother-in-law believed that all the colostrum would be expressed before the baby was born, therefore she should refrain from touching her nipples. The participant explained she had difficulty deciding, could not prepare her breasts for nursing and had cracked nipples after birth. Another participant was advised by her mother-in-law to apply soap on the burnt skin of her baby to treat the burn and relieve pain. However, she remembered reading somewhere and ran cold water on the burn right away. Doctors in the emergency unit praised her for her quick action, and her son's burn healed much faster. These incidences show that participants who had their children young, did not have the courage or sometimes the ability to understand the situation and evaluate their mothers' advice and have their own opinion on the matter. Once they had their own experience from other valuable information sources, they started to interpret the situation and apply health information differently based on science and tradition. Thus, it shows that some participants had 9th and 10th skill and able to update and understand themselves on current health issues and science-based measures, however, when there is conflict with family members 11th and 12th skills are limited in some cases (Table 2).

"They (mother, mother-in-law) did not give any information based on science during pregnancy, during birth, and even now. They do not know about evidence-based knowledge. They just supported me emotionally and was there for me and calmed me down and told me that my baby would get better faster if I stay calm myself." [Participant 3]

The interviewed mothers also explained how they wanted to use and rely on as much evidence-based health information as possible, they are also reluctant to conflict their mothers/mothers-in-law as they understand that they have the best intentions regarding their and their children's health. One of the participants mentioned that her mother worry whenever her baby would cry. Although some interviewees had disagreements with their mothers' views, they often followed specific preventative measures, healthcare decisions according to their mothers' advice. Most of the participants talk to their mothers and explain what they want for their babies based on 12th skill, they either come to an agreement or at least, they try to explain their choices to their mothers before proceeding with their own health decisions without letting to sway their own formed opinion.

In addition, another factors that influence mothers' opinion for 12th skill involves health related information from women including aunts, cousins, female friends who had children, classmates from prenatal yoga class and others. In addition to getting information from other mothers on social media, mothers tend to rely on personal networks and familiar experiences, as mentioned in previous themes. One of the participants explained how she used to help babysit her older sister's baby when she was a student. She gained a lot of traditional and medical knowledge from that experience and used them when she had a baby. Participants had friends and cousins who recently had children and called them often with questions. Mothers interpret according to 11th skill that health information from those sources was considered more up-to-date than their mothers' or mother-in-laws' advice since those women gave birth and raised children in recent years. Unique situations such as having twins required one of the participants to contact her cousin who had twins. Since health information on twins was more challenging to find in Mongolia, her cousin became one of the most trustworthy sources.

"There is an old Mongolian saying, 'old lady who has suffered is better than a doctor who knows prescriptions', so I do not ignore such advice, but I always double-check." [Participant 2]

Women sharing their knowledge was not preferred by all participants. Some saw ladies around them as too 'opinionated' and involved in young mothers' decisions too much as they evaluated with 11th skill. One of the participants pointed out that female family members usually share their life experiences, but those stories do not contain much useful information. It was also mentioned that those experiences tend to be focused on specific topics such as healthcare experiences during pregnancy and birth but not about 24-48 hours after birth for instance. There are information gaps in women's conversations that require mothers to seek that knowledge elsewhere using 9th and 10th skills (Table 2).

"For men it is enough that kids are not sick. Prevention is too far from their interest"

The theme emerged from questions about the involvement of family members in health decisions and conversations at home about health and how mothers are forming their opinions for 12th skill. All participants, except one divorced mother, lived with their husbands or fiancé. Husbands' involvement in forming mothers' health opinions and making decisions based on those opinions was analyzed.

Based on previous themes, women are more involved in health decisions regarding children and actively seek health information. They share experiences with women around them. However, mothers did not mention men sharing experiences with others. Participants note that men typically consider it sufficient that their child is currently happy and do not think about prevention or other health issues as much as mothers related to 9th, 10th, 11th and 12th skills (Table 2). Men's involvement in health decision-making, influencing mothers' opnions thus seems to be relatively low.

Participants explained how they discuss health related issues with their husbands. For example, they share research results, understanding and their evaluation, opinions on health related information with their husbands or seasonal changes initiate conversations about moving to a summer place out of the city during the summer for fresh air, boosting children's immunity

with additional supplements and vitamins during spring, and freezing vegetables and fruits in the fall to make nutritious meals in the winter. Mothers note that their husbands are generally supportive, often listening to them and agree with their suggestions and initiatives. One of the participants mentioned her husband has a more traditional view than her, and they tend to have disagreements on some issues. On the contrary, another participant's husband does not like the traditional childcare and children's healthcare approaches. The rest of the participants did not explicitly mention their partner's views on health and disagreements.

One participant who has been talking to her husband about health and well-being noticed her husband changing, who started to make healthier purchases when grocery shopping, and increasingly read nutritional facts and ingredients and forming his own opinion with 12th skill (Table 2). He pays more attention to his health and visits doctors more frequently. On the other hand, husbands act as a double-check system on women's purchases and lifestyle changes. One of the participants talked about how her husband reads instructions on supplements and vitamins for their children and understands, evaluates with 10th and 11th skills (Table 2). He looks up unfamiliar ingredients and likes to get involved. Another participant's husband listens to his wife relay various health information and decides which sources to follow. In general, however, interviewees did not mention their husbands actively seeking health information themselves, forming their own opnions or influencing participants' opinions and initiating conversations about health at home.

"My husband doesn't get involved in those, and I think men are kind of indifferent in that matter. For men, it is enough that kids are not sick, and prevention is too far from their interest." [Participant 3]

Discussion

Under the Healthcare domain from the HLS-EU framework, mothers' ability to access, understand and interpret medical or clinical issues during pregnancy, birth, and childcare were analyzed (39). 12 sub-dimensions from the framework were analyzed as participants' skills related to HL and closely examined (Table 2).

Themes within the domain show that mothers' most trusted sources of information are professional healthcare providers and mostly OB/GYN and pediatricians. Mongolia has rapidly improved antenatal care and introduced mandatory laboratory tests and monitoring to receive maternity allowance as an incentive (40,41). However, mothers followed the process because it is expected to receive maternity allowance from the government. Mothers indicated PHCs, doctors at public hospitals do not give out enough information about pregnancy and labor preparation, healthcare. Medical professionals are not taking initiatives in improving HL during visits except posters and flyers with limited information are available around PHCs. Mothers further resorted to additional sources for more basic, useful information despite their trust in doctors in dire situations.

There are multiple reasons for this apparent lack of communication between doctors and patients in Mongolian hospitals. The health system's transition from a Soviet-built model to a modern developed model is still in progress. After financial support from the Soviet Union ended, the government and development organizations focused on financing programs targeting patients, importing innovative technologies, but there is still not enough budget allocated for doctors and nurses, resulting in relatively low salaries (42). Doctors get paid USD 100-150 per month, equal to the salary of a factory worker in Mongolia (43). Healthcare workers have long been unsatisfied with their pay and working conditions, considering the heavy workload and long working hours. Mongolian medical workers have been demanding to get compensated fairly for their hard work for a long time, and the issue has been raised more significantly due to the Covid-19 pandemic (44). Even though, all participants indicated to trust doctors and evidence-based medicine with necessary medical care during pregnancy and in the event their children got sick, mothers who could afford private care, evaluated the differences and decided to give birth in private hospitals and trusted private clinics for pediatricians who would explain and guide mothers with open communication. It leads to mothers deciding not to give prescribed medication to their children or choosing to deny advised inpatient care and lacking a skill to evaluate and make informed decision on medical issues due to lack of explanation. Communication between health professionals and patients involving thorough discussions about the causes of sicknesses, risks, and benefits, patients' preferences are significant factors influencing HL in mothers (45). It impacts their understanding and evaluation of the medical condition and influences decisions significant to their children's health (45).

The second domain, 'Disease Prevention', includes mothers' ability to access, understand, and evaluate information on risk factors (39). Sources of health information on disease prevention and risk factors were mostly revolved around the internet and social media. Google search results were mainly in English, and participants observed a lack of reliable information on risk factors in Mongolian for mothers who did not speak a foreign language. Ability to read and understand in a foreign language was an important factor influencing themes

in this domain. Facebook has become the most popular platform for Mongolians for many types of information since smartphones were introduced (46). Many businesses and organizations have Facebook accounts instead of a website, and a large amount of information circulating in social media groups are in Mongolian but impossible to validate for accuracy (46). This result is quite unique to this setting since Facebook became responsible for both formal and informal communication platforms in Mongolia, not limited to its role of social media. Facebook plays a role of a search engine, telemedicine provider, announcer of health and other public announcements, workplace communication device etc. Mothers are aware and concerned about the flaws of social media since it is a matter related to their and their children's health. Multiple participants rely on online courses on Facebook that are taught by doctors, nutritionists which helps them trust their content more. Mothers were able to judge the accuracy and avoid applying irrelevant information on risk factors at times of conflicting health related information sources from social media. It comes back to healthcare professionals being the most trusted source since they are also behind many private accounts on Facebook which help mothers choose and pick information and further improve their HL.

