Priority to the newborn?

Real-life priority setting and intra-household resource allocation for newborn health in Ethiopia

Kristine Husøy Onarheim

Thesis for the Degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
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UNIVERSITY OF BERGEN

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2 LIST OF ABBREVIATIONS

BRHP	Butajira Rural Health Program
CR	Co-researcher
EDHS	Ethiopian Demographic and Health Survey
DALY	Disability-adjusted Life Years
ETB	Ethiopian Birr
FGD	Focus group discussion
FMOH	Federal Ministry of Health
FRP	Financial Risk Protection
GDP	Gross Domestic Product
HDSS	Health and Demographic Surveillance System
HEW	Health Extension Workers
IDI	In-depth interview
IGO	Intergovernmental Organization
IMR	Infant Mortality Rate
LIC	Low-income country
LMIC	Low- and middle-income country
MDG	Millennium Development Goal
MIC	Middle-income countries
NGO	Nongovernmental organization

NMR	Newborn Mortality Rate
OOP	Out-of-pocket
PPP	Purchasing Power Parity
SDG	Sustainable Development Goal
SDI	Socio-Demographic Index
SNNPR	Southern Nations, Nationalities, and People’s Region
SSA	Sub-Saharan Africa
UHC	Universal Health Coverage
UN	United Nations
US$	United States dollar
U5MR	Under-5 Mortality Rate
WHO	World Health Organization

3 SCIENTIFIC ENVIRONMENT

This research was conducted while I was a medical research track student (forskerlinjestudent*,* 2009-2014) and PhD candidate (2015-2017) at the Department of Global Public Health and Primary Care, Faculty of Medicine at the University of Bergen, Norway. I have been affiliated with the Global Health Priorities research group throughout the project, and from 2015 to the Global Health Anthropology research group.

As a visiting PhD candidate, I had short stays at the School of Public Health, Addis Ababa University (2015, 2016), the Department of Maternal, Newborn, Child and Adolescent Health, World Health Organization (2016), the Department of Global Health and Population, Harvard T.H. Chan School of Public Health, Harvard University (2016), and the Brocher Foundation (2017).

Main supervisor: Associate Professor Ingrid Miljeteig (2009-2017). Department of Global Public Health and Primary Care, University of Bergen, Norway.

Co-supervisors: Professor Ole Frithjof Norheim (2009-2017). Department of Global Public Health and Primary Care, University of Bergen, Norway.

Professor Karen Marie Moland (2015-2017). Department of Global Public Health and Primary Care, University of Bergen, Norway.

Associate Professor Mitike Molla Sisay (2015-2017). School of Public Health, College of Health Sciences, Addis Ababa University, Ethiopia.

Funding: University of Bergen

4 ACKNOWLEDGEMENTS

While articles, conferences, and Twitter inspired my interest in global health, development and priority setting, my time in Ethiopia and Butajira left the strongest impressions. Where medical textbooks detail how to treat newborn sepsis, they do not explain why newborns die from treatable infections. Through conversations with participants in this study, I understood more of what books could not reveal. I am truly grateful for what they taught me and hope this thesis presents glimpses of the everyday struggles of the ill newborns, families, and health workers I met.

I would like to thank my supervisors for their generosity, academic advice, and inspirational work. What a dream team! Thank you, Ingrid; your continuous support as my main supervisor has been invaluable as an inspiration, discussant, and co-writer, but also as a travel companion and friend. Among my too-many ideas, your positive, yet constructive, guidance gave me the flexibility to develop ideas I found most interesting.

Thank you, Ole Frithjof, for opening the door to the field of priority setting – and to Ethiopia. Your friendly supervision has been extremely helpful, and at times demanded challenging (and necessary) re-thinking, re-reading, and re-structuring. Your knowledge and genuine interest in fairness and health is impressive and inspirational.

Thank you, Karen Marie, for inspiring a medical doctor to read anthropology and helping me navigate the jungle of qualitative methods. Even with early ideas and drafts, your positive attitude, interest, and kind support made me think that what I did mattered; truly valued by a student lost in too much data or demotivating comments from reviewers.

Prior to our first meeting in Addis in 2015, I was nervous, but it only took a couple of minutes to understand that I was safe. Thank you, Dr. Mitike! Your commitment has been irreplaceable. Your advice and contacts opened doors I would never have found

in planning, data collection, and analysis. I truly enjoyed my time at the Zewditu campus and look forward to more laughter, chai, and Ethio-Norwegian collaboration.

A special thanks goes to my research assistant and friend, Muluken. Throughout data collection, your efforts went far beyond our expectations, from every practical arrangement to explanations of local practices. In endless discussions over breakfast, lunch, and dinner, you helped me understand areas where questions remained unanswered. Though I am still a farangi and newcomer, you did your best. And, you taught me the secret behind the best macchiatos – the dark ones, no sugar!

The project would not have been possible without a PhD grant from UoB and economic support for data collection from UoB and Renèe og Bredo Grimsgaards stiftelse.

Throughout my PhD, the Department of Global Public Health and Primary Care has been my academic home. My time would not have been what it was without my wonderful colleagues. Thank you for stimulating academic input and reflection, company and support on the PhD rollercoaster, and endless discussions over lunch.

I am grateful for my time at the the Butajira Rural Health Program and School of Public Health, Addis Ababa University. My sincere thanks goes to Mulugeta and Abhiwot for your help in data collection, and to Butajira General Hospital and Andualem. Alemnesh and Beza warmly opened their home in Addis; thank you for your hospitality, fun, and discussions.

My interest in global health research and policy was further nourished by rewarding stays at the Department of Global Health and Population at the Harvard T.H. Chan School of Public Health (Professor David E. Bloom), the Department of Maternal, Newborn, Child and Adolescent Health at the World Health Organization (Dr. Rajiv Bahl), and the Brocher Foundation.

A special thanks to my “friend-visors,” Ingrid and Andrea, for sharing motivation and frustration and reading early drafts. Luckily, I early in my medical studies met other students with a strong passion for global health (IFMSA, Nmf, UAEM). Thank you for inspiration, and for advocating for change! I am grateful for my friends, who mostly have been supportive, but sometimes rightly suggested that I should take some time off.

As a daughter of an anesthesiologist and a biochemical engineer, I looked long in every direction other than medicine. Fortunately, I came to discover an area I learned to like. I am grateful for support from my parents', who showed, by example, that dedication and hard work pay off. As researchers yourselves, you have encouraged my sister and me to seek answers to questions and make use of opportunities that are there. Your advice to "at least try" (det er jo bare å prøve) has proven to also work in academia. Thank you, Ingrid, for being the younger sister pushing and cheering for the older one.

5 ABSTRACT

5.1 Abstract in English

Background: Worldwide, 2.6 million newborns die every year. Despite attention to newborn health in policies and plans in Ethiopia, coverage of services remains low, and the decline in mortality is slower than it has been for older children. The Ethiopian health care system is underfinanced, and patients and their families pay out-of-pocket for health care services. When resources for health are limited, priority setting dilemmas arise. Real-life priority setting occurs at macro, meso, and micro levels, and choices affect the health and well-being of patients and their families. At the household level, families with ill newborns make decisions about health care seeking and spending. Few have studied intra-household priorities and resource allocation when newborns fall ill.

Objective: In this PhD project, I aim to describe and analyze real-life priority setting for newborn health in Ethiopia from a micro-level perspective.

Methods: Study I and Study II were based on a qualitative study in Butajira, Ethiopia (autumn 2015) comprising 41 interviews, seven focus group discussions, and observation. Participants included family members experiencing newborn illness or death, health workers, and community members. Data was analyzed drawing upon qualitative content analysis. Study III was a seven-step ethical analysis of the dilemma between concerns for newborn health and family welfare described in Studies I and II. Using a stylized case of an ill newborn in a poor family, we analyzed the ethical acceptability of limiting treatment for an ill newborn to protect against financial risk.

Results and discussion: Study I illustrated families' health care decision making in a resource-constrained setting, and how and why families waited before seeking health care. Decisions to seek care at health facilities were shaped by culturally and structurally embedded understandings of the precarious newborn and families' concerns for the survival of the family. There were gaps between local perceptions and experiences of newborn illness as opposed to academic and policy attention to newborn mortality as an avoidable problem.

Study II found that families experiencing newborn illness struggled to pay out-of-pocket for expenses related to treatment, diagnostics, or use of health care services. In a context with limited welfare protection, the financial burden of health care costs had harmful effects on newborn health and households' economic situations. In decisions about seeking health care, spending money, and adhering to medical advice, there were conflicts between concerns for the ill newborn and the family's welfare.

Study III analyzed the conflict between concerns for health benefits and financial risk protection. In the ethical analysis, we assessed available evidence and relevant regulations and laws. We looked at affected parties, their burdens and benefits, and interests and principles in conflict. If the ill newborn is seen as worse-off in terms of lifetime health, and we give weight to health maximization, then it may seem unacceptable to limit treatment. If financial risk protection is found most important, then it may be acceptable not to treat the newborn. In an all-things-considered judgment, we incline towards that it is not acceptable to restrict treatment. Yet, there is reason to believe that the newborn, family members, and health worker would value treating the newborn while avoiding financial ruin. We claim that micro-level decision makers have limited opportunities to make free choices to seek care. If we accept the dilemma, we thereby accept deprivations of people's substantive freedoms.

Conclusions: The findings illustrate that intra-household resource allocation and care-seeking for ill newborns are shaped in the intersection between socio-cultural and structural factors. The gap between local realities and national and global priorities on newborn health must be considered and underpin policy-making and implementation. The unacceptable trade-off that families and health workers face between concerns for health and welfare indicate that financial risk protection is key on the path to universal health coverage, in particular for high-priority services. Studies of real-life ethical dilemmas are crucial to understanding the present, and as a starting point to improve health, welfare, and fairer priority setting.

