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‘If a Woman Opposes Her Mother-in-Law’s Opinion, She Would Be Labelled as Rude.’ Health-Seeking Behaviour of Ethiopian Caregivers when Infants Are Unwell—A Descriptive Qualitative Study

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Abstract

Objectives: To explore the health-seeking behaviour of Ethiopian caregivers when infants are unwell.

Design: A qualitative descriptive approach was employed using in-depth interviews and focus group discussions. Data were collected using semi-structured interview guides.

Setting: The study was conducted in East Gojjam Zones, Amhara region, northwest Ethiopia.

Participants: Participants were selected using a maximum variation purposive sampling technique across the different study groups; caregivers, community members and health care providers. A total of 35 respondents, 27 individuals in the focus group discussion and eight individuals in the in-depth interviews participated in the study.

Method: In this study, a qualitative descriptive approach was employed to explore the health-seeking behaviour of caregivers. A maximum variation purposive sampling technique was used across the different study groups (caregivers, communities and health care providers).

Results: The decision to take a sick child to healthcare facilities is part of a complex care-seeking process that involves many people. Some of the critical steps in the process are caregivers recognizing that the child is ill, recognizing the severity of the illness and deciding to take the child to a health institution based on the recognized symptoms and illness. In Ethiopia, a significant proportion of caregivers do not seek healthcare for childhood illness, and most caregivers do not know where and when to seek care for their child. This study points out that the health-seeking behaviour of caregivers can be influenced by different contextual factors such as caregiver's disease understanding, access to health services, and family pressures to seek care.

Conclusions: Healthcare seeking practice plays an important role in reducing the impact of childhood illnesses and mortality. In Ethiopia, home-based treatment practice and traditional healing methods are widely accepted. Therefore, contextual understanding of the caregivers' health-seeking is important to design contextual healthcare interventions in the study area.

Strengths and limitations of this study

The strength of this study is that the study covers a wide range of study participants and may help to include a variety of perspectives.

The limitation of this study is that the study participants were from the rural area and they are farmers in occupation so the findings may not be generalizable to urban caregivers.

Introduction

Healthcare-seeking behaviours can be defined as 'any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy' [1]. This implies that healthcare-seeking behaviour with respect to common childhood illness means that the need to take the child for treatment outside the home is recognised, that care is not delayed and that the child is taken to an appropriate health facility or provider [2]. A health behaviour to seek treatment for a sick child is a multifaceted process that has the following identified components: the caregiver's ability to identify that the child is ill, the caregivers should perceive that the illness is severe, and treatment or care should be sought, a process influenced by barriers such as time and money constraints [3]. Healthcare-seeking practices depend on local beliefs, preferences and decision-making with respect to child illnesses [4, 5]. The recognition of signs of ill health, which may have similarities and differences to medically recognised warning signs, is an important starting point for care-seeking [6]. Household responses to signs of ill health, which include the use of home-based treatments and traditional healers, can also affect the use of modern health care [6].

Appropriate care-seeking has the potential to reduce child mortality substantially, and it is of particular importance in areas with limited access to health services [3]. A caregiver's healthcare-seeking behaviour is a crucial part of managing illness and preventing infant mortality [4]. Previous researchers have found that caregivers' healthcare-seeking behaviours have a significant impact on reducing infant mortality from childhood illnesses [7]. The WHO estimated that seeking appropriate health care could reduce child mortality by 20% [8]. In several studies conducted in developing countries, it has also been shown that delays in seeking appropriate care, or not seeking any care at all, cause a large number of child deaths [9, 10]. The proportion of care-seeking behaviours for childhood illness is low in most developing countries; only 26.4% of caregivers seek care when their child is sick [11].

The decision to seek care outside the home is influenced by decision-making dynamics within caregivers' lay referral network (especially involving husbands) and the resulting illness labels and perceptions of severity [12, 13]. Most caregivers seeking care outside the household have stated they wait for more than 24 hours before leaving home to seek care for their sick child [12]. The most common reasons for delaying seeking care [14] are uncertainty about illness progression, difficulties with access to treatment, apprehensions about

presenting to providers and the exigencies of daily life [15]. Poor health-seeking behaviour is not only due to poor awareness or a poor perceived need for this healthcare option, but is also related to cultural problems, such as caregivers' understanding of an episode of child illness and how the awareness can be transferred to the communities and families [14, 16].

In Ethiopia, it has been shown that less than half of caregivers seek treatment for their child's illnesses [17]. According to a health survey in Ethiopia, the proportion of caregivers who sought help for common childhood illnesses—ARI (Acute Respiratory Infection), fever and diarrhoea—from health facilities was 27%, 24% and 31%, respectively [18]. In another small study in Ethiopia, it was indicated that only 55% of caregivers with sick children visited health facilities for treatment [19]. In another community-based cross-sectional household study in Addis Ababa, the capital city of Ethiopia, it was shown that more than two-thirds of caregivers sought care for children aged under five when they were suffering from acute diarrhoeal illness, either at home or health facilities, with the remaining caregivers not seeking help [20].

In a qualitative study exploring care-seeking pathways for sick children in the rural Oromia region of Ethiopia, community members reported that a child's illness was recognised if there was a deviation from an ideal state of child full of health/energy [15]. The most noted symptoms in both acute and long-term child illnesses were recognised primarily by diminished activity, appetite and general lethargy [15]. According to the researchers, mothers were typically reported to be the first to recognise most symptoms of child illness [15]. However, the decision to seek care from a health institution was taken only when the child's symptoms did not improve with home treatment. Caregivers suggested that home-based actions were successful in aiding in the interpretation of an illness [15].

Although progress has been made in Ethiopia towards universal access of standard case management of common childhood illnesses, health care–seeking by caregivers for child illnesses has remained low [18]. Many caregivers do not know where and when to seek care, and health-seeking is delayed even after recognition of a child's illness [21]. Understanding the health-seeking behaviours of caregivers is vital for the rational planning and evaluation of child health service utilisation [20]. However, in rural Ethiopia, there is limited information on the health-seeking behaviours of caregivers for childhood illness. Specifically, there have been no studies that examine the health-seeking behaviours of caregivers in the study area. Therefore, this study aimed to explore the health-seeking behaviours of Ethiopian caregivers when infants are unwell.

Method and Materials

Study Area and Period

The study was conducted in the East Gojjam Zone, in the Amhara Region of Ethiopia, from July to September 2019. The zone is located in the east part of Amhara, which is in the north-western part of the Ethiopia and has a land area estimated at 170,000 km^2, with a population density of 110/km^2. According to a 2007 Central Statistics Agency report, East Gojjam Zone has an estimated population of 2,153,937 and an area of 14,000 km^2, giving a population density of 153.80/km^2 [22]. Nearly 84% of the people living in rural areas are engaged in agricultural activities, mostly comprising subsistence farming [23]. According to the 2015–16 Amhara regional report, the level of poverty in the region was higher than in the nation: 26.1% of the region's population lived in poverty, compared to 23.5% of the entire country's population [23]. Regarding access to health services, the region had a poor health status compared to other regions in Ethiopia [23]. The rate of child mortality in the region was among the highest in the country, 85 deaths per 1000 live births [24] ; it also had the highest stunting rate compared to other regions in the country, 46% of the under five children were stunting in 2016 [23, 24].

Study Design

A qualitative study was used to explore caregivers' and healthcare providers' experiences of health-seeking behaviours when infants were unwell. Qualitative descriptive is a method for research that seeks to present the voice of the particular population under study. Qualitative description approaches helps the researcher remain closer to the words and meanings offered by informants and can offer a comprehensive summary of a phenomenon in simple terms [25, 26]. Naturalistic inquiry involves studying something in its natural state such that variables are neither predetermined nor manipulated, and no a priori commitment is made to any particular theoretical viewpoint [25]. Researchers conducting qualitative descriptive studies stay closer to their data and to the surface of words and events than researchers conducting grounded theoretic, phenomenological, ethnographic or narrative studies [25].

Recruitment

A maximum-variation purposive sampling technique was used across the different groups of participants (caregivers, communities and healthcare providers). In-depth interviews and

focus group discussions were conducted with healthcare providers and caregivers, respectively. A total of five focus group discussions were conducted: two were conducted with primary caregivers at health centres and health posts during child vaccinations and another three were conducted with community members (fathers, grandmothers and community leaders). Additionally, four key informant interviews were conducted with healthcare providers (two with health extension workers and two nurses or midwives) working in maternal and child health units.

Data Collection Procedure

The lead researcher and data collectors who were native speakers of the local language, Amharic, conducted the focus groups discussions and interviews. Two healthcare providers from a local University who had previous experience in interviews and moderating focus group discussions and who had work experience in the area for more than a year were recruited as data collectors. The data collectors undertook appropriate training to understand the cultural context, values and norms of the community prior to conducting the interviews. The interviews were conducted at a private room in the health post and health centre. Audio was recorded with prior consent of the informants, and the recordings were transcribed verbatim. The focus group discussion with caregivers was held at a separate location in the health centre and health post.

Data Processing and Analysis

Data analysis began immediately following data collection and continued throughout the research process. We applied conventional content analysis, which allowed for the continuing data collection to inform and be informed by emerging analyses. Content analysis is a procedure for the categorisation of verbal or behavioural data for the purpose of classification, summarisation and tabulation. It is generally used to describe a phenomenon: in this case, caregivers' health-seeking behaviours for infant and newborn health services. Conventional content analysis involves the identification, coding and categorisation of primary patterns in the data to ultimately draw meaningful relationships for study [27]. It allows for researchers' immersion in the data to allow new insights to emerge [27].

First, audio recordings of focus group discussions and key informant interviews were transcribed to the local language, Amharic, by the data collectors. The transcribed data were then translated into English. After repeated reading of focus group discussion and key

informant interview transcripts, coding frames were generated. We used NVivo 12 [28] to assign codes to text and to assign strict defining parameters to the codes, thereby maximising consistency in the coding process. Once all the interviews and group discussions were coded, the codes were categorised into larger themes that directly corresponded to the primary research questions. Within each of the broad themes, data were sorted into more narrow constructs, concepts and categories to allow for data interpretation [27].

Ethical Considerations

Ethical approval was granted by the Human Research Ethics Committee of the University of Newcastle, Australia (Reference no.: H-2019-0090). All study participants provided informed consent prior to interviews and focus group discussions.

Patient and public involvement

No patient was involved in the development of the research questions and outcome measures, study design or recruitment, and in the conduct of this study.