In Asian culture, living close to older family members and respecting their opinions, advice is relatively common (47). Rapid urbanization influenced modern young people to move away from their elders and live on their own at an earlier age. Elders' role in decision-making remains significant as many young people remain financially dependent on their parents. Since Mongolians had a nomadic lifestyle until the end of the last century, traditional rituals are still widely practiced in day-to-day lives (22). Participants had older family members, including grandparents, parents advising traditional disease prevention approaches and risk factors regarding the child's health. People most likely created and followed traditions due nomadic lifestyle and harsh weather in Mongolia. The traditional approach often contradicts evidence-based medicine, doctors' advice leaving mothers to decide between family members' advice and evidence-based medicine. Even though mothers are left in a difficult position to disagree with respected elders or to not encourage their involvement in health decisions, participants mostly made final decisions based on scientific evidence on disease prevention, risk factors after researching and comparing local and foreign sources. In such cases, mothers' own experience and education, foreign language proficiency were important factors influencing their decisions. Mothers who gave birth when they were young, while in university, did not have the ability to evaluate and judge health information or knowledge to voice their opinions against traditional practices. They trusted elders' advice was the best and trusted them. However, on their second or third children or mothers who are having their first child later in their 20s or early 30s tend to have more experience from their previous births or from sources around them. They became more confident to compare and evaluate traditional practices with evidence-based medicine and decided based on their research. Also, mothers with higher education were more financially and overall independent from extended families and did not seek advice on traditional practices, critically analyzed health advantages and disadvantages accordingly. The literacy rate and tertiary education enrollment levels among the population have been gradually increasing, but numbers are still lower in populations above the age of 65 than younger people (2).

The third domain, 'Health promotion', show active involvement of women surrounding mothers in childcare and health decisions. Women influence mothers' opinions on health issues and help to form those opinions by constantly sharing information and experiences. On the other

hand, husbands' involvement in health decisions was lower than women. The current gender wage gap and gender segmented labor market are examples of many reasons why the improvement has slowed down (48). Women get paid on average about 82.1% of the average man's salary in Mongolia in 2018, and it makes sense for men to take the role of breadwinner in families with young children (48). Husbands' involvement in household chores and children's health decisions are not improving due to a lack of easily accessible information sources and low HL and other reasons that needs to be looked into. Women take up the responsibility of HL regarding children's health and talk to each other more often. It might not leave space for men to talk about these topics and share information with women as mothers might see HL of children's health as their duty that needs to be performed alone or with the help of other women. The study showed that mothers influence their husbands' opinions on health issues more than men influence women's opinions and lifestyle. When there are conflicting opinions between participants versus elders, participants versus medical professionals – husbands are not usually supporting factor that encourages women to make decisions and empowers them. Husbands follow and discuss about normal, common, mandatory procedures during pregnancy such as PHC visits etc., however, no additional interest, support was shown. It could be due to trust they have towards mothers' HL and do not play active role in household health matters in general. On the other hand, other women with close relationship to mothers, support mothers through their HL journey. Starting from basic exchange of information to emotional, physical support come from female siblings, friends, aunts and other experienced mothers in the community and on Facebook. Mothers seek advice and base their decisions on information they heard from other women when there is conflicting information. Women empower each other by discussing extensively and mothers themselves promote HL by actively sharing their experiences and stories as well.

HLS-EU survey domains were used as a framework for the analysis of the study. Even though the analysis took an inductive approach to create themes from codes, HLS-EU domains acted as a guide for HL since it is a relatively broad understanding involving healthcare, disease prevention and health promotion. The framework was relevant to all three objectives of the research as it aimed to cover the experiences and perceptions of mothers. The HLS-EU framework helped themes to fall under three categories and made the results section much more organized. Two themes represented each domain in the framework, and the presentation of results were based on sub-dimensions of HL from HLS-EU (Table 2). However, HL does not cover only individual's decisions and opinions on health issues but involves surrounding environmental factors, traditions, resources, and situations (49). The HLS-EU mainly was based on an individual's ability to access, understand, judge, and apply health information and excluded people, situations, and sources of information other than the individual (39). Therefore, these surrounding factors representing the complexity of HL were explained and included in the results section within domains of the framework.

Strengths and Limitations

Qualitative research is still relatively uncommon approach for the Mongolian scientific community. The study's methodology, based on semi-structured interviews, reflects opinions, experiences and stories of participants and sheds light on the topic from a different perspective than quantitative studies. There was no study available in Mongolia on the HL of mothers, or the

expectations and perceptions of mothers on health-related topics. There is limited literature on HL in general in Mongolia, and the research will contribute to the scientific literature for Mongolian academics. The inductive approach on thematic analysis allowed the themes to emerge naturally from codes and reflect multiple perceptions and complex experiences of mothers regarding pregnancy, childbirth and childcare without being limited to HL. The researcher was familiar with the local context and spoke the local language, which allowed the research to be conducted in a naturalistic setting comfortable to participants.

The study faced multiple limitations unique to the situation and its design. The sample size of 9 participants represents a relatively small share of all Mongolian mothers living in the city of Ulaanbaatar. Inclusion criteria targeted a small sample size. The results do not represent Mongolian women living outside of the capital city and mothers who had children more than five years ago. As the participant recruitment was done through personal networking and a recruiter was used to minimize selection bias as much as possible, there is a possibility of results being influenced by a researcher's biases. In addition, the study was conducted during the Covid-19 pandemic and times of intermittent lockdown. The situation did not allow all participants to be interviewed face-to-face for more observation and limited access to more participants with young children due to safety reasons.

Conclusion

The qualitative study was done on expectations and perceptions on HL of Mongolian mothers living in Ulaanbaatar, Mongolia. Participants' discussion shed light on mothers' experiences of HL, factors influencing the formation of health opinions regarding children's health during pregnancy, childbirth, and childcare. Family members' influence on mothers' health related decisions were explored and analyzed through themes. Participants trust doctors for evidence-based knowledge and learn about Mongolian traditional environmental knowledge from older members in the family. Husbands' involvement and support in understanding, evaluating, and deciding on health issues is relatively low compared to other women surrounding mothers, including grandmothers, mothers-in-law, mothers, aunts, cousins, and female friends. The trend could be due to nomadic Mongolians' historical and traditional division of labor with husbands more responsible for "outside the home" matters. Husbands' involvement is gradually improving. Mothers' medical knowledge sources were mainly based on doctors' instructions and guidance during pregnancy, childbirth, and childcare. Mothers showed good abilities to judge, evaluate and decide on health issues comparing medical versus traditional knowledge. Mongolian mothers' experiences of HL in healthcare, disease prevention, health promotion shows insufficiency in reliable sources of health information accessible to mothers regarding pregnancy, childbirth, childcare. Mothers actively seek health information online in their personal network in Mongolian and English, limited to their foreign language proficiency, since doctors do not actively take part in promoting and supporting mothers' HL. The reliability of popular sources such as Facebook groups and family members is difficult to validate for accuracy. This result represents the lack of accurate health information to improve HL in areas outside the city with less access to healthcare and internet coverage. In addition, mothers with lower education and from lower socioeconomic background have fewer opportunities to empower themselves to improve their HL for health and well-being of their children.

Based on the study's conclusion, the below recommendations are given to improve and encourage HL in mothers and the general population regardless of their financial status and living conditions.

Policy recommendations

- Introducing the concept of HL to the general population through education as a public health understanding through NGOs of interest. Generalizing the population's understanding of 'patient education', 'patient activation', 'health education', 'health knowledge' under the term of HL would increase the population's awareness of HL and further improve reliable health information sources to further use necessary skills related to HL.
- Increase funding for academic research done in the public health field to encourage innovative interventions for improving the HL of the population. Explicitly focusing on the HL of mothers with young children will affect the maternal and child health, further HL, the health status of next generation of the population.

Interventions

To introduce the concept of HL to the population and increase reliable health information sources, it is crucial to focus on academic curriculum in secondary, tertiary education, and online sources targeting the young population. Making changes in school curricula and expanding public health content in secondary schools can encourage children to understand, evaluate and make health decisions for themselves from an early age. Further inclusion of HL concepts in the tertiary education system will improve the HL of the population by empowering them with knowledge at young age. In addition, it is vital to encourage NGOs, private content makers to use and define the term HL through utilizing popular online platforms such as websites, Youtube videos, Facebook posts, Instagram accounts etc. promoting the understanding of HL. Online content can familiarize the public with the HL and increase the ability to navigate health systems, understand disease prevention and health promotion, and improve digital literacy.

Health providers play an essential role in improving the HL of the population. Incentivizing health providers for creating educational programs, explaining and informing health issues to patients and families to empower them, working in remote areas close to population groups far from larger hospitals can motivate providers. HL skills can become part of all health providers' training and education, including doctors, nurses, and assistants with help of international and local NGOs currently focusing on healthcare and public health. It will improve medical professionals' ability to explain and empower patients and answer their questions by creating an ambulatory visit protocol. In addition, mobile health systems can be expanded to increase accessibility in remote areas and improve the HL of patients regarding pregnancy, childbirth, childcare, and disease prevention.

It is necessary to take a multidisciplinary approach to create programs and initiatives to promote HL in a population through incentivizing doctors, NGOs, medical students, and professionals. Designing new, reliable, evidence-based health and prevention information sources through programs would draw people’s interest in health-related topics. In addition, community education programs in remote areas are essential to bridge the gap between healthcare in urban cities and the countryside. Creating abundant printed educational materials such as brochures, handbooks available at clinics and community centers can cover population outside of the city as well as from low socioeconomic groups.

The above interventions should be prioritized to have a solid plan to improve the HL of the population. The initial step includes understanding HL in education and training of health professionals to build human resources that would further create HL programs targeting the rest of the population groups (mainly the old, middle-aged population). Trained human resources would also participate in reforming secondary, tertiary education programs on health sciences, HL in school subjects. This reform would target the young population of Mongolia to learn about HL and adapt the concept in everyday lives as soon as possible. Further steps should be taken to increase the number of reliable health information sources to the population using popular media channels for various population groups.