5.2 Abstract in Amharic

አብስትራክት

መነሻ፣ በአንዴ አመት ውስጥ ብቻ በአሇም አቀፍ ዯረጃ 2.6 ሚሉዮን ጠቅሊሊ ህፃናት ህይወታቸውን ያጣለ፡፡ በኢትዮጵያ ውስጥ ምንም እነኳን ሇጠቅሊሊ ህፃናት ጤና የተሇያዩ ፖሉሲዎችና እቅድች ቢኖሩም የአገሌግልቱ ተዯራሽነት አሁንም ቢሆን አናሳ ነው፣ እንዱሁም የጨቅሊ ህፃናትም ሞት ከፍ ካለ ህፃናት ሞት አንፃር ሲታይ እየቀነሰ የመሄዴ መጠኑ አነስተኛ ነው፡፡ ኢትዮጵያ የጤና እንክብካቤ አገሌግልት በቂ የሆነ በጀት አሌተያዘሇትም ታካሚዎች ከኪሳቸው ነው የጠና አገሌግልት ሇማግኘት ክፍያ የሚፇፅሙት፡፡ ሇጤና አገሌግልት የሚወጣው ገንዘብ ሲያንስ ቅዴሚያ መሰጠት ያሇበት የህክምና አይነትን ሇመመምረጥአስቸጋሪ ይሆናሌ ይህ ችግር በከፍተኛም በመካከሇኛም እንዱሁም በዝቅተኛ ዯረጃም ሊይ ይታያሌ እናም ይህ ችግር ይህ ሁኔታ የታማሚዎችንና የእንሱን ቤተሰቦች ጤናና ሰሊማቸውን ይነሳቸዋሌ፡፡ በቤተሰብ ዯረጃ ጨቅሊ ህፃን የታመመባቸው ቤተሰቦች እንዳት ማሳከም እንዱሇባቸው እና ስንት ብር ማውጣት እንዱሇባቸው የሚወስኑት በራሳቸው ነው፣ በእንዯዚህ ኤነት ሁኔታዎች ሊይ የተወሰኑ ጥናት ተዯርገዋሌ፡፡

አሊማ፣ በዚህ የፒኤችዱ ፕሮጀክት ዋናው አሊማዬ በኢትዮጵያ በአነስተኛ ዯረጃ በጨቅሊ ህፃናት ጤና ሊይ ያሇውን ነባራዊ ዊኔታ ሇመግሇፅና ሇማስረዲት ነው፡፡

የጥናት ዘዳዎች፣ ጥናት 1ና ጥናት 2 ተመስርተው የተሰሩት በበሌግ 2007 ዓ.ም ቡታጅራ ኢትዮጵያ ውስጥ በተዯረገ ኩዋሉታቲቭ ጥናት ሊይ ነው፡፡ በጥናቱም ውስጥ ቃሇ-መጠይቆች፣ የቡዴን ውይይቶች፣ እና የተሇያዩ መረጃዎችን ሇመቃኘት ተችሎሌ፣ በውይይቶቹም ሊይ የጨቅሊ ህፃናት/ሞት ያጋጠማቸው ቤተሰቦች እንዱሁም የቴና ባሇሙያዎችና የተሇያዩ የማህበረሰቡ አባሊት አባሊት ተሳታፊ ሆነዋሌ፡፡ ጥናት 3 በሰባት ዯረጃ የተከፇሇ ሆኖ በጠቅሊሊ ህፃናት ጤና ሊይ ትኩረት ከማዴረግና በጠናት 2 እንዯተገሇፀው የአንዴ ቤተሰብ ኑሮ ሳይቃወስ በሰሊም እንዱኖሩ ማስቻሌ መካከሌ ያሇውን አጠያያቂ ሁኔታ በማገናዘብ ተሰርቷሌ ፣ አንዴ ሌብ ውሇዴ የሆነ ታሪክ በመቅረፅ አንዴን ቤተሰብ በኢኮኖሚ ዯረጃ ችግር ውስጥ እንዱይወዴቅ ሲባሌ ሇጨቅሊ ህፃኑ/ኗ ሉሰጥ ሚገባውን ህክምና ማሳነስ በህብረተሰቡ ዘንዴ ያውን አንዴምታ ሇማየት ተችሎሌ፡፡

የተገኘው ውጤት፣ ጥናት 1 በግሌፅ ሇማየት ያስቻሇን ሁሇት ነጥቦች አለ እንሱም ጨቅሊ ህፃናት ህክምና ማግኘት እንዱችለ የቤተሰባቸው ውሳኔ ከፍተኛ ሚና እንዱሇው እና ሇምንና እንዳት አንዴ ቤተሰብ ወዯ ህክምና ጨቅሊ ሌጁን ሇመውሰዴ እዯሚዘገይ ናቸው፡፡ ወዯ ጤና ተቋማት ሄዴ

ህክምና የማግኘትን እርምጃ ሇመውሰዴ የግንዛቤ ሁኔታ፣ ባህሌ፣ እሴቶች፣ የጨቅሊ ህፃኑ ያሇበት ሁኔታና የአቅም ሁኔታ ወሳኝ መሇኪያ ናቸው፡፡ ጨቅሊ ህፃናትን እንዯ ሰው ያሇመቁጠር ሁኔታ አሇ እንዱሁም በአብዛኛው ስሇ ጨቅሊ ህፃናት ህመም ያሇው ግንዛቤ በአሇም አቀፍ ሁኔታ ሇጠቅሊሊ ህፃናት ሞት እየተሰጠው ያሇው ትኩረት ሊይ ክፍተት ይታያሌ ይህም መቀረፍ ያሇበት ችግር እንዯሆነ ታውቋሌ፡፡

በጥናት 2 መረዲት እንዯተቻሇው ጨቅሊ ህፃናት የታመሙባቸው ቤተሰቦች የህክምና ወጪዎችን ሇመሸፈን ወይንም የጤና አገሌግልቶችን ሇመጠቀም ወጪዎችን መሸፈን ወይንም የጤና አገሌግልቶችን ሇመጠቀም ወጪዎችን መሸፈን ሲከብዲቸው ታይቷሌ፣ በዚህም ተነሳ የህክምና ወጪው በሚያስከትሇው የኢኮኖሚ ጫና ሳቢያ የጨቅሊ ህፃናቱ ጤናና የቤተሰባቸው የኢኪኖሚ ሁኔታ ይናጋሌ፡፡ የህክምና አገሌግልትን ሇማግኘት አንዴ ቤተሰብ ሲወስን ሇታመመው/ቸው ጨቅሊ ህፃን ቅዴሚያ ይሰጠ ወይስ ቀሪው የቤተሰብ አባሊት ሁኔታ ቅዴሚያ ይሰጠው የሚሌ ግጭት ይከሰታሌ፡፡

ጥናት 3 በትኩረት የተመሇከተው በአንዴ ዴሀ ቤተሰብ ውስጥ በህክምና ሉገኝ የሚችሇውን የጤና እገዛን/ተጠቃሚነትን ሉከሰው ከሚችሌ የኢኮኖሚ ስጋት/ሪስክ ጋር በማነፃፀር ሇማየት ተሞክሯሌ፣ እና ጨቅሊ ህፃኑ/ኗ በህይወት የመቆየቱ/ቷ ሁኔታ አሳሳቢ ዯረጃ ሊይ ቢዯርስም እንኳም ህክምናውን አጠናክሮ መቀጠሌ ግዳታ እንዯሆነ ይታመናሌ፣ በላሊ ወገን ዯግሞ ጨቅሊ ህፃን ታመመበት ቤተሰብ ሉዯርስበት የሚችሇው የኢኮኖሚ ጉዲት ከፍተኛ ስሇሆነ ሇቤተሰቡ የኢኮኖሚ ሁኔታ ቅዴሚያ ከተሰጠ ጨቅሊ ህፃናቱን አሇማሳከም ተቀባይነት ሉያገኝ ይችሊሌ፣ ግን አንዴ በቂ ምክንያት ሉታመን የሚችሌ ነገር ቢኖር ጨቅሊ ህፃናቱም የእነሱም ቤተሰቦች እንዱሁም የጤና ባሇሙያዎች ጨቅሊ ህፃናት ቤተሰቦቻቸውን የኢኮኖሚ ችግር ውስጥ ሳይጥለ ህክምና ማግኘት ቢችለ መሌካም እንዯሆነ ነው፡፡ እናም እኛ እንዯሚታየን በትንሽ ዯረጃ ሊይ የሚገኙ ውሳኔ ሰጪዎች የቴና አገሌግልትን በቀሊለ እንዲይገኝ የፈጠሩት ገዯብ እንዲሇ ይሰማናሌ፣ እና ይሄን ችግር እንዲሇ ካመንን የሰዎች መሰረታዊ ነፃነት እንዯተገፈፈ ይገባናሌ ማሇት ነው፡፡

ማጠቃሇያ፣ ከጥናቱ የተገኙት መረጃዎች እንዯሚያሳዩት በአንዴ ቤተሰብ ውስጥ የታመመባቸውን ጨቅሊ ህጻን ሇማሳከም የሚያውለትን ገንዘብ መጠን ሇመወሰን እንዱችለ ከግምት ውስጥ የሚገቡት አንዯኛ የማህበረሰቡ ግንዛቤና አስተሳሰብ ሲሆን ላሊኛው ዯግሞ የቤተሰቡ የኢኮኖሚ አቅም ነው፡፡ በሀገር ውስጥ ያሇው እውነታና በአሇም አቀፍ ዯረጃ ሇጨቅሊ ህፃናት ጤና የተሰጠው ትኩረትና የተዘጋጁ ፖሉሲዎችና ተፈፃሚነታቸው በሀገር

5.3 Abstract in Norwegian

Sammendrag

Bakgrunn: Nyfødthelse har fått oppmerksomhet på den globale helseagendaen. Likevel dør 2.6 millioner nyfødte hver år. I Etiopia er dekningsgraden for helsetjenester til nyfødte lav, og dødeligheten for nyfødte faller langsommere enn for eldre barn. Det etiopiske helsevesenet er underfinansiert, og egenbetaling ved bruk av helsetjenester kan gi høye utgifter for pasienter og deres familier. Med begrensede ressurser til helse oppstår prioriteringsdilemmaer. Helseprioriteringer skjer på makro-, meso- og mikronivå, og påvirker pasienter og familier sin helse og velferd. Få har studert prioriteringer og fordeling av ressurser på husholdsnivå når nyfødte blir syke.

Mål: I dette doktorgradsarbeidet har jeg som mål å beskrive og analysere prioriteringer på nyfødthelse i Etiopia fra et mikronivåperspektiv.

Metode: Studie I og II er basert på en kvalitativ studie fra Butajira i Etiopia (høsten 2015), og inkluderte 41 dybde-intervjuer, syv fokusgruppediskusjoner og observasjon. Hovedinformantene var familiemedlemmer med syke nyfødte eller som hadde opplevd nyfødtdødsfall, helsearbeidere og medlemmer av lokalsamfunnet. Data ble analysert ut fra kvalitativ innholdsanalyse (qualitative content analysis). Gjennom en syv-trinns-modell for upartisk etisk analyse, drøfter vi i studie III et etisk dilemma beskrevet i Studie I og II (hensyn til helsegevinst for den nyfødte versus hensyn til familien sin økonomiske situasjon). Med utgangspunkt i en stilisert kasuistikk av en fattig familie i Etiopia diskuterer vi om det er etisk akseptabelt å begrense behandling til en syk nyfødt for å beskytte mot økonomisk risiko.

Resultater og diskusjon: Studie I beskrev familier sine beslutninger når nyfødte ble syke i Butajira, og hvordan og hvorfor familier ventet med å søke helsehjelp. Valg om dra på helsesentre eller sykehus ble påvirket av kulturelle og strukturelle oppfatninger om den sårbare nyfødte, og hensyn til familiens overlevelse. Funnene peker på forskjeller mellom lokale oppfatninger når nyfødte blir syke, og det akademiske og helsepolitiske fokus på nyfødtdødelighet som et håndterbart problem.

