Social Science & Medicine 195 (2017) 123–130

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

What if the baby doesn't survive? Health-care decision making for ill newborns in Ethiopia

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ARTICLE INFO

Keywords:
Ethiopia
Newborn health
Health-care-seeking
Decision making
Personhood
Poverty
Qualitative research

ABSTRACT

Despite efforts to improve access to and quality of care for newborns, the first month after birth remains the most dangerous period of life. Given high neonatal mortality in low-income countries, saving newborn lives is a key priority for global and national health policy agendas. However, little is known about how these policies resonate with local understandings, experiences and household priorities. In this qualitative study we examined families' decision making and health-care-seeking in Butajira, Ethiopia. Data were collected through observation in hospital, in-depth interviews (41), and focus group discussions (7) with family members, health-care workers, and community members (October–November 2015). Transcripts and field notes were analyzed inductively using qualitative content analysis. Findings indicate that newborn health was not always the family's priority. Local perceptions of newborns as not yet useful members of the household alongside costly health-care services delayed decision making and care-seeking. While sickness was recognized as dangerous for the ill newborn, seeking health-care could be harmful for the economic survival of the family. In a resource-constrained setting, families' focused on productive assets in order to minimize long-term risks, and waited before seeking newborn health-care services. Until the baby had survived the first vulnerable weeks and months of life, the unknown newborn was not yet seen as a social person by the community. Personhood evolved progressively as the baby became a part of the family. A newborn death was surrounded by silence, and families received minimal support from traditional financial associations, *iddirs*. Decisions regarding health-care were contingent upon families' understandings of newborns and their resource-constrained circumstances. Improving newborn health involves recognizing why families choose to (not) seek health-care, and their actual opportunities and constraints in making such decisions. The everyday realities of vulnerable newborns must be at the center of global and national policy discussions and local implementation.

1. Background

While most newborn deaths are avoidable, neonatal mortality remains high (Bhutta et al., 2014; Wang et al., 2016). In medical terms, the neonatal period is the most dangerous period of life. Globally, 2.6 million newborns die within their first 28 days every year (Wang et al., 2016). Newborn health became a central part of the global health agenda during the Millennium Development Goal (MDG) era, where new policies, programs, and guidelines on newborn health-care were developed. The commitment to improving the health of children and newborns has sustained continued focus in the third Sustainable Development Goal (SDG) on health (Kuruvilla et al., 2016).

The medical literature has highlighted that 71% of newborn deaths could be averted with increased access to quality care (Bhutta et al., 2014). However, even with knowledge of effective interventions and increased funding, newborn mortality is not decreasing in a similar pace as mortality in older children. Studies show large variations (10%–100%) as to whether caregivers seek treatment when children are ill (Herbert et al., 2012; Noordam et al., 2015). This may be explained by lack of knowledge about danger signs, disrespectful and low quality care, lack of available and affordable health services (Bhutta et al., 2014; Callaghan-Koru et al., 2013; Sacks, 2017; Shaw et al., 2016), or

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https://doi.org/10.1016/j.socscimed.2017.11.003
Received 28 December 2016; Received in revised form 26 October 2017; Accepted 1 November 2017

by structural barriers, such as poverty, rural location, lack of education, and gender roles (Central Statistical Agency [Ethiopia] and ICF, 2016; Richards et al., 2013).

Little research has focused on how global and national priority to newborn health resonate with priorities at household level. Family level decisions are important for health-care-seeking and survival. Choices about health-care-seeking become particularly important to investigate in contexts like Ethiopia, where three of four newborns are born outside health facilities (Central Statistical Agency [Ethiopia] and ICF, 2016) and newborn illness is detected at home. Negotiation in referral networks and perceived uncertainty of illness and costs influence care seekers' health-care-seeking for older children (Shaw et al., 2016). Yet, for young babies, studies indicate that it is uncommon to seek care outside the home in Ethiopia (Callaghan-Koru et al., 2013; Shaw et al., 2016). In this study, we aim to examine family-level decision making surrounding newborn illness and death in Ethiopia. We study health-care-seeking at formal health facilities (including health posts, health centers, and hospitals).

1.1. Intra-household decision making and health-care-seeking for children in resource-constrained settings

Care-seeking decisions are shaped by local culture and practices embedded in broader social, economic and institutional structures (Hampshire et al., 2009; Millard, 1994; Richards et al., 2013; Shaw et al., 2016). Decisions about seeking health-care – or not - for ill children are often made at the household-level. Primary caretakers' choices are influenced by a range of intra- and extra-household level factors, to which policy and research traditions give more and less importance. Millard discusses how focus often has been on proximate (e.g. biomedical) and intermediate (e.g. practices at household level) causes, while less emphasis has been given to how ultimate (e.g. broader economic and structural) causes impact child mortality (Millard, 1994).

In aiming to improve newborn health in resource-constrained settings it is crucial to understand what matters to families. Whereas newborn health policies are developed in global or national processes, programs are implemented in local worlds. As a starting point for our analysis of intra-household resource allocation for ill newborns we use literature on i) the status of the infant and infant death in high mortality settings and ii) the tension between concerns for the ill child and the welfare of the family.