Research recommendations

The research used qualitative study methods by interviewing participants to describe and explore Mongolian mothers' experiences on HL. There is an urgent need for further research on different aspects of HL in Mongolia to develop efficient and effective interventions to improve HL in the country. Research plays a significant role in making data available to public health professionals, NGOs, policymakers to work on the issue. Quantitative research methods can be used to study the HL levels of the population in Mongolia. This study used HLS-EU as a framework for analysis; however, researchers can use the survey for a quantitative study to measure HL in the country. Depending on the scope of the study, it is crucial to measure the HL of the population in cities, provinces to reflect the HL of both urban and rural areas. It will allow professionals to compare the difference of HL between the capital city versus remote provinces, young people versus older generation, females versus males, and many other factors affecting HL. Such data will be valuable for developing programs and content targeting specific population groups depending on their HL level to promote and improve the overall HL in Mongolia.

Urgent work needs to be done to improve the accessibility and availability of evidence-based health information to promote HL for Mongolian mothers and the general population. This would improve Mongolians' HL by allowing the population to learn, understand, evaluate, and make decisions regarding their health and that of their children for the country's healthy future.

"I hope there will be more (health) information available, and people would live a long and productive life. People become more productive when they are healthy and create more wealth in the country, improving family finances". [Participant 4]

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Annex 1. Interview guide in English

Methods: Semi-structured interviews
DATE:
Code:
Interview time:
Interview Duration:
Moderator: Signature:

General information:

1. Please tell me about your family. How many children do you have and what are their ages?
2. How involved are you in your child's day to day lives and their health decisions? Who else is involved in those decisions?

Healthcare

1. Please share your experience regarding knowledge and your confidence in information you have received during pregnancy?
- Where did you get information?
- When did you think you have received enough information?
- Did you receive contradicting information from different people around you? (Family, doctors etc.)
- Did the information you found were useful for comfortable pregnancy?
- Did you know when to contact a doctor and how to proceed with instructions and prescriptions from the doctor?
2. Please share your experience regarding knowledge and your confidence in information you have received during childbirth?
- Where did you find most useful information?
- Were you able to use the knowledge to have better experience?
- Did you feel more comfortable by having more knowledge about health?
3. Please talk about the time when your child got sick.
- What happened?
- What did you do?
- What did the doctor advise? (If you went to see a doctor)
- What did your family members (including partner) advise?
- What did you feel about the whole experience?

Disease prevention

4. Please share how you prevent your child from getting sick?
- Where do you find most useful information about childcare?
- What does your family members advise?
- Please tell me about your trustworthy sources of information.

5. What are most important steps you take to raise a healthy child and where did you find out about risk factors?
- Where and how do you actively look around for preventative information?
6. How do you perceive traditional approaches in your daily life to raise a child? (Traditional)
- Where do you learn traditional rituals/approaches/practices for childcare?
- Please share your thought process on how you decide between scientific approach from a doctor's advise or traditional rituals/practices.
- Where do you find most effective preventative knowledge that you practice on your child? (Traditional and environmental)

Health Promotion

8. Does your family talk about health issues, child health at home? (Environmental)
- Including your parents, siblings, husband?
- When do you usually talk about this topic?
- How often?
- Does your family members enjoy the conversation about health and well-being?

Conclusion?

Annex 2. Interview guide in Mongolian

Ярилцлагын заавар

Зорилго, зорилт:

1. Эрүүл мэндийн цагаан толгойн тухай ээжүүд хувь хүн мөн гэр бүлийн гишүүний өнцгөөр харах ойлголтыг судлах
2. Монгол ээжүүдийн хүүхэд асаргааны тухай анагаах, орчин ба уламжлалт мэдлэгийг дүрслэх
3. Эмчилгээ, урьдчилан сэргийлэх, эрүүл мэндийг дэмжих хүрээнд эрүүл мэндийн цагаан толгойтой холбоотой монгол ээжүүдийн туршлагыг судлах

Аргачлал: Ярилцлага

Огноо:
Код:
Ярилцлагын цаг:
Үргэлжлэх хугацаа:
Модератор: Гарын үсэг:

Ерөнхий мэдээлэл:

1. Өөрийн гэр бүлийн тухай яриач. Хэдэн хүүхэдтэй вэ? Тэдний нас хэд вэ?
2. Та өөрийн хүүхдийн өдөр тутмын амьдрал болон эрүүл мэндийн тухай шийдвэрүүдэд оролцоотой байдаг уу? Танай гэр бүлд өөр хэн тэр шийдвэрүүдэд оролцдог вэ?

Эмчилгээ:

3. Жирэмсэн байх үеийнхээ эрүүл мэндийн мэдлэг, өөртөө итгэх итгэлтэй холбоотой туршлагаа хуваалцаач.
- Та хаанаас мэдээлэл авдаг байсан бэ?
- Та хангалттай мэдээлэл авсан гэж боддог уу?
- Та эргэн тойрныхноосоо эсрэгцсэн мэдээлэл авч байсан уу?
- Жирэмсэн үедээ авч байсан мэдээллүүд чинь танд хэрэг болсон уу?
- Та хэзээ эмчид хандаж, эмчийн зааврыг дагах ёстойгоо мэддэг байсан уу?
4. Та төрөлтийн үеийн эрүүл мэндийн цагаан толгойтой холбоотой туршлагаа хуваалцааач.
- Та хаанаас хамгийн хэрэгтэй мэдээлэл авдаг байсан бэ?
- Та авсан мэдээллээ ашиглан төрж чадсан уу?
- Та эрүүл мэндийн тухай мэдлэгтэй байснаараа илүү тайван байсан уу?
5. Таны хүүхэд өвдсөн үеийн тухай яриач.
- Юу болсон бэ?

- Та юу хийсэн бэ?
- Эмч юу гэж зөвлөсөн бэ?
- Таны гэр бүл (нөхөр) ямар зөвлөгөө өгсөн бэ?
- Та тэр үйл явдлын тухай юу гэж боддог вэ?

Өвчнөөс урьдчилан сэргийлэх

6. Та хэрхэн хүүхдээ өвчнөөс урьдчилан сэргийлдэг вэ?
- Та хүүхэд асрах тухай хамгийн хэрэгтэй мэдээллийг хаанаас авдаг вэ?
- Та гэр бүлийнхнийхээ зөвлөгөөг сонсдог уу? Тэд юу гэж зөвлөдөг вэ?
- Та итгэдэг эх сурвалжийнхаа тухай хуваалцаач. Та эмэгтэйчүүдийн эмчдээ итгэдэг үү? Хүүхдийн эмчид? Гэр бүл? Найз нөхөд?
7. Та эрүүл хүүхэд өсгөхийн тулд авдаг хамгийн чухал алхмууд юу вэ? Та эрсдэлт хүчин зүйлүүдийн тухай хаанаас мэдэж авдаг вэ?
- Та урьдчилан сэргийлэх тухай мэдээллийг хаанаас хэрхэн идэвхитэй хайдаг вэ?
8. Та хүүхэд өсгөх уламжлалт арга барилыг юу гэж боддог вэ?
- Та уламжлалт зан үйл, арга барил, ёс заншлуудыг хаанаас сурч авдаг вэ?
- Та тэдгээр арга барилд шинжлэх ухаанд суурилсан эмчийн зөвлөмжөөс илүү итгэдэг үү? Итгэхдээ хэрхэн өөртөө дүгнэлт хийж тунгаадаг талаараа яриач.

Эрүүл мэндийг дэмжих

9. Танай гэр бүл эрүүл мэнд болон хүүхдийн эрүүл мэндийн тухай ярилцдаг уу?
- Эцэг эх, эгч дүү, нөхөр
- Та бүхэн ихэвчлэн хэзээ энэ сэдвээр ярилцдэг вэ?
- Хэр ойр ойрхон?
- Танай гэр бүлийн гишүүд эрүүл мэнд, эрүүл амьдрах тухай ярилцах дуртай юу?

Дүгнэлт?

Annex 3. Informed consent form in English

My name is Bayardolgor Bayaraa and I am doing this research as my thesis project for my Master in International Health degree at KIT-Royal Tropical Institute in the Netherlands.

Purpose

WHO defines health literacy in its glossary in 1998 as "implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions". However, health literacy is a relatively new understanding among medical colleagues in Mongolia which was officially translated into Mongolian language and accepted in use in 2020. HL is supposed to be an inseparable part of everyday life of all each Mongolian citizen who is using healthcare services in some way to exercise their right to stay healthy.

The study aims to find out about Mongolian mothers' perceptions and experiences regarding health literacy during pregnancy, childbirth and childcare as an individual and as a member of a family. Questions will be asked to explore health literacy of mothers in three domains – health promotion, disease prevention and healthcare in terms of traditional, environmental and medical knowledge.

Risks and benefits

The participation in this research will not benefit you personally in any way. However, this research can become a guide to increase availability of sources of knowledge that mothers find useful, bring light on real life examples and difficulties regarding lack of accurate sources of health literacy. Further work can be done to find ways to promote HL, bring awareness to the level of HL of mothers to improve recognition of the term for public use. The study can potentially have a greater impact for health accessibility, health equity and healthcare development.

The participation is voluntary, and you can skip questions if you don't feel comfortable answering. The interview will continue for 1-1.5 hours, and you can stop at any time. If you start to feel emotional or uncomfortable due to the questions that are asked about your past experiences, please let the researcher know and the interview will be discontinued. The researcher can give you a referral to a counsellor if needed to address emotional burden during or after the interview. The interview will be conducted in a mutually agreed place that is most comfortable for you where no one will hear our conversation. The option to meet online through Zoom or Google Meet can be arranged if you are not available to meet face-to-face.