Studie II viste at familiene opplevde høye utgifter til egenbetaling for behandling, diagnostikk eller andre kostnader. I en ressursfattig kontekst, førte den økonomiske byrden ved bruk av helsetjenester til skadelige konsekvenser for den syke nyfødte og husholdsøkonomien. Familiene måtte låne penger eller selge eiendeler for å kunne betale for helsetjenestene. Konflikten mellom hensyn til barnets beste og familiens økonomi stod sentralt i familienes beslutninger om å søke helsehjelp, bruke penger eller følge medisinske råd.

Studie III analyserte konflikten mellom hensyn til helsegevinst og finansiell beskyttelse. Syvtrinnsanalysen evaluerte kunnskapsgrunnlaget og relevante lover og retningslinjer. Vi vurderte involverte partner, deres potensielle gode og byrder, og interesser og prinsipper som står i konflikt. Hvis vi vektlegger helsemaksimering og livstidshelsetap (en nyfødt som dør er dårlig stilt), kan det sees uakseptabelt å begrense behandling. Hvis vi vektlegger finansiell beskyttelse for familien, kan det sees akseptabelt å ikke behandle den syke nyfødte. Vår helhetsvurdering heller mot at det ikke er akseptabelt å begrense behandling. Det er imidlertid grunn til å tro at den nyfødte, familiemedlemmene og helsearbeideren ville ha verdsatt behandling av den nyfødte uten å havne i økonomiske vanskeligheter. Vi hevder at beslutningstakerne på mikronivå har begrensede muligheter til å ta frie valg. Hvis vi aksepterer dilemmaet, aksepterer vi også innskrenkninger i folks grunnleggende handlingsfrihet.

Konklusjon: Funnene illustrerer at husholdsprioriteringer og valg om å søke helsehjelp for nyfødte formes av sosio-kulturelle og strukturelle forhold. Erfaringer på mikro-nivå står i kontrast til det globale fokus på nyfødtdødelighet, og lokale forhold må i større grad tas hensyn til i videre helsepolitikk og -planer. Avveiningen mellom hensyn til helse og velferd er uakseptabel. Dette indikerer at finansiell risikobeskyttelse og reduksjon i egenbetaling blir avgjørende for å oppnå universell helsedekning, særlig for livsviktige helsetjenester. Studier av prioriteringsdilemmaer fra folks hverdag kan øke vår forståelse av disse, og er et utgangspunkt for å fremme helse og velferd, og for å sikre mer rettferdige prioriteringer.

6 LIST OF PUBLICATIONS

This thesis is based on the following original articles, after here referred to as Papers I-III.

Paper I

Onarheim KH, Sisay MM, Gizaw M, Moland KM, Miljeteig I. What if the baby doesn’t survive? Health-care decision making for ill newborns in Ethiopia. Social Science & Medicine. 2017;195(Supplement C):123-30.

Paper II

Onarheim KH, Sisay MM, Gizaw M, Norheim OF, Moland KM, Miljeteig I. Selling my sheep to pay for medicines – Household priorities and coping strategies in a setting without universal health coverage. Under review.

Paper III

Onarheim KH, Norheim OF, Miljeteig I. Newborn health benefits or financial risk protection? An ethical analysis of a real-life dilemma in a setting without universal health coverage. Under review.

7 INTRODUCTION

7.1 Understanding priority setting in newborn health

In the middle of the night, the mother delivered a baby girl at home. During the next hours, everything seemed fine, but by the following evening, the baby did not take the breast. The mother worried, but her mother-in-law told her to wait. "Hopefully, it will pass; the baby should get some rest." After the next morning, the mother begged, "Please, let me take her to the hospital. She's not well." The father had no money at hand and went to borrow from his cousin. But time went by, and by sunset, the baby had stopped screaming, and she passed away.

Family in a rural village, Ethiopia[1]

To achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

The Sustainable Development Agenda, target 3.8 (1)

Every year, 2.6 million newborns die within their first month of life (2). From a health perspective, 71% of these deaths could be avoided by cost-effective interventions (3). About 90% of neonatal deaths occur in low- and middle-income countries (LMICs) (4), and there are large inequalities in use of services and health outcomes within and between countries (2, 5). Newborns who die prematurely can be considered worst-off in terms of lifetime health loss (6). From a human rights perspective, the right to the highest attainable standard of health is enshrined in the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child (7, 8). Following these reasons, one can argue that ill newborns should be prioritized, and national and global stakeholders have called for improvements in newborn health (1, 9, 10). Still, coverage of services remains low,

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[1] This story is extracted from the data material and analysis upon which this thesis was based.

and mortality is slower than for older children (2). While newborn mortality and morbidity are getting on the policy agenda (11), we know less about intra-household priorities when newborns fall ill. This initial story about the Ethiopian family raises empirical and normative questions: Is the newborn the priority of the impoverished family? And, *can* an ill newborn be the priority in this poverty context?

In a world with limited resources, there is a need for priority setting. In aiming to distribute resources fairly, the literature on priority setting in health raises questions about how health care resources and health outcomes are and should be distributed, with emphasis on concerns for health maximization and the worse off (12-15). The target of universal health coverage (UHC) highlighted above has raised concerns about financial risk protection (6). Worldwide, patients pay out-of-pocket (OOP) when using health care services, and health care seeking is an economic as well as a health burden. In Ethiopia, the health care system is underfinanced, and household OOP spending accounts for 48% of total health expenditures on child health (16).

Empirical and normative questions and discussions relevant for priority setting in newborn health are interlinked. Since implementation of national and global agendas always occurs in local settings, it is necessary to understand intra-household resource allocation. Empirical studies of families' everyday priorities are relevant for health policy-making and implementation, and may further inform normative discussions. Studying real-life priority setting can help us understand the present, which is necessary to move forward in a way that promotes health justice.

This PhD work is based on questions I asked as a medical student, and later a medical doctor, interested in global health, priority setting, and distributive justice. After spending time in Ethiopia in 2011, I was struck by the distance between discussions in the medical, ethical, and policy literature and what I observed in hospitals and conversations with health workers treating ill children. Were children and newborns prioritized? And, more importantly, could ill newborns be the priority of families? There seemed to be a gap between academic and policy approaches, and the reality and everyday lives of ill newborns and their families. While a PhD project cannot bridge these realities, this thesis is an attempt to bring “a view from below” to ongoing global health debates (6). I aimed to study real-life priority setting and intra-household resource allocation for newborn health. I focused on Ethiopia, where the use of newborn health care services is low, and the decline in mortality is slower than for older children, despite political attention and investment in scaling up health services (4, 17, 18).

The following sections provide an overview of relevant background for the study. Section 7.1 points to why an understanding of newborn health priority setting and intra-household resource allocation is needed (this section). The next section describes trends in newborn health (7.2). I introduce the fields of priority setting and resource allocation more generally and from a theoretical perspective in section 7.3 and 7.4. Section 7.5 reflects upon how non-health outcomes might be of relevance for health care priorities. I then describe the relevance of empirical perspectives and discuss how intra-household resource allocation can be seen as micro-level priority setting (7.6). Finally, section 7.7 presents research gaps within the field. The introduction is followed by chapters describing objectives (8), methodology and methods (9), results (10), discussion (11), conclusions (12), and future perspectives (13).

7.2 Newborn health

7.2.1 Trends in child and newborn health

Child death has been a common experience historically and cross-culturally, and the improved survival of children, infants, and newborns is a quite recent phenomenon. In 1850, four of ten children died during their first five years of life (19). In 1960, one of five children died before their fifth birthday, which today has been reduced to one in 25 (19, 20). While the accelerating decline is promising, too many children die prematurely. In particular, the first hour, day, week, and month are risky. Newborn illness and deaths that occur during the first 28 days of life (21) contribute to 8 % of the global burden of disease, similar to the health loss due to cancer, or to the combined burden of HIV, tuberculosis, malaria and neglected tropical diseases (4). Of the 140.6 million live births that occurred in 2015, 2.6 million newborns died within the first month of life, and three out of four of these deaths occurred during the first week (2). Child mortality is measured by the under-5 mortality rate (U5MR), which describes the number of child deaths before the fifth birthday per 1,000 live births. The U5MR fell from 12.1 million deaths in 1990 to 5.8 million in 2015 (2). Despite promising declines in child mortality, only 58 of 195 countries met the Millennium Development Goal (MDG) 4 target by 2015, which aimed for a two-thirds reduction, or a 4.4% annual reduction in U5MR. Most countries that met the target were middle-income countries (MICs), and only four low-income countries (LICs)[2] – where mortality rates often are higher – met the target (2).

The newborn or neonatal mortality rate (NMR) has been defined as deaths during the first 28 days of life per 1,000 live births (21). While the number of newborn deaths per year decreased from 4.6 to 2.6 million between 1990 and 2015, the rate of decline was more moderate than for older children (2) (Figure 7.A). In 1990, 38% of child deaths occurred in the newborn period, which increased to a relative contribution of 45% of all under-five deaths in 2015. Yet, the number of newborn deaths and stillborn might be higher as many births, and deaths, are not counted in health systems where delivery takes place outside health facilities and where vital statistics registration systems are limited (22, 23).

The global NMR was 19 deaths per 1,000 live births in 2015. Yet, the risk of dying differs both between and within countries. As is true for other patients, the health of newborns is related to socio-economic development. The risk of dying in the newborn period is lowest in countries with high socio-demographic index (SDI) (2 deaths per 1,000 live births), and highest in countries with low SDI (28 deaths per1,000 live births) (2). Within countries, there are vast inequalities in access to and

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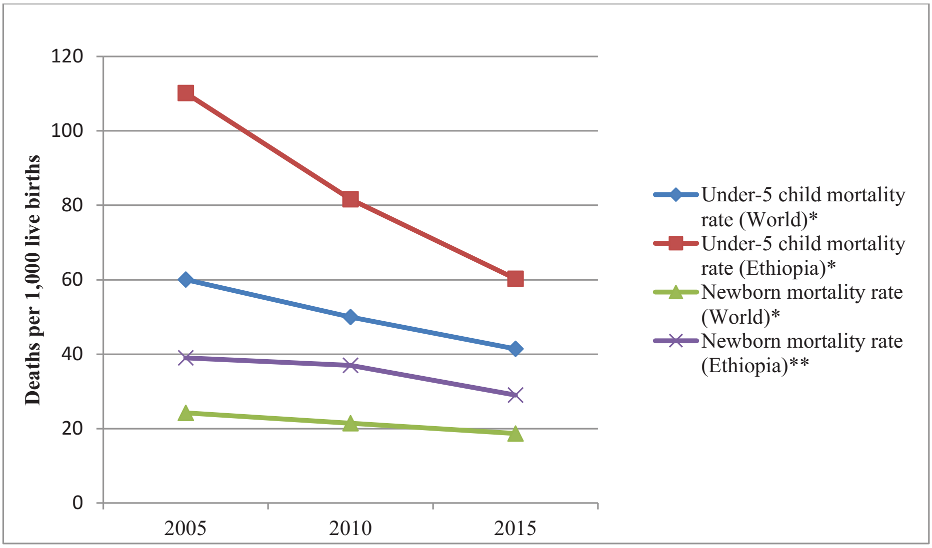
[2] Cambodia, Ethiopia, Liberia, and Nepal.

use of services, in particular for facility-based care (5). Even though the burden of disease often disproportionately affects the poor, coverage of maternal, newborn and child health services has been shown to be pro-rich (5, 24). Further, inequalities in health and health care are seen in differences between regions, rural or urban location, education, and other factors.