Results

Participant Characteristics

A total of 35 respondents—27 in the focus group discussions and 8 individuals in the in-depth interviews—participated in the study. The average number of individuals in each focus group was 7. The mean age of respondents who participated in the focus group discussions and in-depth interviews was 40 (± 12) years. The majority (n = 24) of the respondents were female. Respondents also had a mean of 4 (± 2) children. The majority (n = 29) were married during the focus group discussions and in-depth interviews, and the majority were farmers. The majority of the study participants attend primary education and less.

Caregivers' Understandings of Child Illness

Respondents report that in Ethiopia, specifically in the study area (northern Ethiopia), mothers were usually the ones to first identify a child as sick. Mothers were primary caregivers and had close ties to their children. Fathers spent the majority of their time outdoors in on-field activities like farming. A majority of the participants conceptualised illness in a child under the age of 1 as being manifested in strange symptoms such as *mekremrem* (restlessness), *fenen fenen* (irritability or continuous crying), a loss of strength or

a lack of interest in breastfeeding. Caregivers initially identified child illness when the child showed strange behaviours during playing and eating. For example, if a child could not play and run as usual, then caregivers understood that their child was sick. For a child under the age of 1, caregivers recognised child illness when the child stopped breastfeeding or was unable to eat additional foods:

> I recognised my child's situation has worsened if my sick child decreases his breastfeeding gradually or if he stops taking breastfeed. Moreover, if the child has a fever, the temperature dropped or not, I can measure temperature by touching on their forehead and chest area. If the child's situation worsens, his temperature would be high. But if he shows improvement, his temperature would lower gradually, and he would begin breastfeeding again. (woman, interview)

Local Names and Causes of Illness

Causes of childhood illness were constructed as environmental (e.g., exposed to cold temperature and poor sanitation) and supernatural. Participants reported that *sanba mich* (pneumonia) and diarrhoea were the two most common diseases in children under the age of 1. Sick children mostly complained of fever. Moreover, they might have diarrhoea or *sanba mich*. Caregivers gave different reasons and causes for child illness. For example, if a child showed a sign of illness, such as a 'shouting nightmare' despite being awake, the caregivers perceived that the cause of the sickness was 'evil eye' or *metet*, for which magic and holy water were the preferred cure. Additionally, participants reported that the community recommend crossing a river if a child had been attacked by the evil eye. Once the child crossed the river, they would need to return home via another road because the evil eye would return if the child used on the same road. Moreover, there was a traditional medicine that would be smelled by the patient, and a child who was attacked by an evil eye would also need to smoke a burning tyre:

> There is some illness which we perceived as they can be caused by missing ceremonial activities for the lord of evil. Some women say this is the last day of the month late us celebrate, to not upset the evil. So, if a woman misses such ceremonies and her child becomes sick, she would directly relate with such incidents rather than accepting its real cause. Many households belief on traditional practices and norms for the cause of child illness. (woman, group discussion)

Caregivers in the study area also explained a cause of illness is *bird* (exposure to cold temperatures). Caregivers understood that children could develop pneumonia if they were in a cold environment, and this could happen due to inadequate child-caring practices by the mother. If the caregivers put the child on a cold and muddy floor, the child might be exposed to *bird.* Moreover, if the child put on many clothes or thick clothes, and then took off these clothes, they might be exposed to *bird*. For example, if a child put on a cap and then removed these clothes, then they might be exposed to *bird*, or might experience a clash of hot and cold air and consequently develop a fever, then s*anba mich*:

> Caregivers describe pneumonia as *sanba mich*; they understand that the cause of the disease was when a child has exposed to *bird*. They explained that my child was exposed to 'extremely cold environment', if he has high fever and cough. If a sick child has these symptoms, they would say my child has been developed *sanaba mich*. (woman, interview)

Home-Based Treatments for Childhood Illnesses

Participants reported that it was typical for caregivers and infants to stay at home, especially in the early postnatal stage. In northern Ethiopia, where this study was conducted, a majority of the population follow the Orthodox Christian religion, and according to religious norms, primary caregivers are not allowed to stay outside with the child before the child is baptised on the 40th day for male neonates and the 90th day for female neonates. However, participants reported that mothers would still attend health facilities for postnatal care and if an infant's illness was very serious and could not be managed after many trials of home-based treatments. However participants also reported that the death of a neonate at an early age was considered a *tefa* (stillbirth) rather than infant death; most of these deaths occur before the child is brought to the health facility and are not reported as neonatal deaths.

Home-based treatments for child illness were commonly reported for young children. When asked about home treatments for illness, caregivers reported providing a mixture of lemon, coffee and other ingredients to sick children with diarrhoea and vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers reported that they used *feto* (*Lepidium sativum*; garden cress), chewed or masticated with *zingibil*, at home to treat most child illnesses:

> if the child has a cough, I will give *tenadam* [*Ruta chalepensis*; fringed rue] with coffee, garlic with coffee on coup … it would cure, we also used *lega kibe* [fresh butter without spices]. (Emphasis added in bold; woman, group discussion)

> For child illness than one year, we can give *tenadam*, *nechishinkurt* [garlic] and *feto* with coffee for decreasing the cough. If he has delirium, biting his lip and his teeth, we will give *yebuda medhanit* [traditional herbal medicine for evil eye] per month. We also tie on his neck and hand. (Emphasis added in bold; group discussion with community member)

8.3.5 Caregivers' Access to Health Services

Participants reported that members of communities living far from the health facilities preferred to observe their children's situation at home, hoping their health would improve with time. For example, if a child in a remote area was sick, caregivers would decide not to bring the child to the health centre immediately; instead, they would observe the child for 2 or 3 days. Caregivers from lowland areas found it hard to access services. It was difficult to transport sick children with the traditional ambulance (a stretcher made up from local materials) and it was not possible to build roads to such villages to increase ambulance access. The only option was to use human resources and traveling on foot to bring sick children to a health facility. Accessing health services using traditional transport services was very difficult. Additionally, it was difficult to get people who could provide aid to and also carry sick individuals to a health facility during the summer season. Without such support, caregivers determined that they could not bring children to the health facility. Participants reported that community members might not accept a request for support from sick individuals if the road was too muddy. In contrast however, the social group (known as *edir*) would provide transport support when elder individuals became sick.

> Distance to the health institution it imposes a huge challenge to access health services. For example, there are clusters known as Tiba, Yetayiba, in this *kebele*. The road is not comfortable for health individual, give alone for a sick person to come in such muddy season. If I go through that road one day, I would sleep for at least 2 days due to the difficulty of the trip. They might bring a sick child with great suffering; otherwise, they would let them die on their hand. The road is too difficult. (man, group discussion)

Lack of money was reported to be another barrier to bringing sick children to a health facility. Community health insurance alleviated the financial burden of health care for the majority of the community, but there were some households that did not enter into this system. Such parents might not have the money to obtain treatment for their sick child. Participants recalled that community members might wait for days, thinking the child will recover soon without any treatment, or that the illness is not a serious risk to the child. Sometimes, such individuals might not have enough money, so they wait until they could obtain money; otherwise, those who used community health insurance were more likely to bring their sick children to the health facility immediately. Participants reported that some fathers hesitated to pay for their child's medical bills; they did so not because they had no money from on hand, but rather, they hesitated to pay for other reasons. However, there were some women who saved money from for their household allowance for expenditure when such difficult situations arose.

> Individuals who do not have a community health insurance prefer to buy drugs from the pharmacy, rather than paying for related services like getting examination card, waiting for long queue and passing through other steps. Moreover, they might not be able to bring sick children to the health facility, so they can buy from private clinics without any physical examination and investigation. I met a man whose child was sick and when he went to a private clinic to buy medications, I asked him why he brings the child with him; he said since it is a busy working day in the community, he can access no one to bring his sick child to a health facility, so his only option is to buy medication from the private clinic by telling them his symptoms. (woman, interview)

Participants reported that beliefs around traditional practices was a factor in decision-making. For example, if a family had only one child, and they believed they received this child as a miracle from God, and they may get this child by performing cultural rituals like giving promise for the witch, the witch might perform magical and spiritual things to let couples have a baby. A child who is delivered through such a process would not be taken to the health facility when they are sick, since the mother believes that the witch is the one who can protect and save the child from all the risks the child might experience through their entire life. As such, the mother would prefer to take care of the child at home as per the recommendation of the witch; similarly, the mother would not agree to take her child for vaccination. The mother

would even cut the child's hair in such a way that would expose the child as her only child; such children could thus be easily identified by the community. This indicates that there are harmful traditional practices and norms that prevent children from accessing health care.

> When I tried to convince the woman to take her child to a health centre, she said, 'I get this child by pledging to a witch, if I take him to health centre he might die. I would never take him for any medical care'. (health professional)

> I fear their diseases might adapt the medication through time if I bring them to a health facility for each sickness. It is not a good practice to provide medicines for sick children frequently, since they might develop resistance. Therefore, I observe their progress at home in 2 or 3 days; if they do not show improvement, I would bring them to the health centre. (man, group discussion)

Decision-Making to Seek Care

A caregiver's decision to seek care was influenced by a caregiver's partner and family. Husbands were the decision-makers for seeking care in any circumstance. Most mothers in Ethiopia were dependent on their husbands, specifically in resources. Additionally, elders and religious leaders had a strong influence on the decision-making of caregivers. Though an individual's perception varied, participants reported that the majority of elders did not recommend taking sick children to health facilities. Instead, they preferred to perform a coffee ceremony for sick individuals. A participant recalled that in our community, caregiver believed that if a child was exposed to *mich*, then her mother-in-law would suggest providing a local plant known as *aregessa*. They could provide this for the child to drink and to apply locally to their body. For example, a caregiver might want to take a sick child to the health centre, and her husband partially supports his wife's opinion. However, the grandmother of the ill child never goes to the health facility for medical care; the religious leader also recommends the community bring sick children to church for religious and spiritual services rather than taking them to the health centre. Religious leaders believe that a sick child can be better cured by taking them to holy water and through other religious practices.

> I do not bring my child to the health centre unless I communicate with my husband. My husband prefers to take children once we observe their situation at home, thinking that the illness might be cured by itself. If I bring the child, opposing my husband's opinion, and something wrong happen to our child, he will make me

accountable for that. So I need to wait for his present or recommendation before I bring sick children to the health centre. (woman, group discussion with caregivers)

Discussion

This study has indicated that the health-seeking behaviours of caregivers can be influenced by different contextual factors, such as caregivers' understanding of disease, access to health service and family pressures to seek care. Health care–seeking has the potential to substantially reduce infant mortality in areas with limited access to health services [3]. Caregivers' healthcare-seeking practices depend on local beliefs and understandings of diseases [4, 5]. In this qualitative study, caregivers understood child illness as manifesting through unusual symptoms, such as *mekremrem* (restlessness). Caregivers perceived that their child was sick if the child could not play or run as usual or was unable to breastfeed. They perceived child illness to be severe if the child had difficulty breathing and lost consciousness. A similar study in the Oromia region in Ethiopia reported similar results whereby caregivers understood child illness as a deviation from being full of energy, such as reduced play or physical activities [15].