Infant death has been common experiences historically and cross-culturally, and social and individual responses to infant death have been studied by historians, archaeologists, psychologists and social scientists (Cannon and Cook, 2015). In high-mortality settings, infant death has received less social recognition (Cannon and Cook, 2015). In her debated study *Death Without Weeping* from northeastern Brazil, Scheper-Hughes showed how the cumulative experiences of common infant deaths shaped local perceptions, norms, and practices around young children and their health (Scheper-Hughes, 1992). She argued that in a context of hunger and extreme poverty, mothers detached from infants judged too weak or too vulnerable to survive. Furthermore, she discussed the meaning-making processes surrounding weak children and in particular the justification of *selective neglect* of weak infants. The concept of selective neglect, and its validity and universality, has been questioned. Studies across contexts have revealed that processes of grief are multilayered, and that maternal grief after the loss of a child may be severe even if it is not publicly exposed (among others, see Einarsdóttir, 2004; Smørholm, 2016). Cannon and Cook have distinguished between emotional experiences of grief, expressions of grief, and representations of grief (Cannon and Cook, 2015). This distinction, and their finding that individual and social responses to infant death vary, is useful in this study. While the studies referred to above have looked at children and infants more generally, the neonatal period - where mortality often is highest – deserves further attention. In light of the debated selective neglect thesis, how do perceptions about the status of newborns affect care-seeking? A study about vital registration systems for births, stillbirths, and infant deaths in South Africa illustrated how practices surrounding death [at different ages] were related to “different stages of incorporation of children in to the community,” and how humanness, to a large extent, was socially defined (Jewkes and Wood, 1998, p. 1053). Along the same line, an Ethiopian study described how newborns were considered “strangers to the community,” and early newborn deaths and stillborn were buried without formal recognition (Sisay et al., 2014, p. s112). These studies, which discuss the ascription of personhood, indicate that practices in the newborn period may be linked to when a child is incorporated into society and seen as persons (Sisay et al., 2014; Jewkes and Wood, 1998).

For families living on the margin, concerns for the health of one family member may compete against other household needs. A study from Burkina Faso described mothers' struggles to provide treatment for their sick children. Action, or inaction, was dependent on resources at hand, and benefits of seeking health-care were weighted against lost income and social relations (Østergaard et al., 2016). Hampshire et al. described how local perceptions about risk and the precarious lives' of children influenced intra-household decision making in Niger. Malnourished children – with greater health needs – became “victims of non-discrimination” when families did not provide additional resources or attention (Hampshire et al., 2009). The authors argued that in the context of poverty, families' concern for long-term livelihoods made parents hesitant to seek care for vulnerable children, which can be seen as a form of benign neglect. These findings relate to studies on intra-household resource allocation in resource-constrained settings, which indicate preference for older and productive family members (Sauerborn et al., 1996) and boys (Miljeteig and Norheim, 2006), who are perceived to be more beneficial for households' long-term survival.

These empirical and theoretical accounts from resource-constrained and high mortality contexts are relevant for this study, and may serve as entry points to understand families' decision making and low health-care-seeking for ill newborns in Ethiopia.

2. Methods

2.1. Study setting

Ethiopia has seen rapid economic growth during the past decade, with an annual increase in GDP between 8% and 12% (World Bank, 2016). Still, 34% of the almost 100 million people live below the poverty line (< $1.90 a day, 2011 PPP), and 81% of the population lives in rural areas (World Bank, 2016). While newborn health has been prioritized in Ethiopian health policies (Federal Democratic Republic of Ethiopia Ministry of Health, 2014b), newborn mortality is still high. In Ethiopia, 29 newborns die per 1000 live births, and as much as 74% of all babies are born without skilled birth attendance (Central Statistical Agency [Ethiopia] and ICF, 2016). Hence, the first evaluation of the newborn's health, health-care needs and survival chances are commonly made by family members. Furthermore, the most recent National Health Accounts revealed that 48% and 28% of expenses for child and reproductive health-care, respectively, are covered by the households through out-of-pocket payments (Federal Democratic Republic of Ethiopia Ministry of Health, 2014a).

This study was conducted in and surrounding the town of Butajira, Gurage Zone, which is a semi-urban setting surrounded by rural areas. Butajira is located 130 km south of Addis Ababa, in the Southern Nations, Nationalities, and People's Region. Data were collected using information on demographics and vital events from the Butajira Rural Health Program (BRHP) (Berhane et al., 1999; INDEPTH Network, 2017). The nine rural and urban *kebeles* in the BRHP are located in three districts (Meskan, Mareko, Silte) and the administrative town of Butajira. In this area, the formal education level is low and poverty is high. The study was conducted in October and November 2015, a year with a poor harvest after a drought in the area, among a population of which many are farmers. The majority of the population are Muslims followed by Orthodox Christians. A study from the BHRP catchment area found the total fertility rate to be 5.3, and an average household size of 5.2. Child deaths have been common, as four out of ten women have experienced losing a child (Mekonnen and Worku, 2011). The most recent study from BHRP showed no significant decline in neonatal mortality between 1988 and 2008 (Gizaw et al., 2014). However, national newborn mortality decreased from 46 to 29 per 1000 live births between 2011 and 2016 (Central Statistical Agency [Ethiopia] and ICF, 2016).