Figure 7.A: Trends in child mortality (2005-2016)



Data from Institute of Health Metrics and Evaluation (2) and the Ethiopian Demographic and Health Survey (18, 25, 26).

7.2.2 Causes of child and newborn illness and death

In 2015, the leading causes of child deaths were neonatal illness (45%), pneumonia (13%), diarrhea (9%), injuries (6%), and malaria (5%) (27). Major contributors to newborn deaths were prematurity, intrapartum-related events, and sepsis (27). These biomedical causes of death are shaped by structural and cultural factors. An anthropological description highlights three levels of causes of child mortality (28). At the proximate level, biomedical causes such as infections or malnutrition contribute to child death. Intermediate-level causes describe how care-seeking behavior and households' living conditions cause ill health. Ultimate-level causes refer to economic, social, and cultural factors that cause differences in the distribution of essential goods, such as food or sanitation, which in turn affect child health outcomes (28).

7.2.3 Improving newborn health

When looking at evidence of what works to improve newborn survival, 71% of newborn deaths can be treated or prevented by increasing coverage and quality of existing interventions (3). With access to simple and cost-effective strategies, such as thermal care, resuscitation, kangaroo mother care, breastfeeding, and antibiotic treatment, ill or at-risk newborns can survive (29). Looking ahead from the Millennium Development Goal (MDG) era, it is essential to gain political priority at the national level and improve coverage, quality, and equity of services. This is not only beneficial for the newborn but also can also address the burden of stillbirth and maternal illness, which gives a triple return on investment around birth (29). Scaling up targeted newborn health care services can have substantial effects on newborn and child mortality (3, 30, 31). A package of key interventions to address stillbirth, neonatal and maternal deaths can be provided at US $60 per disability-adjusted life year (DALY) averted, which can be considered highly cost-effective (3).

Low coverage and slower reductions in newborn mortality may indicate that even though knowledge of effective interventions exist, they remain a challenge to implement. From a health system perspective, quality, accessibility, availability, and affordability of services represent barriers to care-seeking, and efforts must take context-specific factors into account in implementation (30, 32). Beyond health care services, analysis of trends in NMR (2000-2010) showed that reductions in newborn mortality were more related to changes in socioeconomic status than in coverage (32). General development is therefore important (32), and cross-sectoral approaches through social, educational, economic and health system efforts are needed (33, 34).

7.2.4 Is newborn health prioritized?

7.2.4.1 A view from above

Political and policy focus on neonatal mortality is a recent phenomenon. Before the year 2000, there was little and fragmented attention on newborn health (35, 36). Shiffman describes how efforts by a newborn survival network in the MDG era helped shift perceptions; newborn mortality now is presented as a severe and tractable problem within the field of global health. In an era where governments were expected to deliver on the MDGs, newborn health was portrayed as key to delivering on MDG 4 (36). After the year 2010, intergovernmental, national and NGO-led initiatives put emphasis on newborn health, including efforts such as from the United Nations (UN) Secretary-General’s first Global strategy for women’s and children’s health (37), The Lancet’s series on newborn health (38, 39) and specific programs such as Born Too Soon (36). Between 2010 and 2015, development assistance for health grew faster for maternal, newborn and child health than for other global health priority areas such as HIV/AIDS (40). Newborn health is visible in the sustainable development goal (SDG) indicator 3.2.2, which aims to end preventable newborn deaths and reduce NMR “to at least as low as 12 [deaths] per 1,000 live births” (1). Looking ahead, the global commitment to newborn health is embedded in continuation of MDG initiatives such as Every Woman, Every Child, and a new Global strategy for women’s, children’s and adolescents’ health (2016-2030) (10, 41). These initiatives have helped highlight the magnitude of the burden, solutions and next steps, and promoted accountability. Their calls for action focus on human rights and dignity for all:

> The *Global Strategy* is universal and applies to all people (including the marginalized and hard-to-reach), in all places (including crisis situations) and to transnational issues. It focuses on safeguarding women, children [including newborns] and adolescents in humanitarian and fragile settings and upholding their human rights to the highest attainable standard of health, even in the most difficult circumstances (41).

7.2.4.2 A view from below

From a macro angle, we have seen attention on newborn health. I now turn to look at how newborn death and illness is understood among caretakers, families, and communities in contexts where child mortality is high. The literature presents views from below, which is relevant to the question about how newborns are prioritized.

Decision making for ill children often takes place at the household level but is influenced by local understandings of child illness and care-seeking, embedded in sociocultural norms and economic scarcity. Individual and social expressions and responses to infant death have been studied by historians, archaeologists, social scientists, and health scholars (42). Scheper-Hughes' work from northeastern Brazil described perceptions and practices surrounding infant ill health and death (43). In a context of high infant mortality and rampant poverty, it was expected that some children would not survive. She described meaning-making processes, justifying practices where mothers allowed weak or vulnerable infants to die, known as "selective neglect"[3] (43). Anthropologists have debated the concept of neglect and opposed Scheper-Hughes' findings (44, 45). Experience and expressions of grief over child deaths differ, but the studies illustrate how context, culture, and structural constraints shape perceptions, practices, and decision making in care for children. Some studies have looked at early child deaths, and describe how newborns are not considered as social persons, as they are not regular household members or known in the community (46, 47). A study from Ethiopia explored how early neonatal deaths and stillborn babies were not talked about. The babies were buried without formal recognition, and mothers were told not to express their personal feelings (46). These readings emphasize how circumstances and poverty concerns shape caretakers' strategies and decision making in a context where the needs of the ill child are balanced against the needs of the family (48, 49).

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[3] Similar descriptions are "benign neglect," "looking away," or discrimination against "failing babies."

This section has highlighted how newborn health has received attention in the MDG era. Contrasting this priority, scholars from different fields have studied perceptions of young babies in high mortality and resource-constrained settings. With some exceptions (46, 47), little is known about how newborn illness is looked upon at the household level, and how intra-household priorities affect care-seeking. Newborns, even more so than other children, rely on decisions made by others and their judgments in health care seeking (50). At a time where newborn deaths represent an increasingly larger burden of child deaths, further scrutiny of families' priorities with regards to the newborn is needed.[4] It seems of relevance to examine whether newborns are – and should be – prioritized. In the following sections, I present central topics on priority setting and resource allocation more generally, which are relevant for my empirical and normative analysis on newborn health in Ethiopia.

7.3 Priority setting and resource allocation

In health care systems worldwide, there is a gap between resources available and resources needed to deliver every beneficial intervention to everyone (6, 51-54). In decisions and choices regarding health and health care, options for preventive services and treatment often exceed what the budget allows. Though more efficiency and increases in budgets may increase the availability of resources (54, 55), the overall budget or resources will always be limited. When there is a scarcity of resources for health but a range of possible options or interventions, there is a need for priority setting (53), which implies that one (or more) option will be chosen over others. When services are withheld from individuals or groups who could benefit from them, priority-setting dilemmas and trade-offs arise (56, 57). What kind of services should be provided, and to whom? As will be discussed in this section,

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[4] Another important and related area is stillbirths. Estimates indicate 2.1 million stillbirths in 2015. Challenges to address newborns and stillbirths are related, but in this thesis, I chose to focus on newborns.

priority setting ranges from rationing decisions about which patients should receive respiratory support when only a restricted number of ventilators are available, to allocative decisions about how large the government's budget for health care should be. If one accepts the premise that priority setting is needed, this leads to new questions. How does priority setting occur, and (when) can priority setting be fair and ethically acceptable (53)?

The terminology used to describe priority setting includes rationing and decision making (58, 59). In this thesis, I use them interchangeably when discussing choices where one or some options are chosen over others with known or acknowledged consequences that other options are not chosen. Priority setting may occur explicitly, where it is recognized that priorities are (to be) set (60). Here, the processes of priority setting and justifications for priorities may be presented to stakeholders involved, the public, or others. When priority setting takes place implicitly, it may not be spelled out that priorities are set, and rationales may not be presented. The dichotomy of explicit versus implicit priority setting can be helpful, as it may push for explicit priority setting, which is particularly valuable in the allocation of public resources. Still, "what happens within the black box of priority setting" can also be blurred in explicit priority-setting processes (61). Both explicit and implicit priorities are shaped by cultural and structural factors and norms and are embedded in local contexts.

7.3.1 Two strands of priority setting research

Priority setting research is interdisciplinary. Studies on priority setting relate to fields such as bioethics, medical ethics, economics, philosophy, law, and human rights (56, 62-64). Research from different contexts has focused on a variety of topics, ranging from practice-oriented clinical ethics, through policy-oriented ethics, to bioethical theory. There are two main strands of research on priority setting in health. One is more prescriptive, builds upon theoretical or normative work, and aims to say something about how priority setting should be done. The other is concerned with priority setting in the real world; it is more descriptive in its scope and has an empirical focus on how priority setting is done. While prescriptive and descriptive strands differ, discussions about how it is and how it should be are closely linked.

7.4 Theoretical perspectives on priority setting

The prescriptive literature on priority setting focuses on relevant theories, principles, and criteria for priority setting. Reflection about fairness and theoretical deliberation and abstraction may add relevant perspectives on how the reality ought to be (65).

In normative discussions, different theories suggest ways in which we can look at distributive justice. In simple form, I highlight five main perspectives:

1. Utilitarian theories focus on maximizing utility, and typically favor acts or outcomes that yield the greatest total utility, wellbeing or happiness (66).
2. Libertarian theories are concerned with individual freedom. If the right to liberty is not respected, it is considered unjust as it violates individuals' rights to do what they wish to do with their own resources (67)
3. A Rawlsian view gives emphasis to protecting equal individual liberties and fair equality of opportunity, with a particular concern for the worst-off (68).
4. A prioritarian view incorporates concerns to maximize utility and concerns for the worse-off, where helping people becomes more critical the more worse-off people are (69).
5. Sen's capabilities approach centers around the idea that a society should be judged based on the substantive freedoms people can enjoy and real opportunities to live the kind of lives they have reason to value (70).

These theories are relevant to health care decision making, but disagreement persists with regards to which of, and how, these theories of justice should be applied to health. Also, discussions on ideal worlds and theories may not always relate to the complex realities of people's lives (65).