The decision to take a sick child to a health institution was part of a complex care-seeking process that involved many people. The process in caregivers health seeking behaviours are: caregivers recognizing that the child was ill, caregivers recognizing the severity of the illness and caregivers deciding to take the child to a health institution based on the recognizing symptoms and illness [18]. A caregiver's understanding about their child's illness can influence the action they take to seek care [29]. Their beliefs can be influenced by the local community's health beliefs, which may, therefore, be important to child health and childhood illness [29]. As several anthropologists have argued, these local beliefs are often multidimensional, dynamic, rational and practical [30].

The participants in this study perceived that environmental and supernatural forces were the most common causes of childhood illness. In studies from various countries, researchers have reported that health-seeking behaviours for childhood illnesses are often inappropriate, and health facilities are under-utilised [15, 18, 31]. In a systematic review of 112 qualitative studies from SSA, some disease-specific etiological patterns were suggested for SSA settings [30]. For example, beliefs related to the causes of child mortality (like pneumonia and malaria) were often related to environmental factors [32]. These beliefs have also been

reported to extend to the negligence of the caregiver in exposing or failing to prevent the exposure of children to these conditions [32]. For instance, a mixed-methods study in Ghana showed that the community perceived childhood pneumonia to be caused by contact with cold temperatures in various forms [33].

Study participants reported that caregivers provided a variety of home-based treatments for a sick child. For example, a mixture of lemon and coffee was provided for a sick child with diarrhoea or vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers participating in the focus group discussion, and in the in-depth interviews, reported that they used *feto* (garden cress), chewed or masticated with *zingibil*, at home to treat most child illnesses. Household treatment practices were diverse and depended on perceived disease causation. While there were ideal household treatment options for particular diseases, the uncertainty with disease diagnosis and experimentation with multiple courses of treatment has commonly been the norm for home-based treatments [32]. Home-based treatments—where caregivers buy medicine from the pharmacy or use traditional medicines—were often the first point of care [34]. Home-based treatments, such as traditional medicines, were often administered by grandmothers [35]. Home-based treatment and care practices might lead to delays in health-seeking and put children at risk. Generally, caregivers' delay in seeking health care is one of the causes of infant mortality [36].

Lack of community access to healthcare facilities was one of the import barriers to seeking health care. Caregivers who were far from health facilities, could not afford transport costs and had a difficult-to-access road preferred to observe their children's situation at home. Areas for improvement in childhood survival include the availability of suitable services staffed by appropriate and trained health professionals, effective management of childhood illness and a strong partnership between families and healthcare providers [37]. Families with sick children should seek appropriate and timely assistance from health workers and follow the recommended treatments appropriately [38]. Research findings from the 2016 EDHS showed that money and distance were the most frequently perceived barriers to healthcare access in Ethiopia [39]. Distance to the health facility and transport cost were also the major barriers for health care–seeking in SSA countries [40, 41]

Caregivers decided to seek care for a sick child when the child's illness reached the stage of showing serious danger signs, such as being unable to breastfeed and becoming extremely hot. The decision to seek care for a sick child was not only influenced by mothers'/caregivers' efforts, but also influenced by elders, relatives and religious leaders. The

decision to seek care might also be guided by how the symptoms were perceived. Caregivers' decisions to seek healthcare were influenced by the status of the child's illness and the symptoms presented. Study participants reported that the final decision to seek care was generally made by grandmothers. In the study area, the father played a greater role in deciding to seek healthcare than the mothers did. Even though caregivers (women) have the right to decide their own health care, more than two-fifths of caregivers have no role in making such decisions [13]; instead, husbands play a major role in making healthcare decisions regarding their wives [13]. Evidence from a synthesis of the literature has indicated that women in developing countries have limited autonomy and control over their healthcare decisions [42].

Health care–seeking has the potential to substantially reduce child mortality, and it is of particular importance in areas with limited access to health services [43]. In Ethiopia, only 10% of children who are unwell are taken to a health post for treatment. Shaw et al. have indicated that this pattern of health-seeking behaviour was not only due to low awareness of this healthcare service option, but was also linked to socio-cultural factors, such as how caregivers in the community context understand and perceive an episode of child illness and how an episode of child illness is negotiated within families and communities [15]. A significant proportion of mothers do not seek help for childhood illness in Ethiopia—most caregivers and mothers do not know where and when to seek care for their child [44].

The validity of our findings was enhanced by methodological triangulation (data collected in the focus groups and individual interviews were compared and contrasted) and investigator triangulation (multiple members of the research team both in and outside the field participated in data analysis, including the coding and identification of themes) [45]. Maximum-variation sampling was used across age groups and across different groups of the community to mitigate the issues of representativeness in terms of study participants [45]. The Consolidated Criteria for Reporting Qualitative Research checklist for interviews and focus groups was used to report this qualitative research [46]. The study however still had some limitations. One of the key limitations was that most of the caregivers participated in this study were from the rural area and were farmers in occupation, therefore the findings from this study may not be generalizable to urban caregivers and community members.

Conclusion

Caregivers' healthcare-seeking practices play an important role in reducing the impact of newborn illnesses, including mortality; the correct recognition of illness in infants and newborns is essential for effective care-seeking. To improve healthcare-seeking practices, it is essential to understand the illness, cause of illness and the nature of decision-making family and the roles that people play. A contextual understanding of the community in health-seeking is important for designing focused child healthcare interventions in the study area. In Ethiopia, home-based treatment practices and traditional healing methods are widely accepted; therefore, the modern healthcare system needs to have strong relationships with local traditional healers to have their place in healthcare provider without putting children at risk.

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Footnotes

Contributors: GK conceived the study design. GK carried out the data collection. GK transcribed and translated the data. CC, DB, DL and GK performed the data analysis. CC, DB, DL and GK interpreted the results. GK drafted the manuscript. All the authors read and approved the final manuscript.

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‘If a Woman Opposes Her Mother-in-Law’s Opinion, She Would Be Labelled as Rude.’ Health-Seeking Behaviour of Ethiopian Caregivers when Infants Are Unwell—A Descriptive Qualitative Study

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Abstract

Objectives: To explore the health-seeking behaviour of Ethiopian caregivers when infants are unwell.

Design: A qualitative descriptive approach was employed using in-depth interviews and focus group discussions. Data were collected using semi-structured interview guides.

Setting: The study was conducted in East Gojjam Zones, Amhara region, northwest Ethiopia.

Participants: Participants were selected using a maximum variation purposive sampling technique across the different study groups; caregivers, community members and health care providers. A total of 35 respondents, 27 individuals in the focus group discussion and eight individuals in the in-depth interviews participated in the study.

Method: In this study, a qualitative descriptive approach was employed to explore the health-seeking behaviour of caregivers. The data was collected from July to September 2019 and conventional content analysis was applied.

Results: The decision to take a sick child to healthcare facilities is part of a complex care-seeking process that involves many people. Some of the critical steps in the process are caregivers recognizing that the child is ill, recognizing the severity of the illness and deciding to take the child to a health institution based on the recognized symptoms and illness. In Ethiopia, a significant proportion of caregivers do not seek healthcare for childhood illness, and most caregivers do not know where and when to seek care for their child. This study points out that the health-seeking behaviour of caregivers can be influenced by different contextual factors such as caregiver's disease understanding, access to health services, and family pressures to seek care.

Conclusions: Healthcare seeking practice plays an important role in reducing the impact of childhood illnesses and mortality. In Ethiopia, home-based treatment practice and traditional healing methods are widely accepted. Therefore, contextual understanding of the caregivers' health-seeking is important to design contextual healthcare interventions in the study area.

Strengths and limitations of this study

- A strength of this study is the diverse sample of participants.
- A further strength is the inclusion of multiple perspectives from those with lived experience of seeking and not seeking healthcare for children
- A limitation of this study is that the findings may not be generalizable to urban caregivers, as the study was focussed on rural settings where healthcare is difficult to obtain.
- Another limitation of this study is that recruiting care givers at health facilities may mean that included participants be more inclined to seek healthcare than caregivers who were not included in the study

Introduction

Healthcare-seeking behaviours can be defined as 'any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy' [1]. This implies that healthcare-seeking behaviour with respect to common childhood illness means that the need to take the child for treatment outside the home is recognised, that care is not delayed and that the child is taken to an appropriate health facility or provider [2]. A health behaviour to seek treatment for a sick child is a multifaceted process that has the following identified components: the caregiver's ability to identify that the child is ill, the caregivers should perceive that the illness is severe, and treatment or care should be sought, a process influenced by barriers such as time and money constraints [3]. Healthcare-seeking practices depend on local beliefs, preferences and decision-making with respect to child illnesses [4, 5]. The recognition of signs of ill health, which may have similarities and differences to medically recognised warning signs, is an important starting point for care-seeking [6]. Household responses to signs of ill health, which include the use of home-based treatments and traditional healers, can also affect the use of modern health care [6].

Healthcare-seeking has the potential to reduce child mortality substantially, and it is of particular importance in areas with limited access to health services [3]. A caregiver's healthcare-seeking behaviour is a crucial part of managing illness and preventing infant mortality [4]. Previous researchers have found that caregivers' healthcare-seeking behaviours have a significant impact on reducing infant mortality from childhood illnesses [7]. The WHO estimated that seeking appropriate health care could reduce child mortality by 20% [8]. In several studies conducted in developing countries, it has also been shown that delays in seeking appropriate care, or not seeking any care at all, cause a large number of child deaths [9, 10]. The proportion of care-seeking behaviours for childhood illness is low in most developing countries; only 26.4% of caregivers seek care when their child is sick [11].

The decision to seek care outside the home is influenced by decision-making dynamics within caregivers' lay referral network (especially involving husbands) and the resulting illness labels and perceptions of severity [12, 13]. Most caregivers seeking care outside the household have stated they wait for more than 24 hours before leaving home to seek care for their sick child [12]. The most common reasons for delaying seeking care [14] are uncertainty about illness progression, difficulties with access to treatment, apprehensions about

presenting to providers and the exigencies of daily life [15]. Poor health-seeking behaviour is not only due to poor awareness or a poor perceived need for this healthcare option, but is also related to cultural problems, such as caregivers' understanding of an episode of child illness and how the awareness can be transferred to the communities and families [14, 16].