Participants were recruited in the BHRP catchment area, and from the public hospital and affiliated health centers in Butajira. The hospital is a general hospital serving a population between 1 and 1.5 million. The hospital is open every day, but with limited services during evenings and weekends, and it often experiences shortages in drug supplies or other equipment. The pediatric unit consisted of about 50 beds, including 10 beds for newborns, but there was no pediatrician.

2.2. Data collection and analysis

In order to grasp micro-level decision making in its broader cultural and structural context, we chose a qualitative explorative study design. Data were collected through 41 semi-structured in-depth interviews (IDIs), 7 focus group discussions (FGDs), and observation. Four groups of participants were purposively selected and included (i) mothers or primary caretakers with sick newborns, (ii) mothers or primary caretakers who had experienced a newborn loss, (iii) health workers, and (iv) community members. As detailed in Appendix i (Supplementary material), the primary investigator (PI) and co-researcher identified and invited potential participants at the hospital and in the BHRP catchment area (in collaboration with BHRP field workers) to take part in the study.

The primary cases of ill newborns were identified at the neonatal care unit at the public hospital, and their *mothers and/or primary caretakers* were invited to participate in the study. After the initial eleven interviews, nine were recruited for a follow-up interview in their homes 1–4 weeks later. Two remaining mothers lived far away from Butajira and were not possible to follow-up.

With assistance from BRHP, we purposively identified five rural and five urban households that had experienced newborn deaths the previous year. We invited *mothers and/or primary caretakers* to take part in the study. The primary caretakers were between 18 and 35 years, and the household size ranged from 2 to 10 family members. The majority of the mothers were doing domestic work or attending to household chores.

At the hospital and health centers, *health-care workers* involved in caring for sick neonates were invited to participate in ten IDIs and two FGDs. The health workers had from 1 month to 10 years of experience. Their ages ranged from 20 to 35 years.

To understand community perceptions and practices, five FGDs with *community members* were conducted; two with mothers (rural and urban) of reproductive age, one with fathers, one with grandmothers, and one with religious leaders and elderly. The community members had from 1 to 11 children, and their ages ranged between 20 and 73 years.

Interview- and topic guides were prepared for each group of participants, which were developed continuously as new issues emerged. To establish trust, initial questions focused on health-care-seeking for newborns. These were followed by inquiries about community practices and norms, and exploration of their own views on decision making and intra-household resource allocation. In-depth probing on these topics and their own experiences was done in follow-up interviews. For the convenience of the participants and to ensure confidentiality, IDIs took place in a room at the hospital or in caretakers' homes. FGDs were conducted outdoors around the BHRP offices or in public locations close to where the participants lived.

IDIs and FGDs were led by the PI in collaboration with the co-researcher. The PI is a Norwegian medical doctor trained in qualitative research. While she speaks limited Amharic, the Ethiopian co-researcher has a Master in Public Health and speaks Amharic. Two IDIs were conducted in English by the PI, while the remaining IDIs and FGDs were conducted with the co-researcher acting as a translator (Amharic-English, English-Amharic). IDIs (25–75 min) and FGDs (80–140 min) were audio-recorded. The PI took notes when (three) participants did not wish to be audio-recorded. Interviews were transcribed verbatim and translated to English by research assistants experienced in transcription and translation (October–December 2015).

To better understand care provided and decision-making at health facilities, we studied actual behaviors and interaction between family members and health workers at the hospital. The PI conducted observation (October 2015), and engaged in informal conversation, and followed daily activities in the pediatric ward with a group of 5–15 health-care professionals. The topics explored in IDIs and FGDs informed observations, and vice versa. At the end of each day the PI and co-researcher discussed impressions, went through notes and adjusted the interview guides for the next day accordingly. Based on this preliminary analysis the data were considered saturated and recruitment ended when new aspects related to health-care decision making for newborns no longer emerged during interviews and observation.

The data were analyzed drawing upon content analysis, where categories were developed from the empirical data (Graneheim and Lundman, 2004). Building on patterns that emerged through preliminary analysis during field work, the collected material was analyzed systematically through the following stages: (i) in-depth reading of the data material; (ii) identifying units of meaning and coding of the data material; (iii) condensing and abstracting meanings within the coded groups; (iv) synthesizing the contents of coded groups to form generalized descriptions that reflected the most important perceptions, norms, and values. NVivo11 software was used in coding and organizing the data material (http://www.qsrinternational.com).

2.3. Ethical considerations

The study received ethical approval from the Institutional Review Board of the College of Health Sciences, Addis Ababa University, and the Regional Ethical Committee Western Norway, Norway. Before commencing any IDI or FGD, the potential participant was informed about the opportunity to participate, that participation was voluntary, and that anonymity would be ensured. Consent, either written or by finger print, was obtained from all of the IDI and FGD participants. The experience of newborn illness and death can be a large burden for a mother (Sisay et al., 2014). When we raised these sensitive topics, we aimed to let the participants talk about their experiences, and gave emphasis to listen to their stories. While some mothers expressed grief and sadness in talking about their losses, these and other mothers articulated gratitude for our interest, and said that no one had come to talk about these experiences earlier. Throughout data collection we payed particular attention to signs of serious illness in the babies. Further, we were attentive to the potential burden of taking part in the study, and the health and wellbeing of mothers and other family members facing newborn illness and death. Only on one occasion it was considered necessary to assist a mother with an ill baby to access care at the hospital.