Some oppose the view that we can come to an agreement on which theories and principles matter, and claims that different people will come to different conclusions, as our values, moral intuitions and preferences differ (65). One may argue that it is better to focus on legitimate processes of decision making. In discussions about fairness in priority setting in health care, Daniel's focus on deliberative processes and procedural fairness has been significant. His application of deliberative theories of democratic justice provided a new angle to address complex, real-world priority setting. If processes of priority setting are fair, we should have reason to come to acceptable health care decisions. In their book, Accountability for reasonableness framework (A4R), Daniels and Sabin suggest four procedural conditions to evaluate whether decision-making processes are fair and legitimate: relevance, publicity, revision and appeals, and regulative conditions (71). Further, power differences between individuals or groups that take part in these processes influence priority setting outcomes, and an additional empowerment condition has been suggested (72).

In this thesis, I support perspectives which assume that theories are relevant, cases should inform normative discussions, and deliberative processes are crucial. With this as a starting point, it is appropriate to look at principles for priority setting in health.

7.4.1. Principles and criteria for priority setting

Where theories of justice provide overall direction, principles may guide or clarify further. Many agree that decisions should not be guided by one principle alone, and that different concerns need to be balanced. The relevance and acceptability of suggested principles and criteria[5], and how these should be weighted, are discussed and debated (56, 73-76). A comprehensive overview of criteria for priority setting

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[5] Principles and criteria are here used interchangeably to describe guiding concerns for priority setting.

goes beyond the scope of this thesis, but I have highlighted some frameworks in Table 7.A.

Table 7.A: Criteria relevant for priority setting and ethical analysis

Source	**Normative criteria**	**Main application of criteria**[6]
Cookson and Dolan (2000) (76)	Need principles Maximizing principles Egalitarian principles	Day-to-day priority setting by clinicians and administrators
Persad et al. (2009) (56)	The complete lives system - Youngest first - Prognosis - Save the most lives - Lottery - Instrumental value	Allocation of scarce medical interventions[7]
Norheim et al. (2014) (77)	Cost-effectiveness Equity¨ - Criteria related to disease and intervention - Criteria related to characteristics of social groups - Criteria related to protection against financial and social effects of ill health	Priority setting by decision makers at national and sub-national levels
World Health Organization (2014) (6)	Health benefit maximization Priority to the worse off Financial risk protection	Priority setting by policymakers and technical advisors in health ministries
Marckmann (2015) (78)	Expected health benefits for target population Potential harm and burdens Impact on autonomy Impact on equity Expected efficiency	Ethical analysis of public health interventions or policy decisions

While suggested criteria differ, two have received particular attention: *priority to health maximization* and *priority to the worse-off* (12-15). Priority to health maximization implies prioritizing the option or intervention with the greatest benefit. Methodologies and tools have been developed to evaluate cost-effectiveness or cost-benefit ratios which are used in health technology assessments and evaluation of new

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[6] The criteria for allocation and priority setting are to be applied in health and public health, but may differ in their definition of what is considered as relevant health resources or outcomes.

[7] Not clear about where principles are to be applied.

health care interventions. While efforts to promote the notion that governments or decision makers get more health for their money is important, many agree that health care investments should not solely be guided by efforts to maximize health. People are also concerned with giving priority to individuals or groups that initially are worse (worst) off (55). The worse-off can be understood from different perspectives, and it has been less clear how concerns for the worse-off should be considered. The worse-off can be those who are worse-off in terms of severity of disease, immediate health need, or lifetime health perspective. Others may look at those who are worse-off overall in terms of both health and non-health wellbeing. This can be seen as poor, less-educated, or marginalized groups or individuals (6). In response to the lack of clarity in the definition of the worse-off and concerns for equity, a checklist was developed to consider alongside cost-effectiveness (Table 7.A) (77):

1. Criteria related to disease and intervention,
2. Criteria related to characteristics of social groups, and
3. Criteria related to protection against financial and social effects of ill health.

In recent discussions of global health, the financial risk[8] of being ill and seeking health care has received attention (79, 80). Research shows that high OOP spending contributes to a substantial economic burden and impoverishment for patients and their families (81, 82). Globally, about 21% of total health care spending comes from OOP payments, however, in lower and lower-middle income countries, OOP expenses contribute to almost half of health care spending (83). In settings without health insurance, patients and their families often rely on informal coping mechanisms to pay for care, such as borrowing money, selling their assets, reduced spending on other needs, and working more (84-87). Unexpected costs seen in health crises affect households' resources, and the poor are at particular risk. They often have a higher risk of illness and cannot depend on self-insurance strategies – such as saving or borrowing – in their risk-management and coping strategies (86, 88-90).

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[8] The term financial risk is used here, but it is also described in the literature with similar terms such as "financial catastrophe," "financial ruin," "financial hardship," or "poverty."

OOP payments may also delay care-seeking or effect health care choices, with potential damaging effects on health and wellbeing (86, 91). Further, by falling into poverty or ill health, patients and their families are at risk of entering the vicious cycle of poverty and ill health (92). With this as a backdrop, concerns for financial risk protection in priority setting are highly relevant. Target 3.8 of SDG 3 aims to "achieve universal health coverage, including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all" (1). Here, the interconnected objective of UHC aims to improve health *and* reduce detrimental impacts on welfare. While UHC is relevant for governance and financing, UHC also brings up questions about priority setting (6, 79).

7.4.1.1 A framework to ensure fairness on the path to universal health coverage

Aiming to achieve UHC, policy makers and planners face choices such as which services to scale up first, who should be included, and how to reduce OOP spending (6). After a request from the World Health Assembly in 2011, WHO established a Consultative Expert Group on Equity and Universal Health Coverage (6). Their report provided new guidance in two important ways: It acknowledged the importance and need for priority setting in discussions of UHC and provided guidance on principles and process to ensure fairness as member states progress towards UHC. In realizing UHC, countries set out from different starting points and may choose different paths related to context, resources, and values. The WHO report described vital steps for countries to secure fairness on this path. Countries must expand priority services, include more people (to receive priority services), and reduce OOP payments. In defining high-, medium-, and low-priority services, three ethical principles were recommended (Box 7.A):

1. The principle of *health benefit maximization* is concerned with giving priority to services that give the greatest total health-related wellbeing.

2. The principle of giving *priority to the worse-off* focus on groups or individuals who are worse-off[9].
3. The principle of *financial risk protection* gives priority to interventions that reduce impoverishment due to ill health and related health expenditures.

These substantive principles were supplemented by the principle of accountability, in which public institutions and mechanisms promote fair processes (6).

Box 7.A: Priority setting criteria from the WHO framework (6)

Criteria	**Description**
Health maximization	Priority to cost-effective interventions.
Priority to the worse-off	Priority to interventions that benefit individuals or groups that are worse off.
Financial risk protection	Priority to interventions that protect against high out-of-pocket expenses.
Accountability	Robust institutional accountability mechanisms and participatory processes for the public to take part in evaluation and deliberation.

7.5 Outcomes relevant for priority setting: Should non-health benefits count?

Priority setting in health relies on the assumption that decisions will have implications for health and health outcomes. Preventive services, such as antihypertensive drugs or antenatal care, may prevent harm or suffering, and treatment such as antibiotics or painkillers may improve patients' survival and wellbeing. Further, benefits of health care may go beyond health effects, and health care interventions and policies may have indirect benefits which influence health and non-health outcomes. In this thesis, I look at non-health benefits as "any benefit that is not a health benefit" (93).

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[9] According to the WHO report, the worse-off can be understood in terms of current or past health, wellbeing more broadly, disadvantages related social or economic status, or those with least access to health care services.

Parallel to the priority setting discussions, the literature on investing in health has described spillovers beyond initial effects on health (94, 95). Healthier often means wealthier; when people are healthy, they can attend school, be more productive, and they often have fewer children. These micro-level spillovers of health investments further benefit prosperity and economic development (95-97). Accordingly, health care investments are seen valuable both due to their intrinsic contribution to improving health and their instrumental role in stimulating development. These arguments for economic development have received attention in the global health literature and calls for investments in health and cost-effective interventions (95, 96). Economic arguments have also been used to direct attention towards specific health areas such as vaccines (98), non-communicable diseases (99), and women's health (100).

As for priority setting described in health care literature, there are different views on whether non-health and indirect benefits are relevant for resource allocation, and if so, how they should be included. Evaluations often focus on health outcomes and give little attention to whether and how non-health outcomes should play a role. Yet, as outlined in Table 7.A, criteria related to financial and social effects take concerns other than health outcomes into account (6, 77). Simplified, one view supports and one opposes the belief that concerns for indirect and non-health benefits should be included in priority setting. On one side, Brock has claimed that we should be concerned with health benefits of health care investments only (101). In what he describes as a separate spheres problem, he asks whether we should consider or include outcomes "such as economic benefits to employers from reducing the lost work time due to illness of their employees" (101). He argues that "different activities have different distinct purposes," and that goods and resources should be distributed based on the primary purposes of these activities, such as health care services to improve health or schools and education services to educate children. Counting non-health costs and benefits may lead us to "violate the moral injunction against treating people solely as means for the benefits of others" (102). Brock writes that concerns for non-health factors in micro-level rationing, by health professionals with implications for individual patients, are even more problematic. He argues "the closer to micro level choices by health professionals between the needs of their individual patients the stronger the case that these indirect non health benefits and costs should be ignored on grounds of fairness" (101).

On the other side, the alternative view argues that non-health and indirect benefits should be considered (93, 103). du Toit and Millum question the claim that counting indirect benefits will uphold existing inequalities (such as giving value to promoting the health of employed over unemployed patients). They discuss that only counting health benefits may also compound unfair inequalities (such as treating impacts of traffic injuries equally for manual workers and office workers). If one simply counts direct benefits – or indirect benefits – either may promote or impede distribution of existing benefits. Thus, counting indirect benefits will not reinforce existing inequalities per se. If one only counts direct benefits, one may only protect the interests of those directly affected, but not those indirectly affected. Following this argument, counting direct and indirect benefits may promote equal concern for all affected parties (103). They argue that there are no sufficiently good arguments for not counting non-health and indirect benefits, and that these should be treated in the same way as health benefits (103). Along this line, Persad and du Toit discuss what weight non-health and indirect benefits should have in policymaking. If one does not account for non-health benefits, the narrow focus of health policy will not recognize the actual benefits of health investments (93).

In this section, I have provided an overview of how concerns for non-health outcomes are increasingly included in the field of global health. Priority setting perspectives provide arguments for and against counting non-health benefits, which require further discussion. For people and patients, health is important, but it is often considered as a part of wellbeing. The pragmatist may argue that inclusion of non-health benefits, and respective measurement of outcomes, will create demands for more information and potential difficulties in defining which non-health-benefits to include. Still, if one fails to consider non-health and indirect benefits, there will be continued inattention in the measurement of these outcomes. This neglect is problematic, as it disregards non-health benefits as desirable outcomes for individuals and societies (93).