In Ethiopia, it has been shown that less than half of caregivers seek treatment for their child's illnesses [17]. According to a health survey in Ethiopia, the proportion of caregivers who sought help for common childhood illnesses—ARI (Acute Respiratory Infection), fever and diarrhoea—from health facilities was 27%, 24% and 31%, respectively [18]. In another small study in Ethiopia, it was indicated that only 55% of caregivers with sick children visited health facilities for treatment [19]. In another community-based cross-sectional household study in Addis Ababa, the capital city of Ethiopia, it was shown that more than two-thirds of caregivers sought care for children aged under five when they were suffering from acute diarrhoeal illness, either at home or health facilities, with the remaining caregivers not seeking help [20].

In a qualitative study exploring care-seeking pathways for sick children in the rural Oromia region of Ethiopia, community members reported that a child's illness was recognised if there was a deviation from an ideal state of child full of health/energy [15]. The most noted symptoms in both acute and long-term child illnesses were recognised primarily by diminished activity, appetite and general lethargy [15]. According to the researchers, mothers were typically reported to be the first to recognise most symptoms of child illness [15]. However, the decision to seek care from a health institution was taken only when the child's symptoms did not improve with home treatment. Caregivers suggested that home-based actions were successful in aiding in the interpretation of an illness [15].

Although progress has been made in Ethiopia towards universal access of standard case management of common childhood illnesses, health care–seeking by caregivers for child illnesses has remained low [18]. Many caregivers do not know where and when to seek care, and health-seeking is delayed even after recognition of a child's illness [21]. Understanding the health-seeking behaviours of caregivers is vital for the rational planning and evaluation of child health service utilisation [20]. However, in rural Ethiopia, there is limited information on the health-seeking behaviours of caregivers for childhood illness. Specifically, there have been no studies that examine the health-seeking behaviours of caregivers in the study area. Therefore, this study aimed to explore the health-seeking behaviours of Ethiopian caregivers when infants are unwell.

Method and Materials

Study Area and Period

The study was conducted in the East Gojjam Zone, in the Amhara Region of Ethiopia, from July to September 2019. The zone is located in the east part of Amhara, which is in the north-western part of the Ethiopia and has a land area estimated at 170,000 km^2, with a population density of 110/km^2. According to a 2007 Central Statistics Agency report, East Gojjam Zone has an estimated population of 2,153,937 and an area of 14,000 km^2, giving a population density of 153.80/km^2 [22]. Nearly 84% of the people living in rural areas are engaged in agricultural activities, mostly comprising subsistence farming [23]. According to the 2015–16 Amhara regional report, the level of poverty in the region was higher than in the nation: 26.1% of the region's population lived in poverty, compared to 23.5% of the entire country's population [23]. Regarding access to health services, the region had a poor health status compared to other regions in Ethiopia [23]. The rate of child mortality in the region was among the highest in the country, 85 deaths per 1000 live births [24] ; it also had the highest stunting rate compared to other regions in the country, 46% of the under five children were stunting in 2016 [23, 24].

Study Design

A qualitative study was used to explore caregivers' and healthcare providers' experiences of health-seeking behaviours when infants were unwell. Qualitative descriptive is a method for research that seeks to present the voice of the particular population under study. Qualitative description approaches helps the researcher remain closer to the words and meanings offered by informants and can offer a comprehensive summary of a phenomenon in simple terms [25, 26]. Naturalistic inquiry involves studying something in its natural state such that variables are neither predetermined nor manipulated, and no a priori commitment is made to any particular theoretical viewpoint [25]. Researchers conducting qualitative descriptive studies stay closer to their data and to the surface of words and events than researchers conducting grounded theoretic, phenomenological, ethnographic or narrative studies [25].

Recruitment

A maximum-variation purposive sampling technique was used across the different groups of participants (caregivers, communities and healthcare providers). In-depth interviews and

focus group discussions were conducted with healthcare providers and caregivers, respectively. The number of focus group discussion was determined by data saturation and a total of five focus group discussions were conducted: two were conducted with primary caregivers at health centres and health posts during child vaccinations and another three were conducted with community members (fathers, grandmothers and community leaders). The focus group discussion with caregivers was held at a separate location away from the health centre and health post. Focus group discussions with community members were conducted at a central place within the village. An investment of time is required of participants, so they received remuneration of AUD$10.00 (the average daily wage for a labourer in Ethiopia) and per diem for health workers. The payment was made at the end of the interview and focus group discussion. Additionally, eight key informant interviews were conducted; four with healthcare providers working in maternal and child health units (two with health extension workers and two with nurses) and another four with community leaders.

Data Collection Procedure

The lead researcher and data collectors who were native speakers of the local language, Amharic, conducted the focus groups discussions and interviews. Two healthcare providers from a local University who had previous experience in interviews and moderating focus group discussions and who had work experience in the area for more than a year were recruited as data collectors. The data collectors undertook appropriate training to understand the cultural context, values and norms of the community prior to conducting the interviews. Male FGD was moderated by male and female FGD was moderated by female. The interviews were conducted at a private room in the health post and health centre. Audio was recorded with prior consent of the informants, and the recordings were transcribed verbatim. In addition, field notes was used and transcribed. The focus group discussion with caregivers was held at a separate location in the health centre and health post. The focus group discussion takes around two hours.

Data Processing and Analysis

Data analysis began immediately following data collection and continued throughout the research process. We applied conventional content analysis, which allowed for the continuing data collection to inform and be informed by emerging analyses. Content analysis is a procedure for the categorisation of verbal or behavioural data for the purpose of classification, summarisation and tabulation. It is generally used to describe a phenomenon: in this case, caregivers' health-seeking behaviours for infant and newborn health services. Conventional content analysis involves the identification, coding and categorisation of primary patterns in the data to ultimately draw meaningful relationships for study [27]. It allows for researchers' immersion in the data to allow new insights to emerge [27].

First, audio recordings of focus group discussions and key informant interviews were transcribed to the local language, Amharic, by the data collectors. The transcribed data were then translated into English. After repeated reading of focus group discussion and key informant interview transcripts, coding frames were generated. We used NVivo 12 [28] to assign codes to text and to assign strict defining parameters to the codes, thereby maximising consistency in the coding process. The interviews with healthcare workers and focus group discussions were coded separately and three data coders codded the data. Once all the interviews and group discussions were coded, the codes were categorised into larger themes that directly corresponded to the primary research questions. Within each of the broad themes, data were sorted into more narrow constructs, concepts and categories to allow for data interpretation [27].

Ethical Considerations

Ethical approval was granted by the University of Newcastle Human Research Ethics committee [H-2019-0090] and Human Research Ethics Committee of Health Science College, Debre Markos University [HC/Coms/Ser/172/11/11]. All study participants provided informed consent prior to interviews and focus group discussions.

Patient and public involvement

No patient was involved in the development of the research questions and outcome measures, study design or recruitment, and in the conduct of this study.

Results

Participant Characteristics

A total of 35 respondents—27 in the focus group discussions and 8 individuals in the in-depth interviews—participated in the study. The average number of individuals in each focus group was 7. The mean age of respondents who participated in the focus group discussions and in-depth interviews was 40 (± 12) years. The majority ($n = 24$) of the respondents were female. Respondents also had a mean of 4 (± 2) children. The majority ($n = 29$) were married during the focus group discussions and in-depth interviews, and the majority were farmers. The majority of the study participants attend primary education or less.

Caregivers' Understandings of Child Illness

Respondents report that in Ethiopia, specifically in the study area (northern Ethiopia), mothers were usually the ones to first identify a child as sick. Mothers were primary caregivers and had close ties to their children. Fathers spent the majority of their time outdoors in on-field activities like farming. A majority of the participants conceptualised illness in a child under the age of 1 as being manifested in strange symptoms such as *mekremrem* (restlessness), *fenen fenen* (irritability or continuous crying), a loss of strength or a lack of interest in breastfeeding. Caregivers initially identified child illness when the child showed strange behaviours during playing and eating. For example, if a child could not play and run as usual, then caregivers understood that their child was sick. For a child under the age of 1, caregivers recognised child illness when the child stopped breastfeeding or was unable to eat additional foods:

> I recognised my child's situation has worsened if my sick child decreases his breastfeeding gradually or if he stops taking breastfeed. Moreover, if the child has a fever, the temperature dropped or not, I can measure temperature by touching on their forehead and chest area. If the child's situation worsens, his temperature would be high. But if he shows improvement, his temperature would lower gradually, and he would begin breastfeeding again. (woman, interview)

Local Names and Causes of Illness

Causes of childhood illness were constructed as environmental (e.g., exposed to cold temperature and poor sanitation) and supernatural. Participants reported that *sanba mich* (pneumonia) and diarrhoea were the two most common diseases in children under the age of 1. Sick children mostly complained of fever. Moreover, they might have diarrhoea or *sanba mich*. Caregivers gave different reasons and causes for child illness. For example, if a child showed a sign of illness, such as a 'shouting nightmare' despite being awake, the caregivers perceived that the cause of the sickness was 'evil eye' or *metet*, for which magic and holy water were the preferred cure. Additionally, participants reported that the community recommend crossing a river if a child had been attacked by the evil eye. Once the child crossed the river, they would need to return home via another road because the evil eye would return if the child used on the same road. Moreover, there was a traditional medicine that would be smelled by the patient, and a child who was attacked by an evil eye would also need to smoke a burning tyre:

> There is some illness which we perceived as they can be caused by missing ceremonial activities for the lord of evil. Some women say this is the last day of the month late us celebrate, to not upset the evil. So, if a woman misses such ceremonies and her child becomes sick, she would directly relate with such incidents rather than accepting its real cause. Many households belief on traditional practices and norms for the cause of child illness. (woman, group discussion)

Caregivers in the study area also explained a cause of illness is *bird* (exposure to cold temperatures). Caregivers understood that children could develop pneumonia if they were in a cold environment, and this could happen due to inadequate child-caring practices by the mother. If the caregivers put the child on a cold and muddy floor, the child might be exposed to *bird.* Moreover, if the child put on many clothes or thick clothes, and then took off these clothes, they might be exposed to *bird*. For example, if a child put on a cap and then removed these clothes, then they might be exposed to *bird*, or might experience a clash of hot and cold air and consequently develop a fever, then s*anba mich*:

> Caregivers describe pneumonia as *sanba mich*; they understand that the cause of the disease was when a child has exposed to *bird*. They explained that my child was exposed to 'extremely cold environment', if he has high fever and cough. If a sick

> child has these symptoms, they would say my child has been developed *sanaba mich*. (woman, interview)

Home-Based Treatments for Childhood Illnesses

Participants reported that it was typical for caregivers and infants to stay at home, especially in the early postnatal stage. In northern Ethiopia, where this study was conducted, a majority of the population follow the Orthodox Christian religion, and according to religious norms, primary caregivers are not allowed to stay outside with the child before the child is baptised on the 40th day for male neonates and the 90th day for female neonates. However, participants reported that mothers would still attend health facilities for postnatal care and if an infant's illness was very serious and could not be managed after many trials of home-based treatments. However participants also reported that the death of a neonate at an early age was considered a *tefa* (stillbirth) rather than infant death; most of these deaths occur before the child is brought to the health facility and are not reported as neonatal deaths.