The purpose of the research project was discussed with the hospital and health center administration prior to the study's initiation, and with health workers throughout the study period. The PI asked permission to attend the rounds and other daily activities from the health professional in charge. It was not seen as appropriate to hamper daily routines at the hospital to inform each family about our presence as researchers.

As in previously conducted studies in the area, IDI and FGD participants were compensated by 100 birr (5 USD) for the time lost and/or to cover transportation costs.

3. Results

Health-care decision making occurred in the intersection of culturally and structurally embedded understandings of the precarious newborn, and families concerns for the survival of the family. Together, these factors mutually reinforced an ambiguous attitude towards the ill newborn, which in turn affected health-care-seeking. In the following section, we detail how this played out in decision making, for families who suffered newborn illness and loss, and in community expectations towards the handling of newborns.

3.1. Wait and see: "you can take her to hospital tomorrow"

Seeking care for sick newborns was subject to negotiations based on the severity of the illness, hope for survival, expected costs and benefits of treatment, and other urgent commitments in the household. The parents were central in making decisions about seeking health-care or not. Generally, it was common to 'wait and see' in the face of illness across all age groups. Health workers explained that care was sought later for children than for adults, and noted severe consequences for newborns in whom illness progress rapidly.

Seeking care in a health facility was not the obvious immediate action to take, but was open to 'next day' consideration. The mothers' stories of newborn illness usually started with a baby struggling to suck or when "*he started refusing my breast's milk*". Mothers who sought health-care typically identified three signs of severe illness: not breastfeeding, difficulties in breathing, and fever. The parents often hoped that the problem was only minor and waited at home to see if the child got better. Other family members or neighbors provided advice on whether and when to seek health-care. Sometimes they suggested rest for the baby, or traditional medicine. As the baby's survival was thought to be in the hands of God, it was common to pray for recovery. Mothers were commonly advised to wait and see if the baby got better, as illustrated below.

> *She [the daughter of a religious leader] was born alive, but after birth she couldn't take breast. Her mouth was dry and her breathing was abnormal. One woman was there and she advised us. 'After 6–7 hours she may breastfeed. If not, you can take her to hospital by tomorrow,' she said. We were not lucky – by the next day she was not alive, meaning she died. (FGD, religious leaders and elderly, urban area)*

If the baby did not get better, most families sought care. However, some mothers had experienced newborns who were very sick or at high risk, such as babies with breathing difficulties at birth, or who were born very early. These were not taken to health-care providers, as they were considered destined to die, irrespective of health-care intervention. Community members also talked about some babies being too sick to survive. Mothers who lost a baby were often told not to protest against the will of God. One mother, who had given birth at home, explained:

> *The baby was weak when he was born. I knew he was going to die because I was also sick when I gave birth to him. I knew that the baby wouldn't be healthy from the start, and that is why I refused to take him to the hospital. So I left his fate to Allah and let him stay at home. (Mother experiencing newborn death, 17, rural area)*

On a general basis, health workers emphasized that many babies were not brought to the health facilities before the illness got complicated, when the baby refused to breastfeed or was "*very annoying*". They explained that lack of awareness delayed health-care-seeking. If the newborn was very sick, the family could lose faith in the survival of the baby. They recounted cases when children did not respond to treatment, where parents who were of the opinion that "everything had been done," gave up and left the hospital.

There were also parents in our material that spoke out against the practice to wait and see before seeking health-care. Some of the parents we met at the hospital, who had decided to seek care, stressed the vulnerability and urgent need for care for sick newborns. These parents, often living in urban areas and with more money at hand, were willing to go far to seek health-care, even to Addis Ababa.

Participants indicated that parents could disagree on whether and when to seek health-care, and which concerns that mattered most. As one mother expressed it:

> *The men do not have the urgency to save a sick infant; they say 'let it die'. They become desperate and they don't think she will survive. (Mother experiencing newborn illness, follow-up interview, 27, urban area)*

Whereas mothers of the newborns admitted at the hospital were very concerned about, and wished to give priority to their sick newborn, other family members, and fathers in particular, could be hesitant to seek health-care, due to the high costs. Although the mother was the primary caretaker for the newborn and often the one recognizing that the newborn was ill, she was rarely the primary decision maker within the family. As the main provider for the family, the husband commonly had the final word in decision making. In the period after birth he was often out of the house, or the wife was at her parents' house. Most mothers could not leave the house without the husband giving his blessing or money to seek care. This process complicated the decision making process, and delayed health-care-seeking even when the baby was identified as in need of treatment.

This finding of differing views within the household was confirmed by health workers. They described conflicting concerns when making decisions about going to the health center or hospital. Treatment could be expensive and staying in the hospital was uncomfortable, unfamiliar, and frightening. While delivery care was provided for free only for the mother, families had to pay for care for the neonate. The fear of high costs for services included drugs, admission, equipment, transportation and other formal payments, which made families reluctant to seek health-care. One husband explained:

> *The money is needed for the treatment. The other expenses are to take the child to the main road by a cart and transportation to the health center. After he reaches the health facility they will pay whatever the doctor charges them for the service. Further they will drink tea and the like, which is an extra expense. Then again there is transportation from the health facility to the nearby road and from the main road to the house etc. (FGD, husbands, rural area)*

Most families did not have money at hand to pay, and had to wait to get money before going to the hospital. It was common to borrow from friends and family to cover user fees at the hospital, and many were forced to work more or sell their belongings to pay the money back (Onarheim et al., in press). One health worker described how a father could evaluate treatment costs and burden on the family economy versus benefits for the family – asking himself "*what if the baby doesn't survive?*" For poor families without opportunity to pay for care, not seeking health-care could have dangerous and even deadly implications for the ill newborns.