7.6 Empirical perspectives on priority setting

Empirical knowledge about the allocation of resources as it occurs in different contexts and levels of health care systems worldwide is relevant for priority setting in several ways. To evaluate legitimacy and fairness in priority setting, it is necessary to understand current priorities, and implications of these decisions, in the real world. Descriptive studies illustrate how priority setting directly and indirectly impacts stakeholders such as patients, families, health workers, bureaucrats, and policymakers. Further, empirical studies may describe ethical issues, practices or moral intuitions which can inform, improve, or criticize practices, theories, and discussions (104-107).

7.6.1 Real-life priority setting and resource allocation

Priority setting decisions are affected by a range of social, political, economic and other factors and are embedded in governance and organizational structures. Scholars have suggested ways to categorize decision making and resource allocation at various levels. One way to make a distinction between types of resource allocation was made by Calabresi and Bobbit (108). They distinguish between first-order determinants, where stakeholders decide how much of a scarce good there will be in the first place (e.g., allocations for the general health budget), and second-order determinants, which decide who will get the scarce good (based on available resources in first-order decisions). Higher-level decisions and priorities shape clinical decision making and vice versa. Klein noted that “microdecisions about priority setting are constrained by macrodecisions about resource allocation taken at superior levels” (109).

A common categorization of decision making separates between macro-, meso- and micro-level resource allocation (110). *Macro*-level decisions typically take place at a national or provincial level. Choices, which often involve politicians and bureaucrats, are related to issues such as proportional spending on health versus other sectors, or whether policies should focus on existing services for communicable diseases or a new mental health program. Above national priorities, agenda setting and funding of actors and institutions[10] in global health (111) can be seen as macro-level priorities. *Meso*-level decisions at regional or institutional levels, such as health regions or hospitals, deal with allocation related to the distribution of resources or personnel (110, 112). *Micro*-level decisions typically play out in clinical settings and involve rationing related to identified individuals (110, 113-117). Bedside rationing is described as denial, selection, deflection, deterrence, delay, dilution, and termination by health workers allocating hospital resources (113) and protecting patients and families against high health care costs (91). Studies of micro-level priority setting often look at health workers' rationing dilemmas. In this thesis, I use a broader scope, where intra-household resource allocations is seen as micro-level decisions.

7.6.2 Intra-household resource allocation

Literature from different academic disciplines challenges our understandings of what can be considered as resource allocation (48, 118-120). Just as policymakers, hospital managers, and health workers have restricted budgets, households have limited resources. Economists study resource allocation within households, which is known as intra-household resource allocation. In theoretical models, experiments, and analysis of survey data, economists focus on how households make decisions about education, nutrition, and health care, and factors that affect decision making (118-120). This research is relevant for priority setting in health. In particular, in settings where health care largely is paid for OOP, it is essential to understand households's.

Micro-economic studies on intra-household resource allocation look at *how* households make decisions, and how those *who* make decisions (and their preferences) matter (119-122). Economic models assume that both health and non-health benefits and burdens are relevant for resource allocation. Thus, spending on health and health care is not from a specific health budget but based on households'

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[10] Intergovernmental organizations (IGOs) such as the United Nations and the World Bank and Nongovernmental Organizations (NGOs) such as Medicines Sans Frontiers and Save the Children.

overall resources. *Unitary models* for intra-household resource allocation assume that a family makes decisions as one unit, whereas *non-unitary models* assume that family members bargain, and that the household's decisions are based on these negotiated matters. Within households, cooperative and conflicting interests might influence decision making (122). In some situations, family members may have similar interests in the outcome of a decision, such as getting clean water to the house, which can be considered as cooperative benefits. In other situations, family members may have conflicting interests, for example, if a decision to seek care for one household member implies that the rest of the family must work more to cover the costs of care[11].

Economists have explored how weighing concerns – or what we may interpret as prioritizing – might vary for different household members. Using empirical data from Ethiopia, Dercon described how an adult might get priority within a household, as his or her "utility," seen in terms of productivity and income, may be higher than, for example, a child.

> If resources are scarce and if returns to health vary by sex and age, we would expect households to allocate more health inputs to those members for whom the marginal product of health on income or wages is higher. This is the pure "life-boat" problem: poor households, who are liquidity-constrained, might, in the face of a shock to their incomes, be forced to allocate limited resources towards those members who are more productive or more likely to survive (88).

Two aspects have been described to influence decision making and outcomes: bargaining power and preferences. Bargaining power can be understood as the ability to realize one's own interests; it can be affected by factors such as financial resources or gender norms. Individuals' preferences may also shape intra-household decisions.

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[11] In this case, there might be additional cooperative benefits for all household members if the family member gets well, e.g. improved working capacity and income.

Given one's *time* preferences for current or future outcomes, one may be more, or less, willing to invest in a child's education or health care. Differences in *risk* preferences may make one more likely to assign higher or lower weight to an investment. *Gender* preferences have been described, and are seen in how boys often are valued over girls in Southeast Asia (123, 124). Intra-household bargaining power and preferences are again influenced by factors (122) such as social norms, values, and attitudes (125). Drawing upon her work on gender, Agarwal argues that bargaining frameworks should look at how extra-household factors influence bargaining power and how social norms and perceptions shape intra-household dynamics (125).

7.6.2.1 Health care decision making and intra-household resource allocation

The literature on priority setting in health has paid little attention to research on intra-household resource allocation and how preferences and bargaining power affect health. While empirical studies show that care-seeking for children with identified illness varies largely (126-129), we know less about families' priorities and decision making. The limited literature that looks at intra-household resource allocation in health indicates that preferences in care seeking differ by age (130, 131), sex (115, 123), and perceived risk (48). These studies indicate that micro-level decision making at the household level is of interest for priority setting in health.

7.7 Research gaps

Despite recent attention to priority setting and advances in deliberation (62), there is a need for more research. There are at least two research gaps to be highlighted. First, while discussions of fairness in priority setting often focus on theory or macro-level processes, the implementation of policies and plans occur at the micro-level. Few have studied implicit and explicit priority setting and rationing at lower levels (110, 116, 132-135). Second, priority-setting discussions have given emphasis to discussions of distributions of health and health care outcomes as from a separate sphere perspective. In many LMICs, health and welfare systems provide limited financial support, and patients face high OOP expenses when seeking health care. UHC and recognition of the interconnected relationship between health and welfare have brought attention to financial risk protection (1, 79) and trade-offs on the path to UHC (6, 136, 137). However, few have looked at how conflicting concerns about health and non-health benefits and burdens are balanced in real-life resource allocation. Confronted with these research gaps, I studied priority setting and intra-household resource allocation in newborn health in Ethiopia.

8 OBJECTIVES

8.1 Primary objective

The primary objective of this study was to describe and analyze real-life priorities and intra-household resource allocation for newborn health in Ethiopia.

8.2 Secondary objectives

The study focused on the following secondary objectives:

- To examine family-level decision making surrounding newborn illness and death in Ethiopia. The objective is explored in Paper I.
- To explore intra-household resource allocation, focusing on how families prioritize newborn health and household needs in Ethiopia. Furthermore, we seek to explore coping strategies families use to manage these priorities. The objectives are studied in Paper II.
- To outline ethical concerns and normative implications of limiting treatment for an ill newborn to protect against financial risk. The objective is addressed in Paper III.

9 METHODOLOGY AND METHODS

This thesis is situated in the intersection between real-life priorities of families facing newborn illness and discussions about fairness in priority setting. The objectives of describing and analyzing real-life priorities and intra-household resource allocation are both empirical and normative and require the use of different methods. While all studies are contributions to the field of priority setting, Papers I and II are mostly empirical, and the ethical analysis in Paper III draws upon both empirical and normative work. This is mirrored in the choice of methods. Where qualitative research is mainly a descriptive discipline, ethical analysis aims to be both descriptive and prescriptive. In this section, I first discuss some methodological aspects and underlying assumptions relevant to the methods employed (9.1). I then describe the study setting and the qualitative study upon which Papers I and II are based (9.2). Finally, I describe the ethical analysis (9.3).

9.1 Methodological perspectives and underlying assumptions

The field of ethics of priority setting differs in scope, content, methodologies, and underlying scientific assumptions. Interdisciplinary research, either through formal collaboration or informal discussions, may enhance our understandings by providing new perspectives. As research from different fields, and related methods, have weaknesses or "blind spots," inter- or cross-disciplinary approaches may improve our overall understanding of our research questions (138). Although the aim of improved knowledge is ambitious, differences in scientific views and traditions across disciplines also pose challenges. This can be exemplified by the discussion of whether qualitative and quantitative research are compatible when based on different theories of knowledge generation (139). Research traditions are embedded in our understandings about the generation of knowledge (epistemology) and reality (ontology) (140). Fundamentally, epistemology and ontology deal with what we as researchers can (and cannot) say something about and assumptions made when we conduct research. Our views on knowledge generation further influence our choices about empirical methods and theoretical inquiry. Foundational questions in priority setting about how resources are and ought to be distributed are inherently interplays between theory and practice. Many will agree that descriptive literature is relevant for the prescriptive strand, and vice versa (65). However, knowledge generation in empirical and normative research rely on different understandings of knowledge and methodologies. It is therefore essential to be clear about underlying assumptions when we draw conclusions based on different sources of knowledge.

9.1.1 Foundations of qualitative research

In presentations of the foundations of qualitative research, we often portray qualitative and quantitative assumptions. Historically, disciplines of public health and medicine have focused on quantifiable health outcomes. To put it in simple terms, one can depict quantitative research as "approaches to empirical inquiry that collect, analyze, and display data in numerical rather than narrative form" (141). Through quantification, using methods such as observational or experimental studies, one aims to test potential hypotheses or causal relationships. Quantitative research relies on the assumption that there are objective "truths" that we aim to observe, measure, quantify, summarize, and analyze (142).

With a different scope and approach, qualitative research aims to explore meanings and experiences, with emphasis on understanding social phenomena and views as experienced by people themselves in their own lives and contexts (140, 143-145). Green and Thorogood write that most people "are rational and sensible in the choices if we can understand the constraints they are under, what their priorities are, and what they are trying to achieve" (140). Where qualitative studies typically say something about the "'what', 'how' or 'why' of a phenomenon," quantitative studies measure "'how many' or 'how much' of these phenomena" (140). When quantitative research aims to reduce bias and the role of the researcher, a vital premise in qualitative research is that our preunderstandings *do* influence our work by shaping researchers' backgrounds, questions asked, in data collection, and interpretation (140, 145).

Research is understood as a social process, produced in the interaction between the researcher and the context.