The study will follow KIT Guidelines on on Data Collection Procedures During Covid-19 as well as local government guidelines during Covid-19.

Confidentiality

If you choose to participate, your participation and identity will be confidential. No information or potential piece of information will be included in the study that can be tracked back to you. We will record the interview with your consent coding your name as "Participant #" and the interview will be transcribed and translated for further analysis and the process will be confidential. Only the researcher will have access to the records. All the recordings and other personal data for the study will be destroyed after submission of the thesis and oral examination on August 30th, 2021.

Results

Findings from this study will be analyzed and written in a thesis report. It will be submitted as the master's degree thesis work of the researcher in August 2021. After the submission, the study can be shared with you through e-mail at any time upon request. The study was approved by the ethics board at KIT in Amsterdam, the Netherlands and Ulaanbaatar, Mongolia.

The participation is voluntary, and you can discontinue your participation at any moment without any consequences.

Agreement:

The study was explained to me, and I agree to participate in the study by getting interviewed after I have given the consent.

Signature:

Date:

If you have any questions or complaints regarding the study, please contact:

Researcher: Bayardolgor Bayaraa
+976 99994318
bayardolgorb@gmail.com

KIT Ethics Committee: Susan Huider
0031 20 568 8237
S.huider@kit.nl

Annex 4. Informed consent form in Mongolian

Зорилго

Эрүүл мэндийн цагаан толгойг 1998 онд ДЭМБ-аас гаргасан эрүүл мэндийн тайлбар толь бичигт "хувь хүн амьдралын хэв маяг, амьдрах нөхцлийг өөрчлөх замаар хувийн болон нийгмийн эрүүл мэндийг сайжруулах арга хэмжээ авах мэдлэг, ур чадвар, өөртөө итгэх итгэлийг олж авсныг хэлнэ" гэж тодорхойлсон байдаг. Гэсэн хэдий ч эрүүл мэндийн цагаан толгой нь монголын анагаахын мэргэжилтнүүд дунд харьцангуй шинэлэг ойлголт бөгөөд 2020 оноос албан ёсоор монгол хэлэнд хөрвүүлэн хэрэглээнд нэвтрүүлсэн болно. HL нь эрүүл байх эрхээ эдлэн эрүүл мэндийн тусламж, үйлчилгээнд хамрагдаж буй Монгол Улсын иргэн бүрийн өдөр тутмын амьдралын салшгүй нэг хэсэг байх ёстой юм. Энэхүү судалгаагаар Монгол эхчүүд хувь хүн болон гэр бүлийн гишүүний хувьд жирэмсэн үе, төрөлт, хүүхэд асаргааны үеийн эрүүл мэндийн цагаан толгойн ойлголт, туршлагын талаар олж мэдэхийг зорьсон. Уламжлалт ёс заншил, хүрээлэн буй орчин, анагаах ухааны мэдлэгийн үүднээс эрүүл мэндийг дэмжих, өвчнөөс урьдчилан сэргийлэх, эмнэлэг эмчилгээ гэсэн гурван салбар дахь эхчүүдийн эрүүл мэндийн боловсролыг судлах асуултууд асууна.

Эрсдэл ба ашиг тус

Тус судалгаа нь амьдралын бодит жишээнүүд дээр тулгуурлаж эхчүүдэд хэрэгцээтэй үнэн зөв мэдлэгийн эх үүсвэрийн дутагдалтай байгаатай холбоотой бэрхшээлүүдийг тодруулж эрүүл мэндийн цагаан толгойн эх үүсвэрүүдийг нэмэгдүүлэх гарын авлага болох боломжтой. Судалгаан дээр үндэслэн цаашид эрүүл мэндийн цагаан толгой гэсэн нэр томъёог олон нийтийн хэрэглээнд хүлээн зөвшөөрч сурталчлах, эхчүүдийн эрүүл мэндийн цагаан толгойн мэдлэгийг дээшлүүлэх арга замыг хайж олох ажлуудыг хийхэд дөхөм болох юм. Энэхүү судалгаа нь эрүүл мэндийн хүртээмж, эрүүл мэндийн тэгш байдал, эрүүл мэндийн тусламж үйлчилгээний хөгжилд илүү их нөлөө үзүүлж болзошгүй юм. Оролцоо нь сайн дурын үндсэн дээр явагдах бөгөөд хариулахыг хүсэхгүй байгаа асуултаа алгасч болно. Ярилцлага 1 цаг үргэлжлэх боловч та хүссэн үедээ зогсох боломжтой. Хэрэв та урьд өмнө тохиолдож байсан үйл явдлын талаар асуусан асуултаас болж сэтгэл хөдлөл, таагүй мэдрэмж мэдэрч эхэлбэл судлаачдаа мэдэгдэж ярилцлагыг зогсоох боломжтой. Ярилцлагыг харилцан тохиролцсон, танд хамгийн тохь тухтай газар явуулах болно. Судалгаа нь Ковид-19-ийн үеэр мэдээлэл цуглуулах тухай KIT-ийн удирдамж, мөн Монгол Улсын Онцгой Комиссын заавар зөвлөгөөг дагаж мөрдөнө.

Нууцлал

Хэрэв та оролцохоор шийдсэн бол таны оролцоо, хувийн мэдээллийг чанд нууцлах болно. Таныг таних тэмдэг болж болзошгүй мэдээллийг судалгаанд оруулахгүй. Ярилцлагын үеэр таны зөвшөөрлөөр дуу бичлэг хийн цаашид бичлэгийг орчуулж анализ хийх ба тэдгээр үе шатууд ч мөн нууцлалын журмын дагуу явагдана. Зөвхөн судлаач л дата, мэдээлэлд

нэвтрэх эрхтэй болно. Судалгааны бүх бичлэг, бусад хувийн мэдээллийг дипломын ажлыг хураалгасны дараа устгана.

Үр дүн

Энэхүү судалгааны үр дүнд анализ хийж дипломын ажлын тайланд бичнэ. Тайланг 2021 оны 8-р сард судлаачийн магистрын зэргийн дипломын ажил хэлбрээр хураалгана. Та хүсэлт илгээвэл судалгааны тайланг цахим шуудангаар тантай хуваалцах боломжтой. Энэхүү судалгааг Нидерландын Амстердам хотын KIT (Royal Tropical Institute) дахь ёс зүйн хороо болон Улаанбаатар хотын Монгол-Япон сургалтын эмнэлэг дээрхи Анагаахын Шинжлэх Ухааны Сургуулийн Эмнэлгийн салбар ёс зүйн хороогоор тус тус батлав.

Оролцоо нь сайн дурын үндсэн дээр явагдах тул та оролцоогоо хүссэн үедээ зогсоож болно.

Зөвшөөрөл:

Тус судалгааг надад тайлбарлаж өгсөн бөгөөд судалгаанд оролцож ярилцлага өгөхийг зөвшөөрч байна.

Гарын үсэг:

Огноо:

Судалгааны тухай асуулт, гомдол байвал дараах хаягаар холбогдоно уу:

Судлаач: Bayardolgor Bayaraa
+976 99994318
bayardolgorb@gmail.com

KIT (Royal Tropical Institute) дахь ёс зүйн хороо: Susan Huider
0031 20 568 8237
S.huider@kit.nl

FOR OFFICE USE ONLY	Date of submission	Date considered	Approval granted?
Application Number			Yes/no
Signatures			(Chair)

THIS FORM MUST BE TYPEWRITTEN

KIT | Health

RESEARCH ETHICS COMMITTEE

APPLICATION FORM FOR ETHICAL APPROVAL

ALL QUESTIONS MUST BE ANSWERED. ANY FORM STATING "SEE PROTOCOL" WILL BE RETURNED.
(This form must stand complete in itself)
PLEASE PROVIDE ONE COPY OF THIS FORM AND OF THE ORIGINAL PROPOSAL AND A TABLE OF ACRONYMS AND REFERENCES

AS FAR AS POSSIBLE YOU SHOULD RESTRICT ALL ENTRIES TO THE SPACE PROVIDED ON THIS FORM
Please use a typing front which is easily distinguishable from the questions of the form

NB This form is available on diskette from the Secretariat.
Have you submitted this proposal to the Royal Tropical Institute before?:

☐ No ☐ Yes Date and outcome:

If you are re-submitting a proposal, you need only provide the title of the project and complete those sections of the form where changes have been made. Please emphasize how the proposal has been amended in the light of previous recommendations from the Royal Tropical Institute Research Ethics Committee.

If this proposal was proposed before to the KIT REC or elsewhere what was the outcome?

Accepted ☐ Pending ☐ Rejected ☐ Date:

NAME OF APPLICANT: Bayardolgor Bayaraa

If this proposal is for work that will go towards a higher degree (e.g. MSc or PhD), please state name and Area of Supervisor *(The supervisor needs to sign signifying agreement with submission)* :

NAME & SIGNATURE OF SUPERVISOR:

NAME & SIGNATURE OF LOCAL SUPERVISOR:

PARTICULARS OF PROJECT AND INVESTIGATORS

1. Project title

Experiences and perceptions of health literacy of Mongolian mothers

2. Principal investigator(s)

Names: Bayardolgor Bayaraa

Positions: MIH Student

3. Institution responsible for the research

Name: KIT – Royal Tropical Institute

.

4. Collaborating institutions

List all collaborators (Please include all overseas collaborators and give their affiliations, qualifications and role in the study).