Home-based treatments for child illness were commonly reported for young children. When asked about home treatments for illness, caregivers reported providing a mixture of lemon, coffee and other ingredients to sick children with diarrhoea and vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers reported that they used *feto* (*Lepidium sativum*; garden cress), chewed or masticated with *zingibil*, at home to treat most child illnesses:

> if the child has a cough, I will give *tenadam* [*Ruta chalepensis*; fringed rue] with coffee, garlic with coffee on coup … it would cure, we also used *lega kibe* [fresh butter without spices]. (Emphasis added in bold; woman, group discussion)

> For child illness than one year, we can give *tenadam*, *nechishinkurt* [garlic] and *feto* with coffee for decreasing the cough. If he has delirium, biting his lip and his teeth, we will give *yebuda medhanit* [traditional herbal medicine for evil eye] per month. We also tie on his neck and hand. (Emphasis added in bold; man, group discussion with community member)

8.3.5 Caregivers' Access to Health Services

Participants reported that members of communities living far from the health facilities preferred to observe their children's situation at home, hoping their health would improve with time. For example, if a child in a remote area was sick, caregivers would decide not to bring the child to the health centre immediately; instead, they would observe the child for 2 or 3 days. Caregivers from lowland areas found it hard to access services. It was difficult to transport sick children with the traditional ambulance (a stretcher made up from local materials) and it was not possible to build roads to such villages to increase ambulance access. The only option was to use human resources and traveling on foot to bring sick children to a health facility. Accessing health services using traditional transport services was very difficult. Additionally, it was difficult to get people who could provide aid to and also carry sick individuals to a health facility during the summer season. Without such support, caregivers determined that they could not bring children to the health facility. Participants reported that community members might not accept a request for support from sick individuals if the road was too muddy. In contrast however, the social group (known as *edir*) would provide transport support when elder individuals became sick.

> Distance to the health institution it imposes a huge challenge to access health services. For example, there are clusters known as Tiba, Yetayiba, in this *kebele*. The road is not comfortable for health individual, give alone for a sick person to come in such muddy season. If I go through that road one day, I would sleep for at least 2 days due to the difficulty of the trip. They might bring a sick child with great suffering; otherwise, they would let them die on their hand. The road is too difficult. (man, group discussion)

Lack of money was reported to be another barrier to bringing sick children to a health facility. Community health insurance alleviated the financial burden of health care for the majority of the community, but there were some households that did not enter into this system. Such parents might not have the money to obtain treatment for their sick child. Participants recalled that community members might wait for days, thinking the child will recover soon without any treatment, or that the illness is not a serious risk to the child. Sometimes, such individuals might not have enough money, so they wait until they could obtain money; otherwise, those who used community health insurance were more likely to bring their sick children to the health facility immediately. Participants reported that some

fathers hesitated to pay for their child's medical bills; they did so not because they had no money from on hand, but rather, they hesitated to pay for other reasons. However, there were some women who saved money from for their household allowance for expenditure when such difficult situations arose.

> Individuals who do not have a community health insurance prefer to buy drugs from the pharmacy, rather than paying for related services like getting examination card, waiting for long queue and passing through other steps. Moreover, they might not be able to bring sick children to the health facility, so they can buy from private clinics without any physical examination and investigation. I met a man whose child was sick and when he went to a private clinic to buy medications, I asked him why he brings the child with him; he said since it is a busy working day in the community, he can access no one to bring his sick child to a health facility, so his only option is to buy medication from the private clinic by telling them his symptoms. (woman, interview)

Participants reported that beliefs around traditional practices was a factor in decision-making. For example, if a family had only one child, and they believed they received this child as a miracle from God, and they may get this child by performing cultural rituals like giving promise for the witch, the witch might perform magical and spiritual things to let couples have a baby. A child who is delivered through such a process would not be taken to the health facility when they are sick, since the mother believes that the witch is the one who can protect and save the child from all the risks the child might experience through their entire life. As such, the mother would prefer to take care of the child at home as per the recommendation of the witch; similarly, the mother would not agree to take her child for vaccination. The mother would even cut the child's hair in such a way that would expose the child as her only child; such children could thus be easily identified by the community. This indicates that there are harmful traditional practices and norms that prevent children from accessing health care.

> When I tried to convince the woman to take her child to a health centre, she said, 'I get this child by pledging to a witch, if I take him to health centre he might die. I would never take him for any medical care'. (health professional)

> I fear their diseases might adapt the medication through time if I bring them to a health facility for each sickness. It is not a good practice to provide medicines for

> sick children frequently, since they might develop resistance. Therefore, I observe their progress at home in 2 or 3 days; if they do not show improvement, I would bring them to the health centre. (man, group discussion)

Decision-Making to Seek Care

A caregiver's decision to seek care was influenced by a caregiver's partner and family. Husbands were the decision-makers for seeking care in any circumstance. Most mothers in Ethiopia were dependent on their husbands, specifically in resources. Additionally, elders and religious leaders had a strong influence on the decision-making of caregivers. Though an individual's perception varied, participants reported that the majority of elders did not recommend taking sick children to health facilities. Instead, they preferred to perform a coffee ceremony for sick individuals. A participant recalled that in our community, caregiver believed that if a child was exposed to *mich*, then her mother-in-law would suggest providing a local plant known as *aregessa*. They could provide this for the child to drink and to apply locally to their body. For example, a caregiver might want to take a sick child to the health centre, and her husband partially supports his wife's opinion. However, the grandmother of the ill child never goes to the health facility for medical care; the religious leader also recommends the community bring sick children to church for religious and spiritual services rather than taking them to the health centre. Religious leaders believe that a sick child can be better cured by taking them to holy water and through other religious practices.

> I do not bring my child to the health centre unless I communicate with my husband. My husband prefers to take children once we observe their situation at home, thinking that the illness might be cured by itself. If I bring the child, opposing my husband's opinion, and something wrong happen to our child, he will make me accountable for that. So I need to wait for his present or recommendation before I bring sick children to the health centre. (woman, group discussion with caregivers)

Discussion

This study has indicated that the health-seeking behaviours of caregivers can be influenced by different contextual factors, such as caregivers' understanding of disease, access to health service and family pressures to seek care. Health care–seeking has the potential to substantially reduce infant mortality in areas with limited access to health services [3].

Caregivers' healthcare-seeking practices depend on local beliefs and understandings of diseases [4, 5]. In this qualitative study, caregivers understood child illness as manifesting through unusual symptoms, such as *mekremrem* (restlessness). Caregivers perceived that their child was sick if the child could not play or run as usual or was unable to breastfeed. They perceived child illness to be severe if the child had difficulty breathing and lost consciousness. A similar study in the Oromia region in Ethiopia reported similar results whereby caregivers understood child illness as a deviation from being full of energy, such as reduced play or physical activities [15].

The decision to take a sick child to a health institution was part of a complex care-seeking process that involved many people. The process in caregivers health seeking behaviours are: caregivers recognizing that the child was ill, caregivers recognizing the severity of the illness and caregivers deciding to take the child to a health institution based on the recognizing symptoms and illness [18]. A caregiver's understanding about their child's illness can influence the action they take to seek care [29]. Their beliefs can be influenced by the local community's health beliefs, which may, therefore, be important to child health and childhood illness [29]. As several anthropologists have argued, these local beliefs are often multidimensional, dynamic, rational and practical [30].

The participants in this study perceived that environmental and supernatural forces were the most common causes of childhood illness. In studies from various countries, researchers have reported that health-seeking behaviours for childhood illnesses are often inappropriate, and health facilities are under-utilised [15, 18, 31]. In a systematic review of 112 qualitative studies from SSA, some disease-specific etiological patterns were suggested for SSA settings [30]. For example, beliefs related to the causes of child mortality (like pneumonia and malaria) were often related to environmental factors [32]. These beliefs have also been reported to extend to the negligence of the caregiver in exposing or failing to prevent the exposure of children to these conditions [32]. For instance, a mixed-methods study in Ghana showed that the community perceived childhood pneumonia to be caused by contact with cold temperatures in various forms [33].

Study participants reported that caregivers provided a variety of home-based treatments for a sick child. For example, a mixture of lemon and coffee was provided for a sick child with diarrhoea or vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers participating in the focus group discussion, and in the in-depth interviews, reported that they used *feto* (garden cress), chewed or masticated with

zingibil, at home to treat most child illnesses. Household treatment practices were diverse and depended on perceived disease causation. While there were ideal household treatment options for particular diseases, the uncertainty with disease diagnosis and experimentation with multiple courses of treatment has commonly been the norm for home-based treatments [32]. Home-based treatments—where caregivers buy medicine from the pharmacy or use traditional medicines—were often the first point of care [34]. Home-based treatments, such as traditional medicines, were often administered by grandmothers [35]. Home-based treatment and care practices might lead to delays in health-seeking and put children at risk. Generally, caregivers' delay in seeking health care is one of the causes of infant mortality [36].