9.1.2 Foundations of empirical ethics and ethical analysis

In using empirical data in ethics, researchers borrow tools and research designs from different fields. As noted earlier, our understandings and interpretations relate to underlying methodological assumptions in knowledge generation, and it seems relevant to discuss how these influence empirical ethics. One example is to clarify how empirical data are used. Is the aim to evaluate social practice, improve moral theory, or both (107)? While the move to empirical ethics in the literature may be well-intended, it can lead to unintended consequences if employed without paying attention to methodological foundations (105, 107). Dunn and Ives point at the inherent challenge that, depending on which methods we use, certain assumptions are made about what kind of knowledge we produce. They argue that a positivistic stand often has been taken: "…there appears to be a tendency in empirical bioethics to treat methodologies as pre-packaged tools that produce data for normative analysis, churning out moral 'facts' that exist 'out there'" (105). If empirical findings employing qualitative methods are presented as objective facts, they disregard the foundations of qualitative research. This discussion highlights that when research in priority setting makes use of methods developed in different epistemological traditions, further reflection is needed about how to employ these methods and how empirical-normative findings should be interpreted. These methodological questions deserve further scrutiny and debate but go beyond the scope of this thesis. In this PhD project, I have, in our empirical inquiry (Papers I and II) and normative analysis (Paper III), aimed to be transparent about the methods and underlying assumptions.

For analysis of ethical dilemmas, there is no agreed-upon method. Different approaches and methods have been suggested, and there are three main tiers: the deductive approach, which is more theory-focused (top-down), the inductive approach, which focuses on cases (bottom-up), and the approach that combines the two (146). The theoretical approaches suggest application of theories, principles, and rules to analyze concrete dilemmas. Case-based perspectives give emphasis to practical decision making and how dilemmas can be discussed based on context and circumstances, guided by other relevant cases. The combination approach draws upon both theoretical reasoning and information from cases as a middle alternative (65, 146). One of these middle approaches, reflective equilibrium, builds upon the idea that judgments from different levels are relevant for moral justification. Following Rawls' suggestion involves "working back and forth" among particular cases, judgments, and principles to seek coherence, and moral justification (68, 147). In this way, ethical analysis and reflection can be looked upon as a two-way street, one which sheds light on ethical theories and principles, and one on real-world cases. By seeing analysis of ethical dilemmas as a two-way street approach, rather than dichotomies of disciplines, we can look at practical ethics and ethical theory together (65).

9.1.3 Methodological assumptions underlying this thesis

By discussing methodological perspectives and underlying foundations of qualitative research and empirical ethics, I have aimed to highlight differences and assumptions that are relevant for the qualitative study and ethical analysis upon which this thesis is based. Our understanding of knowledge generation matters for our interpretation of research, and we should be transparent about assumptions made. The three papers in this thesis aim to contribute to the field of priority setting. Papers I and II are descriptive studies, where empirical findings relate to social sciences (Paper I) and health services literature (Paper II). Paper III is a normative analysis of an empirically identified ethical dilemma (in Papers I and II), and the discussion focuses on the normative literature on priority setting in health.

9.2 Qualitative study: Papers I and II

9.2.1 Study setting

9.2.1.1 Ethiopia

The empirical work for this thesis was carried out in Ethiopia, which has the second-largest population in Africa, close to 100 million people (20). Although classified as an LIC, it has seen rapid economic development the past decade, with growth in the gross domestic product (GDP) of 10% per year (20). Still, 34% of the population lives below the poverty line (< \$1.90 a day, 2011 purchasing power parity). Most people (80%) live in rural areas, and the adult literacy rate is 49% (20) (Table 9.A).

Table 9.A: Economic and social development in Ethiopia 2016[12] (20)

	Ethiopia	**World**
Annual gross domestic product (GDP) growth	10%	3%
Tax revenue (of GDP)	9%	13%
Population below the poverty line (<\$1.90 a day, 2011 purchasing power parity)	34%	13%
Rural population	80%	46%
Adult literacy rate (population >15 years)	49%	85%
Population with access to improved water source	57%	91%
Population with access to electricity	27%	85%

9.2.1.2 Newborn health in Ethiopia

Maternal, newborn, and child health has been prioritized in Ethiopian health policies of the last years; this has been followed by investments and scale up of health facilities nationwide and promotion of health extension workers (17, 148). The NMR declined slowly from 39 deaths/1,000 live births in 2005 to 37 deaths/1,000 live births in 2011, before it fell to 29 deaths/1,000 live births in 2016 (18, 25, 26) (Figure

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[12] Or other year with available data.

7.A).[13] Yet, the absolute number of newborn deaths remains high (61,600 deaths in 2015) (4).

The goal of the National Newborn and Child Survival Strategy (2015) is to reduce U5MR from 64 to 29 deaths per 1,000 live births, and NMR from 28 to 11 deaths per 1,000 live births between 2013 and 2020. Through the implementation of key interventions, this strategy is estimated to avert 415,700 and 210,200 under-5 and newborn deaths, respectively (149). Priority to neonatal health and reductions in NMR is promising, but the use of health care services remains low for newborns. Not more than 26% of women deliver by skilled birth attendants, and only 17% receive postnatal checkups, with sizeable intra-country variation (Table 9.B) (18). Low coverage on care around birth may indicate that decisions made outside health facilities are of particular importance for newborns.

Table 9.B: Use of newborn health care services

Background characteristics	**Delivery in a health facility (%)**	**Postnatal checkup in the first two days after birth (%)**
National average	26	17
Average by wealth quintile		
Highest quintile	65	41
Lowest quintile	12	9
Average by residence		
Urban	79	45
Rural	19	13
Average by mother's education		
Mother more than secondary education	92	54
Mother no education	16	9

Data from Ethiopian Demographic and Health Survey 2016 (18), Table from Paper II.

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[13] This study was planned in 2014, where NMR was 37 deaths per 1,000 live births (EDHS 2011).

9.2.1.3 Health care financing in Ethiopia

National health expenditure in Ethiopia was 26.5 billion Ethiopian Birr (ETB) (US $1.6 billion) in 2010/2011 (16). Significant sources of financing were donors (50%), households (34%), and the government (16%) (16). Health care expenditure per GDP increased from 2.8% in 1995 to 4.7% in 2013, which is lower than average in sub-Saharan Africa (5.5%) and the world (7.1%) (83). The total amount of health spending per capita is low (US $27). This is substantially less than the $86 recommended to promote access to primary care in LICs (150), or the projected $112 per person needed in LICs to meet the health-related SDGs (151). Improved health system infrastructure, education of health workers, and other investments have improved the availability of services, but patients still pay the more substantial part of the bill when seeking health care. The total health care expenditure covered by households (34%) is higher than in sub-Saharan Africa (31%) and the world (21%) (16, 83). Only 5% of the population is covered by health insurance (18), and the National Health Accounts revealed that households cover 48% of child health expenditures (16). While there are no studies of OOP payments for newborn health in Ethiopia, findings from other settings indicate that costs are high, particularly for inpatient services (152, 153).

9.2.2 Study design

We wished to study intra-household resource allocation and micro-level decision making and chose a qualitative study design. Qualitative research is suited to understanding experiences, perceptions, norms, and concepts and how they relate to local cultural and structural contexts (140, 144). Using an explorative approach without a specific hypothesis or theory, a qualitative study was conducted (154, 155).

9.2.2.1 Study area

The fieldwork of this study was conducted in the semi-urban town of Butajira and surrounding rural areas in October and November 2015. Butajira is located 130 km south of Addis Ababa, in the Gurage zone in Southern Nations, Nationalities, and People’s Region (SNNPR). Skilled delivery and postnatal checkups in SNNRP (26% and 17%) is similar to national coverage and makes it a relevant study area (18, 25).

Data were gathered using information about demographics and vital events from the Butajira health and demographic surveillance system (HDSS) platform known as the Butajira Rural Health Program (BRHP). Nine rural and one urban *kebeles* (villages) are part of the BRHP, which are located in three different districts (Meskan, Mareko, Silte) and the administrative town of Butajira. The study region includes kebeles from highland, midland, and lowland areas. BHRP has monitored and collected data on demographics and vital events since 1987 (156, 157). The BRHP population increased from 28,500 to 78,900 between 1987 and 2017. The average household size in the area is 5.2, and the majority of the population are farmers (158). The year the study was conducted (2015), a drought caused by El Niño contributed to a poor harvest. The formal education level is low; poverty is rampant, and food shortages are frequent (156-158). The majority of the population are Muslims or Orthodox Christians (159).

Studies from Butajira have found that child deaths are common (158, 160). Four of ten women have experienced the loss of a child (158). There was no significant decline in NMR between 1988 and 2008 in the catchment area of BHRP (160). The study showed that male sex, distance to hospital, being born to a mother who had no oxen and lived in a thatched house were associated with increased risk of newborn death (160). Though we do not have data on NMR trends in Butajira after 2008, national NMR has declined, and we might expect similar trends in Butajira (18).

Participants were recruited from the catchment area of BHRP, and two hospitals (one public and one private) and affiliated health centers in Butajira. The public hospital is a general hospital serving between 1 and 1.5 million people. At the time of the study, there was a pediatric unit with about 50 beds, and a neonatal unit with ten beds that offered essential treatment for infections, neonatal icterus, and prematurity, in which they used heat and simple incubators. There were one to two doctors in the pediatric unit during the day, but there was not a pediatrician in town. The hospital was open every day, but with limited services during evenings and weekends. The hospital, health centers, and pharmacy often experienced shortages of drug supplies or equipment. For referrals, the families were advised to seek care at tertiary hospitals in Addis Ababa.

9.2.3 Data collection and participant recruitment

The data were collected in Butajira and surrounding kebeles. A combination of 41 semi-structured, in-depth interviews (IDIs), seven focus group discussions (FGDs), and observations in the hospital were used for method-triangulation.

9.2.3.1 Interviews and focus group discussions

Qualitative interviews are suited to explore meanings and perceptions (161). Through IDIs and FGDs, we aimed to gain an in-depth and comprehensive understanding of individuals' experiences and community norms and practices related to ill newborns.

Prior to data collection, semi-structured interview guides and topic guides were prepared for each group of participants. Guides focused on participants' stories and their experiences and perceptions around the research objectives. Particular attention was paid to three main themes: health care seeking and decision making for ill newborns, costs of services, and whether the newborn should receive priority. The topic guides developed for the FGDs put particular emphasis on community views, values, and norms. The guides were developed in collaboration with a team with experience in qualitative research and who had conducted studies in the area earlier. The guides were revised and further developed during fieldwork based on impressions and insights from data collection. The IDIs and FGDs lasted for 25-75 minutes and 80-140 minutes, respectively.

The participants were recruited through purposive sampling. To understand decision making and intra-household resource allocation from different angles, we identified four groups of participants:

1. Family members experiencing newborn illness
2. Family members experiencing newborn death
3. Health workers involved in newborn health care delivery
4. Community members

Together with the co-researcher (CR), I identified the family members and health workers, while field workers in the BHRP assisted in the recruitment of community members. Table 9.C displays details about the participants and the recruitment strategy.