> *He was not willing to breastfeed during day and night and my husband didn't have money to take him for health-care. He was hoping that he'd get money soon - in each day - but time went by, a week passed, and the child died as he had also stopped breastfeeding. (Mother experiencing newborn illness, 4, one twin survived, one died, rural area).*

During admission, mothers were observed to stay in an overcrowded room in the pediatric unit, with limited possibilities for sleep and without any privacy or support from their families, who were not allowed to stay in the ward. Primary care takers received little information about what was happening to their baby, and in follow-up interviews, mothers expressed how staying at the hospital had been uncomfortable and frightening. Many feared going back to the hospital. One mother worried about her sick baby after seeing other children dying:

> *Six children died when I was staying there. It is very scary. Three children were sleeping on one bed, and one of them was my child who was sleeping between them. I lost my hope when both of the two others died on the same day. (Mother, follow-up interview, 29, urban area)*

Health professionals emphasized the newborns' urgent health needs, and saw themselves as protectors of the newborns. They commonly faced situations where they had to negotiate to convince family members to stay in health facilities or seek referral, offering free treatments or even paying themselves to help the babies to survive.

> *When you're managing a patient, and when they are not responding to your initial antibiotics, we consider changing the antibiotics. Sometimes they say they will buy the medication and that they will stay, and in the afternoon when I come, the others will tell me they are just gone. (Health worker, 12)*

3.2. Not yet useful to the family: "you can always have another child"

Child and newborn deaths were common, and the time of birth was known to be dangerous. During field work, emphasis was given to how the participants themselves and also the other community members viewed giving priority to newborns versus older children and adults. Discussing care-seeking for older children versus babies revealed that the newborn was not yet considered a part of the family. Community members explained that children are appreciated when they start to speak, play, and make contact; when the family and community get to know the child. One religious leader described how older children got more attention.

> *The child more than one year looks at you; you can even imagine their reaction, movement 'here and there' and their sound while they are calling mama and dada, which is very tasty, like honey. They can also create some good memories in your mind, but those newly born babies cannot talk and you may not understand their sounds and movements. (FGD, religious leaders, urban area)*

Community members and health workers explained that newborn babies were not yet seen as useful for families, whereas losing an adult could have devastating consequences for the survival of the family. Community members and health workers underlined that care-seeking for adults would be most important for the rest of the family. The implications of an adult death – and in particular the husband, were more severe than if a child or newborn died.

> *What I accept is that the household head, the father, should be given first priority because he is the breadwinner. If he becomes sick, who will be responsible for those children? Who will bring money? Who takes them to the clinic? So from all, father should be taken first. If the father is healthy he can facilitate, even when there are very big challenges. (FGD, religious leaders, urban area)*

Health workers explained that families seemed more willing to invest in treatment for older children, as they were found more useful, and could help out with household activities, such as taking care of the cattle. A health worker reflected on why children with disabilities or physical abnormalities rarely were brought to the hospital.

> *The community believes when that kind of child [children with abnormalities] is born, he will die. Even if the child grows it will be of no use to them. Some fathers even prefer the child to be dead if it is just an infant. They prefer to bear another child rather than spending money on this child. (FGD, health workers)*

A common saying was that the newborn could be replaced by a new baby, particularly in rural areas. Neighbors and relatives told the mother who had survived delivery but lost her baby that she was lucky to be alive, and that she could have another child after 9 months. However, some parents, especially in the urban area, objected the talk about the replaceable newborns.

> *Even if I bear another child, I think he will not replace the one I lost. People say things like 'we are middle-aged parents, so we can bear another child'. (Mother and father experiencing newborn death, 35, urban area)*

The common perception that newborns could not be the priority 'until they had made it' to a certain age was contrasted by urgency to seek care for *precious* children. Community members and health workers explained that these *precious* newborns had been longed for, as firstborns or in families facing repeated infant deaths, and how families would do everything to save *them* if they fell ill. The survival of *precious* babies was closely linked to the long-term survival of the family. Hence, the parents of *precious* children rushed to the hospital to give birth, or if the newborn showed signs of illness.

3.3. Not yet a person: "it was only a neonate so no one was set to mourn"

Newborns deaths were surrounded by silence. Rituals and practices after newborn deaths differed from those when older children or adults passed away. For the elderly, people came from far away to attend the funeral and mourning. This could last up to 60 days for respected persons. When a newborn died within the first few days, the death was not spoken of. The mother, father, or other close family members sometimes gathered for a few days, but neighbors and relatives were not expected to come nor talk about the loss. Community members, health workers and family members noted that the loss of a child could be devastating for the mother. Still, families were not expected to express their grief. It was not seen appropriate for her or others to mourn publicly, which may indicate differences in social expressions of mourning and individuals' experiences of loss and grief. Whereas crying is expected and appropriate for expressing sorrow after a death of an adult, mothers worried about what others would think if they cried out loud or mourned in public after a loss of a baby. One mother suffering after her baby passed away explained how others questioned her grief.