Co-investigators, affiliation and role

Course Coordinator, Academic Advisor:

Fernando Maldonado Costa, MD, MPH
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KIT Royal Tropical Institute
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Thesis Advisor:

Naranchimeg Sodovsuren, MD, Ph.D, Professor
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SECTION A

STUDY OUTLINE *(To save paper the form provides the issues you need to address. You can use more space than is provided in the form)*

A.1 TITLE OF PROJECT

Experiences and perceptions of health literacy of Mongolian mothers

A.2 EXECUTIVE SUMMARY

Give a short overall summary of the proposal using lay terminology (Background and justification, purpose and design of the study).

Mongolia is a country located in Central Asia with a population of 3.3 million. The country, with a nomadic tradition, was an informal part of the Soviet Union until 1990 when a democratic government was established after 70 years of socialist rule. Historically, Mongolian mothers were known to take care of politics and their children simultaneously when husbands were away fighting in wars (1). In a harsh environment with temperatures as low as -40°C, mothers were adept at knowing what was best for their children (2). However, the lifestyle and traditions transitioned to socialism in the twentieth century, leaving mothers living in urban cities with limited knowledge of western medical advice for raising a healthy child (2).

The term "health literacy" (HL) was first introduced by Simonds in 1974 (3) and was later defined by the World Health Organization (WHO) in 1998 as "the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" (4). HL is a relatively new concept in Mongolia, as it was officially translated into Mongolian and accepted in 2020 (5). High levels of health literacy (HL) are essential for all Mongolian citizens who use healthcare services in order to exercise their right to stay healthy. Studies have demonstrated that low maternal HL is associated with poorer health outcomes in children, while low patient HL can lead to inaccurate diagnosis and ineffective treatment (6). Moreover, parental HL is a key factor in the development of the health system and the well-being of children, who are the future of the country.

This qualitative research aims to explore the HL of Mongolian mothers living in an urban city, as well as their experiences related to HL during childbirth and subsequent years of raising a healthy child. Although this is an understudied area with a lack of local literature, the methodology will be based on similar studies that have been conducted on the HL of mothers around the world.

A.3 INTRODUCTION; BACKGROUND AND JUSTIFICATION

Give a brief summary of the literature review, including references and search strategy. State the relevance of the research and how it will be used. Provide references at the end of this sections

In 2020, health literacy was introduced and translated for the purpose of research in Mongolia, terms such as patient education, health education, and health knowledge, which had been used to promote health and well-being for the general public, but were too broad to provide an organized framework for public health from a public health perspective. Additionally, there was a lack of multidisciplinary understanding of health terms to enable further discussion of public health knowledge in finance, education, and other fields. As a result, the term was introduced among medical workers, but its use has been limited to professionals only.

In order to broaden the recognition and use of this term, a comprehensive literature review was conducted on the development of health literacy in different countries around the world. To further emphasize the importance and awareness of health literacy, the significant relationship between mother's health literacy and child health were highlighted through snowballing technique, as this is an unexplored area in Mongolia. It has been observed that since the end of the past century, developed countries around the world have made progress in raising awareness and implementing policies, protocols to achieve health literacy as a public health goal and to improve life quality in general, as health literacy has become one of the determinants of health over the years (6)(7)(8). In Mongolia, low health literacy levels have been associated with higher numbers of hospital and emergency department visits, low immunization rates, and poor drug adherence (7).

An example of assessing HL through questionnaires based on a conceptual model is The European Health Literacy Project (HLS-EU). This method was able to quantify the relationship between HL and health status in the population in general (8). On the other hand, qualitative studies were conducted on mothers in developing countries, such as Samoa and Hungary, to gain insight into their understanding of HL and their engagement, experiences during childcare related to HL (9,10). As mothers are primary caretakers of their children, it was found that low HL of mothers was directly proportional to low pediatric health status (9,10).

This research can become a guide to increase availability of sources of knowledge that mothers find useful, bring light on real life examples and difficulties regarding lack of accurate sources of health literacy. Further work can be done to find ways to promote HL, bring awareness to the level of HL of mothers to improve recognition of the term for public use, and develop strategies to improve health literacy. The study can potentially have a greater impact for health accessibility, health equity, and healthcare development by providing mothers with more access to accurate and comprehensive health information.

A. 4 OBJECTIVES

Overall goal of the research

Explore experiences and perceptions of Mongolian mothers who are living in Ulaanbaatar regarding their health literacy on pregnancy and childcare.

Specific objectives of the research:

1. To explore and analyze perception of health literacy as an individual and as a member of a family among Mongolian mothers and their ability to access and understand medical and health-related information, information on risk factors;

2. To examine medical and traditional knowledge on pregnancy, childcare of Mongolian mothers with children up to 5 years of age and mothers' ability to judge and apply medical and health-related information, information on risk factors;

3. To analyze experiences regarding health literacy in healthcare, disease prevention, health promotion domains during pregnancy and childcare for further interventions among Mongolian mothers with children under the age of 5

4. To recommend actions including policies and interventions for NGOs operating in Mongolia towards improving public health, maternity and child health;

A.5 METHODOLOGY

Outline how you intend to achieve the objectives of the study.

Guidance notes:

For each objective:-

- *define the issues/ variables to be explored*
- *define the techniques to be used (e.g. structured, semi-structured interview, focus group discussion)*
- *define the target population*
- *describe the rationale for each of the data collection methods.*

Give some detail on how methods are already validated (e.g. literature, earlier use) and how you will pre-test/ pilot them

Please provide the draft research instruments in the annex

Type of study

This is a qualitative study with primary data. The research will take a narrative approach in order to explore the experiences of mothers and to examine both their perspectives and the researcher's view.

Achieving the objectives

To achieve the first, second and third objective, it is suitable to conduct open-ended interviews with mothers with children up to 5 years of age, living in Ulaanbaatar, in order to explore their perceptions and understanding of health literacy and to give them the opportunity to tell their stories in private.

To achieve the fourth objective, results are analyzed to recommend interventions and policies on improving health literacy (HL) in the general population based on findings. Multiple local and international NGOs are operating in Mongolia focusing on improving public health, maternal and child health, and providing respectful maternity care independent from government and public entities. This study will suggest actions for NGOs to promote the understanding of HL in Mongolia, and further incorporate the term into the public health field to educate and empower the general population. Furthermore, the study should also provide recommendations on how to better track and monitor the progress of HL initiatives.

Conceptual framework and tools (questions, adaptation)

Interviews for this research are structured using the HLS-EU-16 survey as a framework. The questions focus on specific skills from the HLS-EU framework: access/obtain, understand, and apply relevant health information. The domains of the framework provide a guide for further analysis. Questions from the original HLS-EU survey have been adapted and changed to collect qualitative data related to pregnancy, birth, and child's health from mothers.

Table 1: Matrix of Sub-Dimensions of Health Literacy Based On the HLS-EU Conceptual Model, Used for Questionnaire Construction

Health Literacy	Access/obtain information relevant to health	Understand information relevant to health	Appraise/judge/evaluate information relevant to health	Apply / use information relevant to health
Health Care	1) Ability to access information on medical or clinical issues	2) Ability to understand medical information and derive meaning	3) Ability to interpret and evaluate medical information	4) Ability to make informed decisions on medical issues
Disease Prevention	5) Ability to access information on risk factors	6) Ability to understand information on risk factors and derive meaning	7) Ability to interpret and evaluate information on risk factors	8) Ability to judge the relevance of the information on risk factors
Health Promotion	9) Ability to update oneself on health issues	10) Ability to understand health related information and derive meaning	11) Ability to interpret and evaluate information on health related issues	12) Ability to form a reflected opinion on health issues

Sorensen et al. (2012)

A.6 PARTICIPANTS
Please provide the following information on the participants *with/from* whom you *expect to* be collecting data:

A.6.1 Age / Sex: (please enter the expected number in each of the boxes)

	Neonates (<28 days)	Infants (1-11 months)	Young children (1-9 years)	Adolescents (10-19 years)	Adults (>19 years)
Males					
Females					10<

Guidance notes:
This age/sex breakdown helps convey how vulnerable the participants will be
If you are unable to give precise figures, state estimates and give an explanatory sentence in the space below

Inclusion criteria:

Mothers
– age (undefined)
- has 1 or more children under the age of 5
- Lives in Ulaanbaatar

Qualitative research will be conducted with mothers who have one or more children under the age of 5 living in the urban city of Ulaanbaatar, capital of Mongolia. Participants will be recruited using a network of beneficiaries from an NGOs resource related to the researcher. The NGO operates in ger districts of Ulaanbaatar city, with families from lower socioeconomic status. At least two mothers from each five districts of Ulaanbaatar city will be recruited. The exact number of participants will be determined while implementing the study until the data reaches a point of saturation. The study aims to target mothers with various occupations, increasing diversity among participants. Mothers will vary in number of family members, family structure, education level and foreign language proficiency.The participant's age is not defined, however they must have one or more children aged 5 and under. This criterion narrows the selection to mothers with relatively young children, who have been pregnant in the past five years. This is to ensure data accuracy, by selecting mothers with a relatively fresh memory of their pregnancy and childcare experience.