Lack of community access to healthcare facilities was one of the import barriers to seeking health care. Caregivers who were far from health facilities, could not afford transport costs and had a difficult-to-access road preferred to observe their children's situation at home. Areas for improvement in childhood survival include the availability of suitable services staffed by appropriate and trained health professionals, effective management of childhood illness and a strong partnership between families and healthcare providers [37]. Families with sick children should seek appropriate and timely assistance from health workers and follow the recommended treatments appropriately [38]. Research findings from the 2016 EDHS showed that money and distance were the most frequently perceived barriers to healthcare access in Ethiopia [39]. Distance to the health facility and transport cost were also the major barriers for health care–seeking in SSA countries [40, 41]

Caregivers decided to seek care for a sick child when the child's illness reached the stage of showing serious danger signs, such as being unable to breastfeed and becoming extremely hot. The decision to seek care for a sick child was not only influenced by mothers'/caregivers' efforts, but also influenced by elders, relatives and religious leaders. The decision to seek care might also be guided by how the symptoms were perceived. Caregivers' decisions to seek healthcare were influenced by the status of the child's illness and the symptoms presented. Study participants reported that the final decision to seek care was generally made by grandmothers. In the study area, the father played a greater role in deciding to seek healthcare than the mothers did. Even though caregivers (women) have the right to decide their own health care, more than two-fifths of caregivers have no role in making such decisions [13]; instead, husbands play a major role in making healthcare decisions regarding their wives [13]. Evidence from a synthesis of the literature has indicated

that women in developing countries have limited autonomy and control over their healthcare decisions [42].

Health care–seeking has the potential to substantially reduce child mortality, and it is of particular importance in areas with limited access to health services [43]. In Ethiopia, only 10% of children who are unwell are taken to a health post for treatment. Shaw et al. have indicated that this pattern of health-seeking behaviour was not only due to low awareness of this healthcare service option, but was also linked to socio-cultural factors, such as how caregivers in the community context understand and perceive an episode of child illness and how an episode of child illness is negotiated within families and communities [15]. A significant proportion of mothers do not seek help for childhood illness in Ethiopia—most caregivers and mothers do not know where and when to seek care for their child [44].

The validity of our findings was enhanced by methodological triangulation (data collected in the focus groups and individual interviews were compared and contrasted) and investigator triangulation (multiple members of the research team both in and outside the field participated in data analysis, including the coding and identification of themes) [45]. Maximum-variation sampling was used across age groups and across different groups of the community to mitigate the issues of representativeness in terms of study participants [45]. The Consolidated Criteria for Reporting Qualitative Research checklist for interviews and focus groups was used to report this qualitative research [46]. The study however still had some limitations. One of the key limitations was that most of the caregivers participated in this study were from the rural area and were farmers in occupation, therefore the findings from this study may not be generalizable to urban caregivers and community members.

Conclusion

Caregivers' healthcare-seeking practices play an important role in reducing the impact of newborn illnesses, including mortality; the correct recognition of illness in infants and newborns is essential for effective care-seeking. To improve healthcare-seeking practices, it is essential to understand the illness, cause of illness and the nature of decision-making family and the roles that people play. A contextual understanding of the community in health-seeking is important for designing focused child healthcare interventions in the study area. In Ethiopia, home-based treatment practices and traditional healing methods are widely accepted; therefore, the modern healthcare system needs to have strong relationships with

local traditional healers to have their place in healthcare provider without putting children at risk.

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Footnotes

Contributors: GK conceived the study design. GK carried out the data collection. GK transcribed and translated the data. CC, DB, DL and GK performed the data analysis. CC, DB, DL and GK interpreted the results. GK drafted the manuscript. All the authors read and approved the final manuscript.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	7
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	7
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6-7
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	7
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	15-17
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Health-Seeking Behaviour of Ethiopian Caregivers when Infants Are Unwell—A Descriptive Qualitative Study

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Abstract

Objectives: To explore the health-seeking behaviour of Ethiopian caregivers when infants are unwell.

Design: A qualitative descriptive approach was employed using in-depth interviews and focus group discussions. Data were collected using semi-structured interview guides.

Setting: The study was conducted in East Gojjam Zones, Amhara region, northwest Ethiopia.

Participants: Participants were selected using a maximum variation purposive sampling technique across the different study groups; caregivers, community members and health care providers. A total of 35 respondents, 27 individuals in the focus group discussion and eight individuals in the in-depth interviews participated in the study.

Method: In this study, a qualitative descriptive approach was employed to explore the health-seeking behaviour of caregivers. The data was collected from July to September 2019 and conventional content analysis was applied.

Results: The decision to take a sick child to healthcare facilities is part of a complex care-seeking process that involves many people. Some of the critical steps in the process are caregivers recognizing that the child is ill, recognizing the severity of the illness and deciding to take the child to a health institution based on the recognized symptoms and illness. In Ethiopia, a significant proportion of caregivers do not seek healthcare for childhood illness, and most caregivers do not know where and when to seek care for their child. This study points out that the health-seeking behaviour of caregivers can be influenced by different contextual factors such as caregiver's disease understanding, access to health services, and family pressures to seek care.

Conclusions: Healthcare seeking practice plays an important role in reducing the impact of childhood illnesses and mortality. In Ethiopia, home-based treatment practice and traditional healing methods are widely accepted. Therefore, contextual understanding of the caregivers' health-seeking is important to design contextual healthcare interventions in the study area.

Strengths and limitations of this study

- A strength of this study is the diverse sample of participants.
- A further strength is the inclusion of multiple perspectives from those with lived experience of seeking and not seeking healthcare for children
- A limitation of this study is that recruiting care givers at health facilities may mean that included participants be more inclined to seek healthcare than caregivers who were not included in the study

Introduction

Healthcare-seeking behaviours can be defined as 'any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy' [1]. This implies that healthcare-seeking behaviour with respect to common childhood illness means that the need to take the child for treatment outside the home is recognised, that care is not delayed and that the child is taken to an appropriate health facility or provider [2]. A health behaviour to seek treatment for a sick child is a multifaceted process that has the following identified components: the caregiver's ability to identify that the child is ill, the caregivers should perceive that the illness is severe, and treatment or care should be sought, a process influenced by barriers such as time and money constraints [3]. Healthcare-seeking practices depend on local beliefs, preferences and decision-making with respect to child illnesses [4, 5]. The recognition of signs of ill health, which may have similarities and differences to medically recognised warning signs, is an important starting point for care-seeking [6]. Household responses to signs of ill health, which include the use of home-based treatments and traditional healers, can also affect the use of modern health care [6].

Healthcare-seeking has the potential to reduce child mortality substantially, and it is of particular importance in areas with limited access to health services [3]. A caregiver's healthcare-seeking behaviour is a crucial part of managing illness and preventing infant mortality [4]. Previous researchers have found that caregivers' healthcare-seeking behaviours have a significant impact on reducing infant mortality from childhood illnesses [7]. The WHO estimated that seeking appropriate health care could reduce child mortality by 20% [8]. In several studies conducted in developing countries, it has also been shown that delays in seeking appropriate care, or not seeking any care at all, cause a large number of child deaths [9, 10]. The proportion of care-seeking behaviours for childhood illness is low in most developing countries; only 26.4% of caregivers seek care when their child is sick [11].

The decision to seek care outside the home is influenced by decision-making dynamics within caregivers' lay referral network (especially involving husbands) and the resulting illness labels and perceptions of severity [12, 13]. Most caregivers seeking care outside the household have stated they wait for more than 24 hours before leaving home to seek care for their sick child [12]. The most common reasons for delaying seeking care [14] are uncertainty about illness progression, difficulties with access to treatment, apprehensions about

presenting to providers and the exigencies of daily life [15]. Poor health-seeking behaviour is not only due to poor awareness or a poor perceived need for this healthcare option, but is also related to cultural problems, such as caregivers' understanding of an episode of child illness and how the awareness can be transferred to the communities and families [14, 16].

In Ethiopia, it has been shown that less than half of caregivers seek treatment for their child's illnesses [17]. According to a health survey in Ethiopia, the proportion of caregivers who sought help for common childhood illnesses—ARI (Acute Respiratory Infection), fever and diarrhoea—from health facilities was 27%, 24% and 31%, respectively [18]. In another small study in Ethiopia, it was indicated that only 55% of caregivers with sick children visited health facilities for treatment [19]. In another community-based cross-sectional household study in Addis Ababa, the capital city of Ethiopia, it was shown that more than two-thirds of caregivers sought care for children aged under five when they were suffering from acute diarrhoeal illness, either at home or health facilities, with the remaining caregivers not seeking help [20].

In a qualitative study exploring care-seeking pathways for sick children in the rural Oromia region of Ethiopia, community members reported that a child's illness was recognised if there was a deviation from an ideal state of child full of health/energy [15]. The most noted symptoms in both acute and long-term child illnesses were recognised primarily by diminished activity, appetite and general lethargy [15]. According to the researchers, mothers were typically reported to be the first to recognise most symptoms of child illness [15]. However, the decision to seek care from a health institution was taken only when the child's symptoms did not improve with home treatment. Caregivers suggested that home-based actions were successful in aiding in the interpretation of an illness [15].

Although progress has been made in Ethiopia towards universal access of standard case management of common childhood illnesses, health care–seeking by caregivers for child illnesses has remained low [18]. Many caregivers do not know where and when to seek care, and health-seeking is delayed even after recognition of a child's illness [21]. Understanding the health-seeking behaviours of caregivers is vital for the rational planning and evaluation of child health service utilisation [20]. However, in rural Ethiopia, there is limited information on the health-seeking behaviours of caregivers for childhood illness. Specifically, there have been no studies that examine the health-seeking behaviours of caregivers in the study area. Therefore, this study aimed to explore the health-seeking behaviours of Ethiopian caregivers when infants are unwell.

Method and Materials

Study Area and Period

The study was conducted in the East Gojjam Zone, in the Amhara Region of Ethiopia, from July to September 2019. The zone is located in the east part of Amhara, which is in the north-western part of the Ethiopia and has a land area estimated at 170,000 km^2, with a population density of 110/km^2. According to a 2007 Central Statistics Agency report, East Gojjam Zone has an estimated population of 2,153,937 and an area of 14,000 km^2, giving a population density of 153.80/km^2 [22]. Nearly 84% of the people living in rural areas are engaged in agricultural activities, mostly comprising subsistence farming [23]. According to the 2015–16 Amhara regional report, the level of poverty in the region was higher than in the nation: 26.1% of the region's population lived in poverty, compared to 23.5% of the entire country's population [23]. Regarding access to health services, the region had a poor health status compared to other regions in Ethiopia [23]. The rate of child mortality in the region was among the highest in the country, 85 deaths per 1000 live births [24] ; it also had the highest stunting rate compared to other regions in the country, 46% of the under five children were stunting in 2016 [23, 24].