> *They [people in the neighborhood] were asking if I had not faced any death. I became nervous and even started shaking. The baby was already dead, but I felt sorry for him, he didn't know me. I felt bad inside - that was where he came from. (Mother experiencing newborn death, 34, urban area)*

Formal representation of grief also differed following a newborn death. This was seen in practices such as burials and in the financial support systems (*iddirs*). If a baby was a stillbirth or died at the hospital, it was often buried with other dead babies at the hospital compound. The exception was in Muslim families, where full term newborns were buried in the cemetery the same day. For babies that had survived the first weeks or following deaths of *precious* children, formal burials were carried out. In rural areas it was common practice to bury the newborn close to the home right after death, but as one mother expressed, this could be experienced as a constant and stressful reminder of the loss of her baby.

> *We buried him in the traditional way, in our backyard. Then my father came and insisted that he should be buried normally, as an adult person. He claimed that since the baby is a human being, he should be treated as a normal person, but the people [neighbors and relatives] refused to accept our opinions and they buried him in the backyard (…) I go to the backyard to spill dirty water or to grind coffee. At that time I see his grave and I get sad. Usually, my mother tells me to forget about him and she reminds me that I wasn't the only person this happened to. (Mother experiencing newborn death, 18, rural area)*

Iddirs are traditional financial associations commonly found in Ethiopian communities (Pankhurst & Mariam, 2000). Households voluntarily join *iddirs*, and *iddir* members make monetary contributions every month to be used during emergencies. When a death occurred in

Butajira, *iddir* members received support, such as money or help for the burial and mourning. For early newborn deaths no financial support was given. In rural communities, compensation started one week to two months after death, while in the city, *iddir* compensation was given from 24 h after birth. When deemed to be of appropriate age by the local *iddir*'s rules and regulations, a newborn death received support similar to that for older children and youths (45–90 USD in rural areas, 140–235 USD in urban areas), which was half the amount received when an older person died.

The *iddir* committees who decided dates and amounts comprised respected members of the community, most often men. The choice not to include early newborn deaths was explained in the FGDs as a traditional and cultural issue, anchored in the existing *iddir* rules. Husbands and religious leaders discussed that it would become very costly to contribute financially from day one, given the high number of early newborn deaths. They worried about where to draw the line: if a family did not take good care of the newborn, it would be problematic if other families had to pay. For families who had received *iddir* support after facing subsequent infant deaths, there could be shame and stigma when not being able to raise a healthy child.

Some families experiencing newborn death and illness opposed that the social responses to newborn deaths differed compared to older people and children. They argued that small babies should be valued based on their future potential.

> *When an infant dies, no one knows what they could have been. Yet people say they could simply be replaced. In short, we don't support this idea; this is a traditional way of thinking. Everyone was an infant at the beginning. It is infants who grow to become great leaders. (Father experiencing newborn death, 35, urban area)*

4. Discussion

This study outlined perceptions and experiences of health-care decision making for newborns in the resource-constrained setting of Butajira. Decisions on care-seeking were made in the intersection between understandings of the newborn and structural barriers in to access health-care. Early newborns were unknown, and not yet initiated or acculturated into the families or neighborhoods. In the community, newborns had not yet received status as social persons. By some, they were said to be replaceable. However, this was a multifaceted issue. The expression that newborns could be replaced and the different social representation of grief for newborn deaths must be interpreted in a context of high mortality and resource-constraints. Health-care was costly and the future of the newborn was uncertain, which left both ill newborns and their families in jeopardy. In this poverty setting the newborns had not yet proved themselves useful, and could not be prioritized. This tendency was contrasted by willingness to seek care for newborns defined as *precious* children, and babies of well-off families. This demonstrates the importance of the households' economic situation, and how families balanced risks and benefits in health-care-seeking.

The past five to ten years newborn health-care services have been scaled-up in Ethiopia, and health extensions workers and others bring services and messages about newborn health out to peripheral rural communities (Federal Democratic Republic of Ethiopia Ministry of Health, 2014b). Academic and policy priority to newborn health have mobilized attention and resources, but these were not always reflected in everyday lives and priorities in Butajira. Though caretakers have been told to - and many wished to - seek care, decisions about seeking health-care are made in a context were newborn survival is uncertain and overall conditions of deep poverty and high newborn mortality persist. Participants explained that priority was given to adults or older children, who were useful to the family. For a sick newborn it was common to wait and see how the disease progressed, while action was taken more urgently, and willingness to pay was higher for an adult.

4.1. *Understanding the status of newborn*

In the medical and policy literature on newborn health, a neonatal death is depicted as an event that that can and should be avoided (Bhutta et al., 2014; Kuruvilla et al., 2016). We argue that this understanding of newborns as persons differs from community perceptions and responses following a newborn death in Butajira, where humanness and personhood is developed gradually during the time after birth. Our findings indicate that the recognition of when an individual becomes a person, and can attain a social role with rights and obligations, impacts practices around newborn illness and death.