A.6.2 Describe how the participants are to be recruited?
Guidance notes:
You should outline the procedures for recruitment of each group op participants, include details on:
- *the setting (e.g. on the ward, out-patient department, factory floor, in the home)*
- *inclusion and exclusion for selection, if relevant (e.g. "Women of child-bearing age will be excluded")*
- *who will recruit*
- *If patients are recruited or patient records are used state if the person has routinely access to the patient e.g. treating clinician, nurse*
- *how the recruitment will be carried out in detail*

Participants will be recruited and contacted by a third-party assistant approved by the researcher's thesis advisor. The assistant will be given a short overview of the study which will include the purpose, objectives, risks and benefits, methodology of the study, and an introduction to qualitative study in general. The assistant will also be provided with a confidentiality protocol and will make sure to have the same understanding of the study's purpose as the researcher. A purposeful sampling approach will be employed to recruit mothers, taking into account the inclusion criteria, as well as their active involvement in childcare. Participants will be identified among the network of beneficiaries using the NGO's service. The specific NGO

works for awareness and education of respectful maternity care. The researcher will aim to recruit a diverse group of participants within the inclusion criteria to collect data and accurately describe different experiences and avoid data redundancy due to similar experiences. The purpose of the research will be explained to the assistant when recruiting participants.

A.7 PROCEDURES

A.7.1 What procedures or methods will be employed in the collection of data (e.g. patient interviews / focus group discussions) and by whom?

Attach additional sheets if necessary

Procedure	To be carried out by (profession):	Experience in procedure:
Semi-structured interview	Researcher	Limited

A.7.2 Please indicate that the persons are competent to carry out the techniques used as identified in A.5.1 are competent to carry out these procedures. List any training of staff which may be required prior to commencement of the study.

The researcher does not have prior experience in performing qualitative study and prepared for the study by taking a Qualitative Methods advanced course at the University of Bergen. The study will be advised and reviewed by Dr.Naranchimeg who has extensive experience in working and conducting a study in Mongolia and works as a Head of Scientific Committee in Nursing Education and involved in review of numbers of scientific studies. Dr.Naranchimeg has done multiple qualitative studies with colleagues on communication and evaluation of nursing services. Dr.Fernando Maldonado will be advising the study from a distance as well and he has experience in both qualitative and quantitative studies.

A.8 SAMPLING

A.8.1 Please justify your choice of sampling method(s) and if relevant sample size(s); For qualitative research provide rationale and criteria for the selection of participants for each technique

-

DATA ANALYSIS

A.8.2 Explain how you will analyse the data and, if applicable, which software you will use.

Guidance note

- *If applicable explain what statistical method you will use to analyse the data (relate these to each of your objective).*
- *For qualitative data describe the conceptual framework you will use to analyse the data*

The research is based on an overarching question on perception of health literacy in Mongolian mothers. Semi-structured interviews with additional probes will be conducted in the preferred language of the participant, either Mongolian or English, and audio-recorded with consent. Notes from additional observations will be taken when deemed necessary. The interviews will be transcribed and translated by the researcher and reviewed by an independent party for quality control. Data will be coded and analyzed to determine how participants experience the health literacy concept and its role in their lives. The findings will be reported with its implications and reviewed by the thesis advisor.

A deductive method has been selected to classify and examine the data based on the four skills and three domains outlined in the framework. This allows a methodical investigation and thorough understanding of the health literacy of mothers in Mongolia.

Deductive analysis:

Access/obtain information: Qualitative research should focus on identifying the sources of information available to subjects related to health care, disease prevention, and health promotion. This includes identifying the type of information, such as health care data, educational materials, and other resources.

Understand information: Qualitative research should focus on understanding the context in which the information is being used. This includes exploring the beliefs, attitudes, and values of the subjects in relation to the information they are utilizing.

Appraise/judge: Qualitative research should focus on evaluating how the subjects are using the information they have access to and how this is impacting their health care decisions and behaviors. This includes exploring the factors they consider when making decisions and the obstacles they face in accessing or utilizing the information.

Apply/use information: Qualitative research should focus on how the subjects are applying the information they have access to in their health care decisions and behaviors. This includes exploring their strategies for using the information and the results of their efforts.

QUALITY ASSURANCE and STUDY LIMITATIONS
A.8.3 What procedures are in place to ensure the quality of the research?
Data management
(sub-questions from protocol USR module)

Both advisors Dr.Naranchimeg and Dr.Fernando Maldonado will be looking over the study process to ensure quality of the research. In addition:

- Data will be collected in the language most comfortable for participants to avoid any changes in meaning.
- Data collected in Mongolian will be translated into English by a researcher with an advanced English ability and transcription will be reviewed by someone who is not involved in the research.
- The researcher will hold a weekly meeting with Dr.Naranchimeg to often review the quality of the study and overview the research progress. Dr.Fernando Maldonado will be contacted weekly with the summary of the meeting with Dr.Naranchimeg and will step in and ensure the quality when necessary.
- The researcher and advisor have same cultural background as all participants and familiarity with the culture ensures the credibility to an extent (16)

A.8.4 Explain expected limitations of the study design and how you will deal with these limitation

It is essential to consider a researcher's potential bias when conducting a study. To mitigate this, the researcher should strive to recruit participants from diverse backgrounds, including both rural and urban communities. Additionally, when asking questions related to pregnancies and births that happened in the past, it is important to be mindful of potential recall bias, as the participants' memories could be inaccurate. Furthermore, during the interviews, participants may feel ashamed or sensitive to certain topics, which could lead to them providing socially acceptable answers. It is important to ensure that participants feel comfortable enough to respond honestly.

A.9 DISSEMINATION OF RESULTS
Please outline what plans you have for dissemination of results.
Guidance notes:
Where possible a mechanism should be in place to inform study participants of the outcomes of the study. It is important that important study findings are made known to local services / policy makers before they are discussed (e.g. at international scientific meetings)

The research is primarily for the master’s degree final thesis work of the researcher. Thus, the results will be submitted for review of the thesis to the KIT- Royal Tropical Institute.

Results of the study will be distributed through e-mail to the participants upon request and it will be available for all the participants in the future. Short oral summary of the findings can be given to participants through a phone call upon request.

Since the study is covering a topic not well discussed in the country, it will be available to anyone upon request for further use for scientific, medical, educational or public health purposes in Mongolia. In addition, results will be disseminated through social media platforms including Facebook, Instagram partnering with accounts targeting young parents, pregnant women that contain contents with educational purposes in public health.

A Financial implications and Budget
Guidance notes:

- please provide a budget for the research
- please indicate how the financial implications will be catered for

The study is Master's degree thesis work of the researcher and does not require financial costs. Advisor costs are funded by the student tuition paid by the researcher to the KIT-Royal Tropical Institute.

SECTION B ETHICAL CONSIDERATIONS

CONSEQUENCES FOR THE LOCAL COMMUNITY/ENVIRONMENT AND PATIENTS

B.1 State the country(ies) and town(s) / district(s) where the work will be carried out.

The research will be carried out in Mongolia.

B.2 Describe the setting in which the study will be carried out (e.g. community centre / home / village / District Hospital / Health Centre)

The interview will be scheduled in a quiet environment which is most comfortable for participants which can be in their homes or other locations preferred by a participant which will allow some privacy.

B.3 Outline the potential adverse effects, discomfort or risks that may result from the study in the following areas:

B.3.1 Participants
Guidance note:
It should be borne in mind that interviews and focus group discussions may sometimes trigger painful or distressing memories (e.g. questions about sexual practice o the death of a child)

The research involves questions and potential stories about participants' children which can trigger painful memories when their child got sick or hospitalized. To ensure the participant's comfort, the main goal of the research does not require digging deep on such occasions and the researcher will maintain a neutral view and standpoint to avoid any discomfort due to bias and judgment. The interview will be held in a comfortable environment with a consent of the participant and the participant will be informed about the study, its purposes and objectives, as well as their right to skip any questions if they feel uncomfortable. Furthermore, their privacy will be ensured by keeping all names and other information anonymous as well as removing any piece of information that allows tracking back to the participant before the dissemination of the results. Additionally, referral information to a local counsellor will be provided in the case that the participant becomes unable to continue the interview due to emotional distress.

B.3.2 Investigators
Guidance note:
Social science investigators may be exposed to narratives of violence or severe grief

The researcher is prepared for any discomfort during the study and the study does not involve violent narratives.

B.3.3 Members of the public

Members of the public will not be included in the study. There will be no effect directed to the public.

B.4 **OUTLINE WHAT STEPS WILL BE TAKEN TO MINIMIZE THE ADVERSE EFFECTS, DISCOMFORT OR RISKS THE ADVERSE EFFECTS, DISCOMFORT OR RISKS DESCRIBED ABOVE**

B.4.1 For participants
Guidance notes:
It may be necessary to ensure that counselling or other relevant services are available. Please indicate what will be available if relevant, and will be available at the Consent Form.

The interview will be held in a comfortable environment with the consent of the participant. Zoom call or Google Meet call can be arranged if the participant is not available to meet face-to-face. Participants will be informed about the study, its purposes and objectives prior by a recruiting assistant and will have time to decide on their participation. The participation is voluntary and mothers will be informed that they can skip answering any of the questions from the interview if they feel uncomfortable. The interview will be privately held involving one participant and a researcher and privacy of the participant will be ensured by keeping names and other information anonymous. Any piece of information that allows tracking back to the participant will be removed from the report before the dissemination of the results.

The researcher will do her best to conduct the interview without making participants feel judged in any way and will improve continuously through discussing the interview experience with advisors during weekly meetings.

B.4.2 For investigators
Guidance notes:
Where the research may involve adverse experiences for investigators (see B.3.2), de-briefing / support meetings may be important.

B.4.3 For members of the public

Not applicable.

B.5.1 What demands will this research place on local health services?

Not applicable.

B.5.2 Detail how the design of the research project takes into account the above demands.

Not applicable.

B.6 What steps will be taken to ensure privacy and confidentiality for participants?