Study Design

A qualitative study was used to explore caregivers' and healthcare providers' experiences of health-seeking behaviours when infants were unwell. Qualitative descriptive is a method for research that seeks to present the voice of the particular population under study. Qualitative description approaches helps the researcher remain closer to the words and meanings offered by informants and can offer a comprehensive summary of a phenomenon in simple terms [25, 26]. Naturalistic inquiry involves studying something in its natural state such that variables are neither predetermined nor manipulated, and no a priori commitment is made to any particular theoretical viewpoint [25]. Researchers conducting qualitative descriptive studies stay closer to their data and to the surface of words and events than researchers conducting grounded theoretic, phenomenological, ethnographic or narrative studies [25].

Recruitment

A maximum-variation purposive sampling technique was used across the different groups of participants (caregivers, communities and healthcare providers). In-depth interviews and

focus group discussions were conducted with healthcare providers and caregivers, respectively. The number of focus group discussion was determined by data saturation and a total of five focus group discussions were conducted: two were conducted with primary caregivers at health centres and health posts during child vaccinations and another three were conducted with community members (fathers, grandmothers and community leaders). The focus group discussion with caregivers was held at a separate location away from the health centre and health post. Focus group discussions with community members were conducted at a central place within the village. An investment of time is required of participants, so they received remuneration of AUD$10.00 (the average daily wage for a labourer in Ethiopia) and per diem for health workers. The payment was made at the end of the interview and focus group discussion. Additionally, eight key informant interviews were conducted; four with healthcare providers working in maternal and child health units (two with health extension workers and two with nurses) and another four with community leaders.

Data Collection Procedure

The lead researcher and data collectors who were native speakers of the local language, Amharic, conducted the focus groups discussions and interviews. Two healthcare providers from a local University who had previous experience in interviews and moderating focus group discussions and who had work experience in the area for more than a year were recruited as data collectors. The data collectors undertook appropriate training to understand the cultural context, values and norms of the community prior to conducting the interviews. Male FGD was moderated by male and female FGD was moderated by female. The interviews were conducted at a private room in the health post and health centre. Audio was recorded with prior consent of the informants, and the recordings were transcribed verbatim. In addition, field notes was used and transcribed. The focus group discussion takes around two hours.

Data Processing and Analysis

Data analysis began immediately following data collection and continued throughout the research process. We applied conventional content analysis, which allowed for the continuing data collection to inform and be informed by emerging analyses. Content analysis is a procedure for the categorisation of verbal or behavioural data for the purpose of classification, summarisation and tabulation. It is generally used to describe a phenomenon: in this case, caregivers' health-seeking behaviours for infant and newborn health services. Conventional content analysis involves the identification, coding and categorisation of primary patterns in the data to ultimately draw meaningful relationships for study [27]. It allows for researchers' immersion in the data to allow new insights to emerge [27].

First, audio recordings of focus group discussions and key informant interviews were transcribed to the local language, Amharic, by the data collectors. The transcribed data were then translated into English. After repeated reading of focus group discussion and key informant interview transcripts, coding frames were generated. We used NVivo 12 [28] to assign codes to text and to assign strict defining parameters to the codes, thereby maximising consistency in the coding process. The interviews with healthcare workers and focus group discussions were coded separately and three data coders codded the data. Once all the interviews and group discussions were coded, the codes were categorised into larger themes that directly corresponded to the primary research questions. Within each of the broad themes, data were sorted into more narrow constructs, concepts and categories to allow for data interpretation [27].

Ethical Considerations

Ethical approval was granted by the University of Newcastle Human Research Ethics committee [H-2019-0090] and Human Research Ethics Committee of Health Science College, Debre Markos University [HC/Coms/Ser/172/11/11]. All study participants provided informed consent prior to interviews and focus group discussions.

Patient and public involvement

No patient was involved in the development of the research questions and outcome measures, study design or recruitment, and in the conduct of this study.

Results

Participant Characteristics

A total of 35 respondents—27 in the focus group discussions and 8 individuals in the in-depth interviews—participated in the study. The average number of individuals in each focus group was 7. The mean age of respondents who participated in the focus group discussions and in-depth interviews was 40 (± 12) years. The majority ($n = 24$) of the respondents were female. Respondents also had a mean of 4 (± 2) children. The majority ($n = 29$) were married during the focus group discussions and in-depth interviews, and the majority were farmers. The majority of the study participants attend primary education or less.

Caregivers' Understandings of Child Illness

Respondents report that in Ethiopia, specifically in the study area (northern Ethiopia), mothers were usually the ones to first identify a child as sick. Mothers were primary caregivers and had close ties to their children. Fathers spent the majority of their time outdoors in on-field activities like farming. A majority of the participants conceptualised illness in a child under the age of 1 as being manifested in strange symptoms such as *mekremrem* (restlessness), *fenen fenen* (irritability or continuous crying), a loss of strength or a lack of interest in breastfeeding. Caregivers initially identified child illness when the child showed strange behaviours during playing and eating. For example, if a child could not play and run as usual, then caregivers understood that their child was sick. For a child under the age of 1, caregivers recognised child illness when the child stopped breastfeeding or was unable to eat additional foods:

> I recognised my child's situation has worsened if my sick child decreases his breastfeeding gradually or if he stops taking breastfeed. Moreover, if the child has a fever, the temperature dropped or not, I can measure temperature by touching on their forehead and chest area. If the child's situation worsens, his temperature would be high. But if he shows improvement, his temperature would lower gradually, and he would begin breastfeeding again. (20-24-year-old woman, interview)

Local Names and Causes of Illness

Causes of childhood illness were constructed as environmental (e.g., exposed to cold temperature and poor sanitation) and supernatural. Participants reported that *sanba mich* (pneumonia) and diarrhoea were the two most common diseases in children under the age of 1. Sick children mostly complained of fever. Moreover, they might have diarrhoea or *sanba mich*. Caregivers gave different reasons and causes for child illness. For example, if a child showed a sign of illness, such as a 'shouting nightmare' despite being awake, the caregivers perceived that the cause of the sickness was 'evil eye' or *metet*, for which magic and holy water were the preferred cure. Additionally, participants reported that the community recommend crossing a river if a child had been attacked by the evil eye. Once the child crossed the river, they would need to return home via another road because the evil eye would return if the child used on the same road. Moreover, there was a traditional medicine that would be smelled by the patient, and a child who was attacked by an evil eye would also need to smoke a burning tyre:

> There is some illness which we perceived as they can be caused by missing ceremonial activities for the lord of evil. Some women say this is the last day of the month late us celebrate, to not upset the evil. So, if a woman misses such ceremonies and her child becomes sick, she would directly relate with such incidents rather than accepting its real cause. Many households belief on traditional practices and norms for the cause of child illness. (20-24-year-old woman, group discussion)

Caregivers in the study area also explained a cause of illness is *bird* (exposure to cold temperatures). Caregivers understood that children could develop pneumonia if they were in a cold environment, and this could happen due to inadequate child-caring practices by the mother. If the caregivers put the child on a cold and muddy floor, the child might be exposed to *bird.* Moreover, if the child put on many clothes or thick clothes, and then took off these clothes, they might be exposed to *bird*. For example, if a child put on a cap and then removed these clothes, then they might be exposed to *bird*, or might experience a clash of hot and cold air and consequently develop a fever, then s*anba mich*:

> Caregivers describe pneumonia as *sanba mich*; they understand that the cause of the disease was when a child has exposed to *bird*. They explained that my child was

> exposed to 'extremely cold environment', if he has high fever and cough. If a sick child has these symptoms, they would say my child has been developed *sanaba mich*. (25-29 year-old woman, interview)

Home-Based Treatments for Childhood Illnesses

Participants reported that it was typical for caregivers and infants to stay at home, especially in the early postnatal stage. In northern Ethiopia, where this study was conducted, a majority of the population follow the Orthodox Christian religion, and according to religious norms, primary caregivers are not allowed to stay outside with the child before the child is baptised on the 40th day for male neonates and the 90th day for female neonates. However, participants reported that mothers would still attend health facilities for postnatal care and if an infant's illness was very serious and could not be managed after many trials of home-based treatments. However participants also reported that the death of a neonate at an early age was considered a *tefa* (stillbirth) rather than infant death; most of these deaths occur before the child is brought to the health facility and are not reported as neonatal deaths.

Home-based treatments for child illness were commonly reported for young children. When asked about home treatments for illness, caregivers reported providing a mixture of lemon, coffee and other ingredients to sick children with diarrhoea and vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers reported that they used *feto* (*Lepidium sativum*; garden cress), chewed or masticated with *zingibil*, at home to treat most child illnesses:

> if the child has a cough, I will give *tenadam* [*Ruta chalepensis*; fringed rue] with coffee, garlic with coffee on coup … it would cure, we also used *lega kibe* [fresh butter without spices]. (Emphasis added in bold; 25-29-year-old woman, group discussion)

> For child illness than one year, we can give *tenadam*, *nechishinkurt* [garlic] and *feto* with coffee for decreasing the cough. If he has delirium, biting his lip and his teeth, we will give *yebuda medhanit* [traditional herbal medicine for evil eye] per month. We also tie on his neck and hand. (Emphasis added in bold; 40-44-year-old man, group discussion with community member)

8.3.5 Caregivers' Access to Health Services

Participants reported that members of communities living far from the health facilities preferred to observe their children's situation at home, hoping their health would improve with time. For example, if a child in a remote area was sick, caregivers would decide not to bring the child to the health centre immediately; instead, they would observe the child for 2 or 3 days. Caregivers from lowland areas found it hard to access services. It was difficult to transport sick children with the traditional ambulance (a stretcher made up from local materials) and it was not possible to build roads to such villages to increase ambulance access. The only option was to use human resources and traveling on foot to bring sick children to a health facility. Accessing health services using traditional transport services was very difficult. Additionally, it was difficult to get people who could provide aid to and also carry sick individuals to a health facility during the summer season. Without such support, caregivers determined that they could not bring children to the health facility. Participants reported that community members might not accept a request for support from sick individuals if the road was too muddy. In contrast however, the social group (known as *edir*) would provide transport support when elder individuals became sick.

> Distance to the health institution it imposes a huge challenge to access health services. For example, there are clusters known as Tiba, Yetayiba, in this *kebele*. The road is not comfortable for health individual, give alone for a sick person to come in such muddy season. If I go through that road one day, I would sleep for at least 2 days due to the difficulty of the trip. They might bring a sick child with great suffering; otherwise, they would let them die on their hand. The road is too difficult. (45-49-year-old man, group discussion)

Lack of money was reported to be another barrier to bringing sick children to a health facility. Community health insurance alleviated the financial burden of health care for the majority of the community, but there were some households that did not enter into this system. Such parents might not have the money to obtain treatment for their sick child. Participants recalled that community members might wait for days, thinking the child will recover soon without any treatment, or that the illness is not a serious risk to the child. Sometimes, such individuals might not have enough money, so they wait until they could obtain money; otherwise, those who used community health insurance were more likely to bring their sick children to the health facility immediately. Participants reported that some

fathers hesitated to pay for their child's medical bills; they did so not because they had no money from on hand, but rather, they hesitated to pay for other reasons. However, there were some women who saved money from for their household allowance for expenditure when such difficult situations arose.