In Butajira, there was an expectation that not all newborns would survive, in particular in rural areas and for babies that showed signs of weakness. We argue that this can be explained by the communities' shared experiences of newborn illness and death. Based on these experiences, the community recognized the newborn later – when the baby “had made it”. Our findings links to the discussions of the practice of selective neglect of high-risk infants. Sheper-Hughes' contention that it was considered necessary to allow very sick babies to die was mirrored in our findings (Scheper-Hughes, 1992). However, as noted in the introduction, many have challenged her findings on grief and mourning, and have argued that mothers may experience grief even if it is not expressed in the same way as for adults (Einarsdóttir, 2004; Smørholm, 2016; Cannon and Cook, 2015). In line with the findings of the study from Ethiopia (Sisay et al., 2014), it was not considered appropriate to grieve in public for early neonatal deaths in Butajira. Mothers were expected to suppress personal feelings. Family members and neighbors explained to the mother that the baby was in God's hands, or that she could have a new baby. Nordanger's work from northern Ethiopia described how it was common to advise family members to forget about the sorrow, and not to cry in the time after adult deaths (Nordanger, 2007). In Butajira, the emphasis on telling mothers and family members to move on after a newborn death and silence surrounding these deaths can be interpreted as a necessity in trying to make them move on, and in the interest of the mothers themselves and their families (Smørholm, 2016). This can be seen as a social coping mechanism to make mothers move on, or as a lack of recognition by the newborn as a person.

Einarsdóttir described that the mourning of the Papel mothers in Guinea Bissau was not only emotional, but also for social and economic considerations for the future. If their children did not survive, they would not have children who could take care of them when they got older (Einarsdóttir, 2004). Nordanger noted the interdependence between psychosocial and socioeconomic factors in mourning for adults and older children, and how the manifestations of the relation between personal and economic losses were seen in the expressions of sorrow and bereavement among Orthodox Christians. The loss of a husband prolonged sorrow among the very poor, as they were reminded constantly of their loss when they did not have access to basic goods (Nordanger, 2007). Sorrow and grief in these poor communities are therefore not only for the loss of a person, but illustrates the broader bereavements of the families.

While birth is a mark of a baby's first day of life, children in Butajira gradually received recognition as they became known to the family and community. The recognition or social construction of personhood can be looked upon as a process in which the baby has survived and become known, and not something achieved during pregnancy or at birth (Jewkes and Wood, 1998). Similar to other studies mourning practices in Butajira were related to age and how much the baby had been integrated into the community (Jewkes and Wood, 1998; Sisay et al., 2014). Jewkes and Wood discuss how the socially sanctioned displays of grief that depend on age “provide an indication of how social importance is constructed” (Jewkes and Wood, 1998, p. 1049). In Butajira, burials of dead newborns occurred immediately after death, while for the known members of the community – including older children and adults – the burial and mourning happened later, to make time for people to join. The *iddir* regulations can be understood as social institutions set up to provide financial protection, but which shape and reflect norms, which influence perceptions about when a newborn is recognized as a person. The differences in dates set for *iddir* compensation illustrate the differences in social recognition between rural and urban areas. Further, for all deaths occurring on the day of birth, no financial compensation was made.

4.2. Local priorities: the survival of the newborn, or the family?

In striving to meet goals for child and maternal health, attention has been on scaling-up and making high-quality health-care services available and accessible (Bhutta et al., 2014). Emphasis on major causes of mortality and morbidity has been important in setting the agenda, but evidence-based policies have been criticized for their over-emphasis on biomedical concepts and practices (Roalkvam and McNeill, 2016). The recent concept of nurturing care has put emphasis on how “a large array of social contexts—from home to parental work, child care, schooling, the wider community, and policy influences” matter for children's development (Britto et al., 2017, p. 91). Our findings are relevant to these ongoing discussions, and indicate differences between global and local understandings and priorities on newborn health. In global goals and policies, newborn deaths are often presented as avoidable events that should receive priority, whereas ill newborns in Butajira were seen as particularly vulnerable and risky to prioritize at household level. Though medical and policy attention to newborn health is important, these initiatives do not necessarily recognize or reflect what matters to families with ill newborns. This study highlights that in real-life decision making concerns for overall survival of the family competes with health needs of ill newborns. These types of mismatches in worldviews have also been noted by others. Hampshire et al. describe contrasts between families' allocation patterns and humanitarian agencies' focus on individual and immediate needs in the aftermath of a food crisis in rural Niger (Hampshire et al., 2009). Where the humanitarian agencies targeted malnourished children at-risk, the parents had to balance current and future risks of all members of the household. Attention to diverging views is relevant when looking at the literature on newborn health versus the local realities in Butajira. From a medical perspective ill newborns can be seen as the *vulnerable of the vulnerable*, and worse-off in terms of life time health. From the perspective of a poor family in Butajira, the known vulnerability and risk of dying for a sick newborn made health-care-seeking particularly risky. When paying out-of-pocket, health-care-seeking posed large risk for a family's limited economic resources. If they spent their money - or money they did not have - on treatment for a baby that did not survive, their much-needed resources were lost. Decisions to wait and see can be understood as coping strategies to balance concerns for immediate needs of the newborn and the household's long-term wellbeing and risks. Whereas older children and adults were key for the survival of the family, a newborn could be replaced by a new baby. We argue that as long as families' opportunities to seek care for newborns depend on abilities to pay out-of-pocket, families will face trade-offs between concerns for the ill baby and the future of the family.