Privacy and confidentiality for participants will be kept by:

- Following privacy and confidentiality lessons learned during the Qualitative methods course at the University of Bergen
- Informing participants about the study extensively prior to signing consent and informing them the participation is voluntary

- The consent form will be read by the researcher prior to signing and all parts will be explained and questions will be answered
- Interviews will be conducted in a safe, comfortable and quiet space where participants agreed or chose themselves
- The option to meet online through Zoom or Google meet will be given if the participant is not available to meet face-to-face and in that case only audio recording will be done without including the video portion of the call.
- The recordings of the interviews will be coded with the designated code of each participant to ensure privacy
- The collected data will be stored in a safe place without any access to unauthorized users and all the information that can be traced back to identify participants will be deleted as soon as possible.
- The recordings will be destroyed after the research

SOCIAL AND CULTURAL SENSITIVITY ISSUES

B7.1 Describe what cultural and or social sensitivities your research raises

The interview might contain questions that can lead to experiences including family conflicts and disagreements on childcare ideas. Traditionally Mongolian culture has relatively strict family hierarchy and such incidents can be sensitive for participants to disclose to a researcher.

B7.2 Explain how you plan to deal with cultural and social sensitivities within your research and how you will minimize potential risk.

Participants will be informed prior to the interview that they can skip questions that they prefer not to answer at any given time. Also, the researcher will try her best to make participants feel comfortable and not feel judged for having issues with her family if the interview contained such stories.

GENDER ISSUES

B8.1. Describe how the research addresses a demonstrated public health need and a need expressed by women and/ or men

Low mother's health literacy is directly associated with a child's lower health status and further relates to hospitalization rate, treatment continuity and overall well-being of a child (6). The research will focus on health literacy experiences during pregnancy, birth and childcare of Mongolian mothers to explore health literacy status and perceptions in Mongolia.

B8.2. Explain how the research contributes to identifying an/ or reducing inequities between women and men in health and health care.

Mongolian statistics show about 66% of mothers breastfeed their children even though women have higher literacy and education rate in Mongolia (17,18). The study will raise awareness of health literacy of mothers and health information availability to mothers who are increasing their responsibility by seeking health knowledge to raise healthy children while working and earning for their family and childrearing at the same time.

B.8.3. Does the nature or topic of the research make it important that the researchers are women rather than men or vice versa? Please explain. What is the sex composition of the research team and what are their duties and responsibilities in the proposed research?

One female researcher/interviewer will be working alone in the field and the study is her thesis work for the master's degree. It can be an advantage to have a female researcher conducting interviews because participants will be all females and might feel more comfortable talking about their stories involving pregnancy, childbirth.

B.9 INFORMED CONSENT
Please provide consent forms for every participant group and each instrument.

B.9.1 Information given to *participants*:
Guidance notes

- Please indicate what you will tell the *participants* in simple language. The procedure or treatment which will be applied should be described and reference should be made to possible side effects, discomfort, complications and/or benefits. Provide information to the participant in the research about the purpose, type of research technique, type of questions or issues addressed, time involved and arrangement for privacy.
- State how confidentiality is maintained. For focus group discussions clearly state that confidentiality cannot be guaranteed and that participants should **not** share personal experiences.
- It must be made clear to the participants that he/she is free to decline to participate or to withdraw at any time without suffering any disadvantage or prejudice.
- At the end of the consent form provide space for a signature of the participant. If a signature is inappropriate then a witness should sign on behalf of the participant.
- State name and contact details where complaints can be directed to.
- If applicable provide contact details for counseling or other referral.

Attach the consent forms.

Please see attached informed consent forms in Annex 2.

B.9.2 Outline who will deliver the above information and how?

The researcher will deliver the content of the consent in a simple language keeping ethical and professional manner. All questions will be answered and terms will be explained prior to signing. Participants will be informed of the purpose and objectives of the study and participation will be voluntary and they can discontinue the interview without any consequences. The term health literacy will be explained to each participant to have the same understanding between the researcher and a participant.

B.9.3 Please indicate how consent will be obtained, given local circumstances.
Guidance notes:
In some societies, the concept of giving consent on an individual basis is unfamiliar. It may be necessary to obtain consent both at community and individual level.
Obtaining consent from minors requires both consent from the guardian and, where possible, the minor.

All participants of the study will be adults above 18 who are legally authorized to sign. All participants will be literate and able to read the consent form themselves and ask questions. Every interview will be in private with the researcher and one participant which will keep privacy of the identity of participants.

B.9.4 Are any inducements to be offered to either participants or the individuals who will be recruiting them? (e.g. improved patient care / cash) (please tick appropriate box)

Yes/**No**

B.9.5 If Yes, please give details
B.9.6 Outline any hidden constraints to consent.
Guidance notes:
Examples where hidden constraints may be important include:

- *situations where participants are employees of the investigator*
- *women in antenatal care who may feel the health of the unborn child could be compromised if they do not consent to research initiated by their carers.*

Not applicable.

B.10 **LOCAL ETHICAL COMMITTEE**

B.10.1 State the name and address of the local ethical committee who is requested for approval

Mongolian National University of Medical Sciences Ethical Committee Branch

13270 Ulaanbaatar city, Bayanzurkh district, 12th khoroo,
Amgalan, Botanical garden

B.10.2 Indicate a timeline: when is approval expected?

June 22nd, 2021 (approved)

SECTION C
DECLARATION: TO BE SIGNED BY MAIN APPLICANT

- I confirm that the details of this proposal are a true representation of the research to be undertaken.
- I will ensure that the research does not deviate from the protocol described.
- If significant protocol amendments are required as the research progresses, I will submit these to the Royal Tropical Institute Research Ethics Committee for approval.
- Where an appropriate mechanism exists, I undertake to seek additional local Ethical Approval in the country(ies) where the research is to be carried out.
- I have no conflict of interest in this research

I expect the project to commence on (Date): 15/07/2021
and be completed by (Date): 01/08/2021

[Signed] 2023/08/27

Signed Date

Agreement advisor:
I have seen and agree with the application. I have no conflict of interest in advising this research
[Signed]

Signed Date

Additional comments advisor:

Annexes: **Please include the following annexes**:

Annex 1 Research Instruments to be used
Annex 2 Informed consent forms
Annex 3 CV of applicant

References

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16. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. Vol. 22, Education for Information. IOS Press; 2004.
17. Mongolia is marking the World Breastfeeding Week with health promotion and artistic performances. 2016.
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Annex 1 Research Instruments to be used
Interview guide draft

Methods: Semi-structured interviews

DATE:

Code:

Interview time:

Interview Duration: Moderator:
General information:
Signature:

1. Please tell me about your family. How many children do you have and what are their ages?

2. How involved are you in your child's day to day lives and their health decisions? Who else is involved in those decisions?

3. Are you familiar with the concept of health literacy? Can you explain in your own words, what does it mean?

4. How important is health literacy for you? and why is it important? **(before explaining ask about HL)**

- In general
- In daily life

Explain the concept in simple words (is it important for them as a mother, as a member of the family)

Healthcare

1. How did you **find** information on treatments of illnesses that concerned you during your pregnancy?
2. How do you **find** information on treatments of illnesses that concern you or your child?
3. How do you find doctors when you or your child is ill?
    - Feelings about healthcare system in your area
    - Challenges to accessing healthcare system
4. Have you ever experienced any challenges **understanding** what your doctors say to you about your health or your child's health? Was it easy or difficult? For example, medical terms, explanations etc.
    - Whether asked questions
    - Clarified misunderstandings
    - Risks/factors, causes, side effects
    - Do you have any examples?
5. Have you ever experienced any challenges **understanding** doctor's or pharmacists' instructions on how to take medications?
6. How and when did you **decide** to get a second opinion on health matters? Do you have an example?
    - How do you do research
    - Where do you find information
    - Which one did you trust and why?

7. How do you **use** information from a doctor or information that you found to make decisions about you and your child's health?
    - Do you trust the information
    - Do you share the information with others (family members, friends)

Disease prevention

1. How did you **find** information about pregnancy and labor?
2. How do you **find** information on disease prevention for yourself and your child?
3. Have you ever experienced any challenges **understanding** health warnings during pregnancy such as smoking, excessive weight gain, alcohol consumption, stress?
4. Have you ever experienced any challenges **understanding** preventions from conditions and warning regarding your child's health, such as excessive weight gain, lack of exercise, mental health, or lack of nutrition?
5. (Explain health screening, annual check-up) How important is it for you to participate in health screening?
    - Annual screening
    - Screenings during pregnancy
6. Where do you get information on health risks of you and your child and how do you **judge** whether it is reliable?
    - Resources
    - Who do you ask
7. How do you **decide** and **use** information from the media on health risks and disease prevention? Do you have any examples?
8. What are the **actions** that you take to prevent health risks daily, weekly, monthly?
    - Habits
    - Schedules

Health promotion

1. How and where did you **find** information on activities for mental well-being during your pregnancy?
2. How and where do you **find** information on activities for mental well-being for yourself and for your child?
3. Have you ever experienced any challenges **understanding** advice on health from family members and friends?
    - During pregnancy
    - Related to birth
    - Traditional and medical
    - In-laws, parents
4. How often do you research and have you ever experienced any challenges **understanding** health information in the media on getting healthier and supporting the immune system of yourself and your child?
5. What **actions** did you take everyday to have a healthy pregnancy?
6. What **actions** do you take everyday to live a healthy life as a family?

Given the discussion that we just had, what do you think about HL and its importance?

How can you use HL more in your daily life?