> Individuals who do not have a community health insurance prefer to buy drugs from the pharmacy, rather than paying for related services like getting examination card, waiting for long queue and passing through other steps. Moreover, they might not be able to bring sick children to the health facility, so they can buy from private clinics without any physical examination and investigation. I met a man whose child was sick and when he went to a private clinic to buy medications, I asked him why he brings the child with him; he said since it is a busy working day in the community, he can access no one to bring his sick child to a health facility, so his only option is to buy medication from the private clinic by telling them his symptoms. (20-24-year-old woman, interview)

Participants reported that beliefs around traditional practices was a factor in decision-making. For example, if a family had only one child, and they believed they received this child as a miracle from God, and they may get this child by performing cultural rituals like giving promise for the witch, the witch might perform magical and spiritual things to let couples have a baby. A child who is delivered through such a process would not be taken to the health facility when they are sick, since the mother believes that the witch is the one who can protect and save the child from all the risks the child might experience through their entire life. As such, the mother would prefer to take care of the child at home as per the recommendation of the witch; similarly, the mother would not agree to take her child for vaccination. The mother would even cut the child's hair in such a way that would expose the child as her only child; such children could thus be easily identified by the community. This indicates that there are harmful traditional practices and norms that prevent children from accessing health care.

> When I tried to convince the woman to take her child to a health centre, she said, 'I get this child by pledging to a witch, if I take him to health centre he might die. I would never take him for any medical care'. (20-24 –year-old health professional)

> I fear their diseases might adapt the medication through time if I bring them to a health facility for each sickness. It is not a good practice to provide medicines for

> sick children frequently, since they might develop resistance. Therefore, I observe their progress at home in 2 or 3 days; if they do not show improvement, I would bring them to the health centre. (40-44-year-old man, group discussion)

Decision-Making to Seek Care

A caregiver's decision to seek care was influenced by a caregiver's partner and family. Husbands were the decision-makers for seeking care in any circumstance. Most mothers in Ethiopia were dependent on their husbands, specifically in resources. Additionally, elders and religious leaders had a strong influence on the decision-making of caregivers. Though an individual's perception varied, participants reported that the majority of elders did not recommend taking sick children to health facilities. Instead, they preferred to perform a coffee ceremony for sick individuals. A participant recalled that in our community, caregiver believed that if a child was exposed to *mich*, then her mother-in-law would suggest providing a local plant known as *aregessa*. They could provide this for the child to drink and to apply locally to their body. For example, a caregiver might want to take a sick child to the health centre, and her husband partially supports his wife's opinion. However, the grandmother of the ill child never goes to the health facility for medical care; the religious leader also recommends the community bring sick children to church for religious and spiritual services rather than taking them to the health centre. Religious leaders believe that a sick child can be better cured by taking them to holy water and through other religious practices.

> I do not bring my child to the health centre unless I communicate with my husband. My husband prefers to take children once we observe their situation at home, thinking that the illness might be cured by itself. If I bring the child, opposing my husband's opinion, and something wrong happen to our child, he will make me accountable for that. So I need to wait for his present or recommendation before I bring sick children to the health centre. (40-44-year-old woman, group discussion with caregivers)

Discussion

This study has indicated that the health-seeking behaviours of caregivers can be influenced by different contextual factors, such as caregivers' understanding of disease, access to health service and family pressures to seek care. Health care–seeking has the potential to

substantially reduce infant mortality in areas with limited access to health services [3]. Caregivers' healthcare-seeking practices depend on local beliefs and understandings of diseases [4, 5]. In this qualitative study, caregivers understood child illness as manifesting through unusual symptoms, such as *mekremrem* (restlessness). Caregivers perceived that their child was sick if the child could not play or run as usual or was unable to breastfeed. They perceived child illness to be severe if the child had difficulty breathing and lost consciousness. A similar study in the Oromia region in Ethiopia reported similar results whereby caregivers understood child illness as a deviation from being full of energy, such as reduced play or physical activities [15].

The decision to take a sick child to a health institution was part of a complex care-seeking process that involved many people. The process in caregivers health seeking behaviours are: caregivers recognizing that the child was ill, caregivers recognizing the severity of the illness and caregivers deciding to take the child to a health institution based on the recognizing symptoms and illness [18]. A caregiver's understanding about their child's illness can influence the action they take to seek care [29]. Their beliefs can be influenced by the local community's health beliefs, which may, therefore, be important to child health and childhood illness [29]. As several anthropologists have argued, these local beliefs are often multidimensional, dynamic, rational and practical [30].

The participants in this study perceived that environmental and supernatural forces were the most common causes of childhood illness. In studies from various countries, researchers have reported that health-seeking behaviours for childhood illnesses are often inappropriate, and health facilities are under-utilised [15, 18, 31]. In a systematic review of 112 qualitative studies from SSA, some disease-specific etiological patterns were suggested for SSA settings [30]. For example, beliefs related to the causes of child mortality (like pneumonia and malaria) were often related to environmental factors [32]. These beliefs have also been reported to extend to the negligence of the caregiver in exposing or failing to prevent the exposure of children to these conditions [32]. For instance, a mixed-methods study in Ghana showed that the community perceived childhood pneumonia to be caused by contact with cold temperatures in various forms [33].

Study participants reported that caregivers provided a variety of home-based treatments for a sick child. For example, a mixture of lemon and coffee was provided for a sick child with diarrhoea or vomiting. *Zingibil* (ginger root) was also used for stomach aches and respiratory problems. Most of the caregivers participating in the focus group discussion, and in the in-

depth interviews, reported that they used *feto* (garden cress), chewed or masticated with *zingibil*, at home to treat most child illnesses. Household treatment practices were diverse and depended on perceived disease causation. While there were ideal household treatment options for particular diseases, the uncertainty with disease diagnosis and experimentation with multiple courses of treatment has commonly been the norm for home-based treatments [32]. Home-based treatments—where caregivers buy medicine from the pharmacy or use traditional medicines—were often the first point of care [34]. Home-based treatments, such as traditional medicines, were often administered by grandmothers [35]. Home-based treatment and care practices might lead to delays in health-seeking and put children at risk. Generally, caregivers' delay in seeking health care is one of the causes of infant mortality [36].

Lack of community access to healthcare facilities was one of the import barriers to seeking health care. Caregivers who were far from health facilities, could not afford transport costs and had a difficult-to-access road preferred to observe their children's situation at home. Areas for improvement in childhood survival include the availability of suitable services staffed by appropriate and trained health professionals, effective management of childhood illness and a strong partnership between families and healthcare providers [37]. Families with sick children should seek appropriate and timely assistance from health workers and follow the recommended treatments appropriately [38]. Research findings from the 2016 EDHS showed that money and distance were the most frequently perceived barriers to healthcare access in Ethiopia [39]. Distance to the health facility and transport cost were also the major barriers for health care–seeking in SSA countries [40, 41]

Caregivers decided to seek care for a sick child when the child's illness reached the stage of showing serious danger signs, such as being unable to breastfeed and becoming extremely hot. The decision to seek care for a sick child was not only influenced by mothers'/caregivers' efforts, but also influenced by elders, relatives and religious leaders. The decision to seek care might also be guided by how the symptoms were perceived. Caregivers' decisions to seek healthcare were influenced by the status of the child's illness and the symptoms presented. Study participants reported that the final decision to seek care was generally made by grandmothers. In the study area, the father played a greater role in deciding to seek healthcare than the mothers did. Even though caregivers (women) have the right to decide their own health care, more than two-fifths of caregivers have no role in making such decisions [13]; instead, husbands play a major role in making healthcare decisions regarding their wives [13]. Evidence from a synthesis of the literature has indicated

that women in developing countries have limited autonomy and control over their healthcare decisions [42].

Health care–seeking has the potential to substantially reduce child mortality, and it is of particular importance in areas with limited access to health services [43]. In Ethiopia, only 10% of children who are unwell are taken to a health post for treatment. Shaw et al. have indicated that this pattern of health-seeking behaviour was not only due to low awareness of this healthcare service option, but was also linked to socio-cultural factors, such as how caregivers in the community context understand and perceive an episode of child illness and how an episode of child illness is negotiated within families and communities [15]. A significant proportion of mothers do not seek help for childhood illness in Ethiopia—most caregivers and mothers do not know where and when to seek care for their child [44].

The validity of our findings was enhanced by methodological triangulation (data collected in the focus groups and individual interviews were compared and contrasted) and investigator triangulation (multiple members of the research team both in and outside the field participated in data analysis, including the coding and identification of themes) [45]. Maximum-variation sampling was used across age groups and across different groups of the community to mitigate the issues of representativeness in terms of study participants [45]. The Consolidated Criteria for Reporting Qualitative Research checklist for interviews and focus groups was used to report this qualitative research [46]. The study however still had some limitations. One of the key limitations was that most of the caregivers participated in this study were from the rural area and were farmers in occupation, therefore the findings from this study may not be generalizable to urban caregivers and community members.

Conclusion

Caregivers' healthcare-seeking practices play an important role in reducing the impact of newborn illnesses, including mortality; the correct recognition of illness in infants and newborns is essential for effective care-seeking. To improve healthcare-seeking practices, it is essential to understand the illness, cause of illness and the nature of decision-making family and the roles that people play. A contextual understanding of the community in health-seeking is important for designing focused child healthcare interventions in the study area. In Ethiopia, home-based treatment practices and traditional healing methods are widely accepted; therefore, the modern healthcare system needs to have strong relationships with

local traditional healers to have their place in healthcare provider without putting children at risk.

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Footnotes

Contributors: GK conceived the study design. GK carried out the data collection. GK transcribed and translated the data. CC, DB, DL and GK performed the data analysis. CC, DB, DL and GK interpreted the results. GK drafted the manuscript. All the authors read and approved the final manuscript.

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Data sharing statement: The transcribed in-depth interview and focus group discussion will be available at any reasonable request.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	7
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	7
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6-7
Sample size	12	How many participants were in the study?	7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	7
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	7
Data saturation	22	Was data saturation discussed?	7
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	15-17
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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