4.3. Choice or circumstance?

In her studies on nutrition policy and the Work Bank, Sridhar examines the tension between structure and agency (Sridhar, 2008). She shows how the World Bank's efforts to combat malnutrition centered on women's choices and attitudinal barriers rather than underlying circumstances. She defines agency as “the capacity of individuals to make free choices”, and structure as “the external factors (e.g., societal, economic, political) that influence the choices that individuals make” (Sridhar, 2008, p. 13). Although agency was seen among caretakers in Butajira, health-care services were not accessible, affordable or within reach for poor women and their families. While policies and implementation often focus on increasing coverage and behavioral changes to make mothers seek health-care, we argue that this literature represents a naive understanding that relies on women as sole decision makers. We found that two structural aspects were of particular importance for care-seeking for ill newborns; poverty and gendered intra-household decision making power (Millard, 1994; Richards et al., 2013). Our findings illustrate how local concepts and priorities were shaped in a context where poverty is rampant and newborn deaths were common. In health-care-seeking and economic reasoning, socio-economic and structural barriers are internalized as part of everyday life. What was at stake in these decisions was not only the individual baby, but the survival of the household. The gendered bargaining power within the household shaped health-care decisions about going to the hospital or borrowing money, and actual opportunities to seek health-care for the ill newborn. While the mother was the primary caretaker, she did not control the household's resources, and was not the financial decision maker. Most often the father was responsible for the household's assets or money, and could be concerned about the welfare of the family. These findings are in line with a review on gendered intra-household bargaining which describes how women's access to and control over financial resources limit opportunities and influence health behavior (Richards et al., 2013). These structures, seen in deep poverty, institutional payments for health-care services and gendered decision making, continue to shape people's and communities' perceptions about newborns and health-care decision making. Just as Scheper-Hughes reports on mothers' selective neglect of weaker babies as a consequence of the selective neglect of the poor mothers in Brazil, local realities that are described as private troubles are linked and embedded in larger social and economic issues (Scheper-Hughes, 1992).

4.4. Study limitations

Some important methodological considerations should be noted. The sample was recruited to follow ongoing experiences of newborn illness for families seeking health-care, and past experiences of families who had faced newborn deaths. As only 26% of Ethiopian women deliver in facilities (Central Statistical Agency [Ethiopia] and ICF, 2016), we aimed to learn about experiences of families giving birth both in and outside of health facilities. Yet, our purposive recruitment may have influenced our findings. Although community members and cases of newborn deaths were recruited from urban and rural communities, our sampling of families experiencing newborn illness was done at a general hospital. Health workers were recruited from hospitals, health centers and health posts. Thus, experiences of care-seeking and costs are likely to differ in our sample than for those seeking health-care at health posts or centers. Our data, including observations in hospital, might therefore present families more predisposed to seeking health-care, and may not be generalizable to a population where health coverage is low. At the same time, we cannot rule out that our focus on negative cases (newborn deaths) may have led to an overrepresentation of those that sought care when cases got complicated, or chose not to seek health-care. The triangulation of data and inclusion of different groups of participants is a strength of the study, and have hopefully counteracted some of these potential biases. In-depth case studies of families' actual decisions when experiencing illness is an underused approach in studies on health-care utilization. Yet, as our analysis foremost is based upon what people said they did, rather than observational data of what they actually do, further study is needed. Comprehensive ethnographic studies and experimental approaches may further improve our understandings of health-care decision making, families' adaptation strategies, and possibly impacts on health outcomes.

Another limitation, for our as well as other studies on care-seeking for children, is that we have most information on maternal care-seeking, and know less about the views of fathers. Interviews with primary care takers most often involved mothers who followed their ill baby to the hospital. During home visits, fathers were often not present. In some IDIs both the mother and father took part, and we recruited men to our FGDs. As males commonly are head of households in Ethiopia and are involved in decisions to seek care outside the home (Central Statistical Agency [Ethiopia] and ICF, 2016; Shaw et al., 2016), we need further study of fathers' experiences and priorities in health-care decision making.

5. Conclusion

In aiming to improve newborn health, it is key to recognize why families choose to (not) seek health-care. Our study found that decisions about health-care-seeking in Butajira were contingent upon the local understandings of newborns and the economic constraints that pervaded everyday life and choices. We suggest that the everyday realities in which decisions about care for vulnerable newborns are made, must inform and underpin global and national policy-making and local implementation processes. Recent policy attention to multi-sectoral action on child development – beyond health-care systems – and the roles of families and parents are promising efforts to move beyond biomedical understandings of care-seeking (Britto et al., 2017). Approaches that connect knowledge and policies to provide effective and high quality health-care with attention to how cultural practices and structural action affect health-care-seeking are much needed to address low utilization of services. To support survival of newborns in Butajira, and globally, the local worlds' in which health-care decisions are made must be at the center.

Acknowledgements

We are grateful to the participants who by sharing their stories made this study possible. We would like to thank Butajira Rural Health Program for helpful assistance and facilitation in data collection. Finally, we thank Andrea Melberg, members of the Global Health Priorities and Global Health Anthropology research groups, four anonymous reviewers and the editor for their valuable feedback and comments.

Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.socscimed.2017.11.003.

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