Annex 2 Informed Consent Forms

My name is Bayardolgor Bayaraa and I am doing this research as my thesis project for my Master in International Health degree at KIT-Royal Tropical Institute in the Netherlands.

Purpose

WHO defines health literacy in its glossary in 1998 as "implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions". However, health literacy is a relatively new understanding among medical colleagues in Mongolia which was officially translated into Mongolian language and accepted in use in 2020. HL is supposed to be an inseparable part of everyday life of all each Mongolian citizen who is using healthcare services in some way to exercise their right to stay healthy.

The study aims to find out about Mongolian mothers' perceptions and experiences regarding health literacy during pregnancy, childbirth and childcare as an individual and as a member of a family. Questions will be asked to explore health literacy of mothers in three domains – health promotion, disease prevention and healthcare in terms of traditional, environmental and medical knowledge.

Risks and benefits

The participation in this research will not benefit you personally in any way. However, this research can become a guide to increase availability of sources of knowledge that mothers find useful, bring light on real life examples and difficulties regarding lack of accurate sources of health literacy. Further work can be done to find ways to promote HL, bring awareness to the level of HL of mothers to improve recognition of the term for public use. The study can potentially have a greater impact for health accessibility, health equity and healthcare development.

The participation is voluntary and you can skip questions if you don't feel comfortable answering. The interview will continue for 1-1.5 hours and you can stop at any time. If you start to feel emotional or uncomfortable due to the questions that are asked about your past experiences, please let the researcher know and the interview will be discontinued. The researcher can give you a referral to a counsellor if needed to address emotional burden during or after the interview. The interview will be conducted in a mutually agreed place that is most comfortable for you where no one will hear our conversation. The option to meet online through Zoom or Google Meet can be arranged if you are not available to meet face-to-face.

The study will follow KIT Guidelines on on Data Collection Procedures During Covid-19 as well as local government guidelines during Covid-19.

Confidentiality

If you choose to participate, your participation and identity will be confidential. No information or potential piece of information will be included in the study that can be tracked back to you. We will record the interview with your consent coding your name as "Participant #" and the interview will be transcribed and translated for further analysis and the process will be confidential. Only the researcher will have access to the records. All the recordings and other personal data for the study will be destroyed after submission of the thesis and oral examination on August 30th, 2021.

Results

Findings from this study will be analyzed and written in a thesis report. It will be submitted as the master's degree thesis work of the researcher in August, 2021. After the submission, the study can be shared with you through e-mail at any time upon request. The study was approved by the ethics board at KIT in Amsterdam, the Netherlands and Ulaanbaatar, Mongolia.

The participation is voluntary and you can discontinue your participation at any moment without any consequences.

Agreement:

The study was explained to me and I agree to participate in the study by getting interviewed after I have given the consent.

Signature:

Date:

If you have any questions or complaints regarding the study please contact:

Researcher: Bayardolgor Bayaraa
+976 99994318
bayardolgorb@gmail.com

KIT Ethics Committee: Susan Huider
0031 20 568 8237
S.huider@kit.nl

Annex 3 CV of Applicant

BAYARDOLGOR BAYARAA

Dalsteindreef 6547, Diemen 1112 XJ
+31687623805 | bayardolgorb@gmail.com

EDUCATION

KIT-Royal Tropical Institute — Amsterdam, The Netherlands
Master in International Health — September 2020 – Present

University of Minnesota- Twin Cities — Minnesota, USA
Bachelor of Art – Physiology — September 2016 - May 2018

Inver Hills Community College — Minnesota, USA
Bachelor of Art – Physiology — September 2016 - May 2018

RELATED COURSEWORK

- Completed a research paper on "Jet lag after transmeridian flight and how to help adjust to a new time zone" (Advisor Dr.Germaine Cornelissen-Guillaume)

EXPERIENCE

Mederva Health Inc. — California, USA
Patient Experience Manager — December 2021- Present

- Partner with local hospitals and local doctors to receive, organize, translate and submit patient cases to Mederva Health US Board-certified partner physicians for second opinion.
- Receive a second opinion from Mederva Health US Board-certified partner physicians and translate, deliver reports to local doctors.

TRIA Orthopaedics Center
Minnesota, USA
Patient Care Assistant — July 2019- July 2020

- Admit patients and collect, record vital signs, weight, height and make necessary pre-operative preparations according to each surgeon's preference. Assist post-operative patients and provide with care and comfort under direct supervision of RNs.
- Maintain pre/post-op area efficiently stocked-up with all necessary equipment and tools daily.
- Received Basic Life Support (BLS) Certification from American Heart Association (AHA).

Emergency Physicians Professional Association — Minnesota, USA
Medical Scribe — July 2018 – May 2019

-Exhibited ability to fluently understand and apply medical terminology in patient's medical chart and successfully recorded for further medical record and use on EPIC.
-Included history of present illness, physical exam, review of systems, medical procedures, past medical history, allergies and medical decision making for 20 different providers by actively listening and effectively matching their styles and preferences and ensured to comply with provided guidelines.

Mongolian Health Initiative NGO
Ulaanbaatar,Mongolia
Intern May 2017- December 2019

- Participated in the process of organizing the Central Eurasian Nutrition Forum, Zero TB Ulaanbaatar Initiative in June of 2017 in Ulaanbaatar, Mongolia initiated by Harvard University
- Translated over 15 power point presentations of international speakers regarding nutrition, tuberculosis and food fortification to and from English, Mongolian and Russian
- Continued distance-based interpretation, project assistance, research from the USA.

Inver Hills Community College Learning Center
Minnesota, USA
Peer Tutor November 2015-
May 2016

- Mentored students in Chemistry to help them succeed in the course by providing academic support.
- Developed interpersonal skills by making 2-3 appointments each with more than 5 peer students every week and giving advice on organization skills, note-taking and preparing for exams
- Completed College Reading & Learning Association (CRLA) level 1training and became certified tutor

New Aspiration International House Minnesota,
USA
Member of the community August 2014- May 2016

- Lived as a community for two years with 11 other people from different backgrounds and age groups as part of an unique non-profit organization and international student.
- Volunteered in fundraising events and assisted staff daily with cleaning, cooking and managing the organization efficiently.
- Documented the past moments and events in 12 short videos by editing and exporting using a software program

ACTIVITIES AND ACHIEVEMENTS
Minnesota-Mongolian Student Association, Vice President September 2017- May 2018
Phi Theta Kappa, Chapter Secretary April 2015-May, 2016
All-USA Community College Academic Team Scholarship – Fall 2015
AllergyMed Hospital, Volunteer July 2015- August, 2015
Dean’s list, Add It Up Scholarshop - Fall 2014 Add It Up Scholarship

Name: Bayardolgor Bayaraa
Date: 2023.08.27

Reflection Letter

The qualitative study was proposed and initiated in the spring of 2021 as a thesis work for the MIH program at KIT-Royal Tropical Institute. I returned to Mongolia in the midst of the COVID-19 pandemic in December 2020 to continue my MIH studies online and finish my degree. After unsuccessful attempts, I am writing this letter for my last attempt to reflect on my experience and gain understanding on required changes based on previous feedback.

To ensure that my research was informed by the local public health field, I sought out an advisor familiar with the context in Mongolia. Despite the challenges of the pandemic, I worked with my Mongolian advisor. Yet, I eventually realized that the writing style expected by KIT was different from her style. To ensure I met KIT's standards, I sought out help from KIT which was very helpful in identifying shortcomings of my work from a different perspective.

The first problem identified by the examiners' on the last submission was about an understanding of health literacy (HL) and implementation of methodology. The objectives of the study included HL skills specific to the framework, but these were not closely reflected and applied in the methodology. The topic guide and analysis was initially using three domains from the framework: healthcare, disease prevention and health promotion and not focusing on skills of mothers related to HL which did not bring out results specific to mothers skills and perceptions of HL as a whole. The topic guide was restructured and revised to include specific questions on each skill within each domain, as suggested by the framework: find, understand, judge and apply. To come up with the questions, the HLS-EU-16 quantitative questionnaire was taken into account and interview questions were adapted to the qualitative study with mothers as participants. By broadly applying the framework, I was able to gain a deeper understanding of HL in a structured way and focus on each domain based on the suggested skills. This allowed me to include health promotion, which was previously left out, and potentially collect comparable data in all three domains.

The second problem arises from the previous issue of not applying the broad framework to the thesis and the inductive approach was chosen initially for the analysis. It was due to my inexperience in qualitative research methodology and lack of understanding of differences between analytical approaches. The inductive approach limited me to only three domains of the framework as mentioned above and I was not able to collect enough data and eventually analyze the whole dataset. After studying the qualitative research analysis methods carefully, I chose to suggest a deductive approach to address this issue this time. This approach allowed me to analyze the four skills from the four columns of the framework within each domain, thus providing a comprehensive understanding of the Health Literacy of mothers in Mongolia, and explain the relationship between domains and skills as variables, whilst adhering to the purpose of the research.

As a result of the above changes, I re-created a comprehensive topic guide focused on the framework, and made changes in the initial proposal. This new version could have different limitations including diverse background and diverse levels of participants' skills and their attitude towards the interview. Asking and focusing more on mothers' skills could cause mothers to feel ashamed and give socially acceptable answers to these questions. It is important to make mothers feel comfortable without feeling judged and ask questions in a way that mothers will answer honestly for research purposes.

This assignment has been a great experience for me to understand the concept of HL, methodology of a qualitative study and personal growth. I have already started applying my learnings from this assignment into my work and I know I will use the knowledge in the future for public health of Mongolia.