Table 9.C: Participants in in-depth interviews and focus group discussions

Type of participants	**Recruitment of participants**
In-depth interviews (IDIs)	
*Mothers or primary caretakers of ill newborns** - 11 IDIs at hospital during illness - 9 Follow-up interviews	Families with ill newborns admitted to hospital > one day, recruited by primary investigator (PI)/co-researcher (CR)
*Mothers or primary caretakers facing newborn death** (during past year) - 5 Urban IDIs - 5 Rural IDIs	Families who experienced newborn death, recruited through Butajira Rural Health Program (BHRP)
1 key informant from health bureau	From health bureau
Health workers involved in newborn health care - 3 IDIs with medical doctors - 7 IDIs with nurses and midwives	From hospitals and health centers, recruited by PI/CR
Focus group discussions (4-8 participants)	
Nurses and midwives (urban) Health extension workers (rural and urban)	Nurses and midwives from hospital and health centers, HEWs from kebeles. Recruited through BHRP
Community members	
Women of reproductive age with child <1 year (urban) Women of reproductive age with child <1 year (rural) Husband with wife of reproductive age with child <1 year (rural) Grandmothers (rural) Religious leaders and elders (urban)	From communities in three selected kebeles, recruited through BHRP

Table adapted from Papers I and II.

Family members experiencing newborn illness

Cases of ill newborns were identified through purposive sampling at the neonatal unit at the hospital. Mothers or primary caretakers of ill newborns admitted were invited to take part of the study. Neonatal illness was understood as ill health starting in the first 28 days of life. Newborns could be identified as ill at birth, in the postnatal period, or as newborns at risk (including, but not limited to, low birth weight, asphyxia, prematurity, intrapartum-related complications, sepsis, meningitis, other infections, malformations, and newborns with disabilities). Based on family members’ preferences, two parents were present in some interviews. The family members were invited to take part in a follow-up interview. If they accepted and we would be able to contact them (nine of eleven), we received their contact information and visited them after one to four weeks. The second interview focused on the baby's illness and consequences of health care seeking, with particular attention to costs and experiences at the hospital. The first interview took place in a separate room at the hospital, while the follow-up interview took place close to or in the family member's home.

Family members experiencing newborn death

With assistance from BRHP field workers, we identified rural and urban households that had experienced newborn deaths in the past year. Using this information, we visited these families, provided information about the study, and invited the mother and/or primary caretaker of the deceased newborn to take part in the study. A newborn death was understood as death occurring after illness starting during the first 28 days of life[14]. The interviews took place in the family member's home.

Health workers

Together with the CR, I identified health care workers (medical doctors, midwives, nurses) at the hospitals or health centers with delegated responsibility in the treatment of sick neonates to take part in the study. BRHP field workers assisted in the recruitment of health extension workers from selected BRHP kebeles. IDIs took place in a separate room at the participants' workplace, and FGDs were done at the BHRP site.

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[14] One death occurred later, but was included as illness started < 28 days and to ensure a heterogeneous sample.

Community members

Community members' views were relevant to understand local norms and practices. Participants were identified with help from BRHP field workers, and community members were invited to participate in five FGDs:

1. Mothers in reproductive age (rural),
2. Mothers in reproductive age (urban),
3. Fathers (rural),
4. Grandmothers (rural), and
5. Religious leaders and elderly (urban).

The FGDs were conducted outdoors, either at the BHRP site or in a chosen location close to the participants' homes.

The IDIs and FGDs were conducted in collaboration with the CR. His mother tongue is Amharic, and he had taken part in earlier studies in the area. Two IDIs were conducted in English, while the remaining IDIs and FGDs were conducted using translation (Amharic-English, English-Amharic). The IDIs and FGDs were generally audio-recorded. Interviews were transcribed verbatim, and the Amharic transcripts were translated into English by trained research assistants. As I do not speak Amharic, random checks were done by Ethiopian colleagues. When (three) participants did not wish to audio-record their participation, I took notes, with permission from the participants.

9.2.3.2 Observation

Observation is used as a separate or additional source of information and can be useful for the study of interaction in everyday life and practice, and informal and formal behavior (162). As a foreigner to the context, the observation was intended to strengthen my understanding of the setting. Furthermore, observation made it possible to study actual behavior as well as interaction between family members and health care workers. These impressions indirectly informed questions asked in subsequent IDIs, FGDs, and observation. As the primary investigator, I systematically observed daily activities in the pediatric and neonatal unit at the hospital and spent time at the maternity and labor ward (about four weeks). I followed rounds and engaged in informal conversation and unstructured interviews with health care workers. IDIs with family members experiencing newborn death and follow-up interviews were conducted in or close to the participants' homes, which gave room for observation of the families' socio-economic situation as well as household composition and dynamics.

Field notes were taken every day, and impressions from interviews and observation were discussed in detail with the CR. Data collection ended when new aspects with regards to the study objectives no longer emerged. While there would always be new participants and stories, our main themes were considered saturated (163).

9.2.4 Data analysis

The data were examined drawing upon qualitative content analysis (164). The analysis was ongoing throughout fieldwork and writing up results. Preliminary topics were identified and discussed during data collection and were given attention in following interviews and observations.

After the fieldwork, the collected data material was analyzed systematically, involving the following stages: After discussion of preliminary topics with the team of researchers, I read all the data material (transcripts and field notes) in depth, giving emphasis to latent and manifest meanings of the material. We identified main themes and categories with a focus on units of meaning and coded the data material, such as "selling or borrowing to pay for care" or "funeral rituals". I used NVivo 11 software to organize the data (http://www.qsrinternational.com). The coded material was then grouped, and the content was condensed. Not all coded data material is presented in this thesis, as I focused on two themes that were of particular relevance to the objectives of the study: health care decision making for ill newborns (Paper I) and the role of costs of seeking health care (Paper II). Last, we synthesized the contents of coded groups, and re-read the data material. The findings from the analysis are presented in Papers I and II.

9.2.5 Local dissemination of research and validation

In preparation for the study, we planned to disseminate the results to study participants and local stakeholders. Local dissemination is important because it enables dialogue between study participants, local stakeholders, and researchers on the validity and relevance of our findings. It was important to present our results to members of the study population, who rarely read peer-reviewed publications. The main results were discussed as a part of the 30-year anniversary of the BHRP in April 2017. Participants included community members, implementers, policymakers, and researchers[15], in total about 180 people. In discussions of the findings, they emphasized current efforts to address newborn mortality, such as health insurance schemes and health extension workers. Questions were raised regarding generalizability and triangulation, where we explained our data and method triangulation, as well as similarity with findings from previous studies (46).

9.2.6 Ethical considerations

The study received ethical approval from the Institutional Review Board, University College of Health Sciences, Addis Ababa University, Ethiopia and Regional Ethical Committee, Helse Bergen, Norway.

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[15] Participants included religious leaders and community members (kebele leaders), health extension workers, representatives from regional health bureau, and zonal, district, and kebele health offices, and representatives from Addis Ababa University, Ethiopian Indepth networks, Ethiopian HDSS network heads, Ministry of Health; Ethiopian Public Health Institute.

Before commencing any IDI or FGD, potential participants were informed verbally about the study, the opportunity to participate, that participation was voluntary, that their responses would be made anonymous, and then invited to participate in the study. Two letters of consent (one for the study, one for the participant) were marked by the primary investigator and each participant by written consent or fingerprint. Participants were informed that they could withdraw from the study at any point. Contact details were provided in the letter of consent if they should wish to withdraw. To ensure confidentiality, interviews and FGDs took place in a private location at a time aimed to be convenient for the participants. Despite our efforts, level of trust and confidence varied among participants. Local health workers' and officials' efforts to promote institutional delivery became evident in many interviews. We repeatedly explained that we did report to government offices if a baby had not been born at a health facility, nor did we evaluate the quality of services. Yet, we cannot rule out that participants did not feel they could speak honestly. We did not know the participants, and although IDIs and FGDs were conducted in locations that aimed to ensure confidentiality, participants may have felt threatened. In the follow-up interviews, we found that participants talked about difficulties faced while being admitted more openly than in our initial interviews, which took place at the hospital.

In the reporting of the study, no identifiers are revealed. The informed consent forms are kept separately from transcripts and in a locked place and will be destroyed when articles are published. The transcripts are saved without any identifiable information. The analysis was done on a password-protected computer.

We paid attention to the wellbeing of the newborn and mother or other family members throughout the data collection. We did not discover any mother in need of physical or mental health care. In one of the follow-up interviews, we recommended the parents to seek health care for the ill baby and covered the family's costs of transportation and fees for services, as they explained that they could not afford to seek care.

All participants received 100 birr (5 USD) to compensate for the time lost and/or to cover transportation costs. This level of compensation has been given to participants in other studies that have taken place in the BHRP area (165).

9.3 Ethical analysis: Paper III

We wished to analyze the ethical dilemma between financial risk protection and newborn health benefits identified in Papers I and II. Evaluation and analysis of empirical cases can help describe and analyze ethical issues at stake (107). Empirical ethics is relevant in the evaluation of social practice to improve clinical practice and develop moral theory and may increase our understanding of how values[16] – indirectly and directly – influence health care and daily practices (104, 107).

9.3.1 A seven-step ethical case analysis

Real-life ethical dilemmas take place in everyday life, where decisions influence lives of patients and other affected parties. An ethical analysis can be used as a structured way to analyze an identified ethical dilemma. While the given setting and content of an analyzed situation will be context-specific, systematic approaches may highlight ethical issues relevant beyond the particular case, such as conflicts between interests or ethical principles.

While applying principles or relying on cases is useful (146), we found the theoretical and principal approaches too narrow. Direct application of the ethical principles to the identified case (the conflict between financial risk protection and newborn health benefits) seemed distant from the real-life dilemma described in Papers I and II. Also, looking at the case itself and other relevant cases did not provide proper guidance on how to resolve the dilemma at stake. We, therefore, chose a middle alternative and emphasis on the ethical dilemma identified. We wished to analyze the ethical

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[16] These values influence norms and further play out in laws, guidelines, and institutional organizations.

dilemma systematically, to look at outcomes of alternatives and affected stakeholders, and clarify how it related to relevant principles. To do so, we wished to analyze the identified dilemma drawing upon strengths from both top-down and bottom-up approaches.

We chose a stepwise model for ethical case analysis, building upon Kymlicka's ethical case analysis (114, 132, 166, 167). We employed the seven-step analysis developed by Miljeteig et al. that has been used by clinical ethics committees in hospitals in Norway and in academic work (114, 132, 168) (Box 9.A). The seven-step analysis relies upon systematic evaluation of an identified ethical dilemma and is used a tool for a more transparent, explicit, and less-partial analysis. It is particularly suited for priority-setting dilemmas, with emphasis on interests at stake and outcomes for the affected stakeholders. Analysis is based on sufficient relevant information being gathered, and the fact that systematic evaluation and clarification of trade-offs can guide a discussion about what is at stake, which can illuminate acceptable solutions or options.

Box 9.A: A seven-step ethical analysis (114)

Gather information. If insufficient, ask for more.
Step I: What is the ethical dilemma and alternative actions?
Step II: What do we know about the outcomes of alternatives?
Step III: What laws, rules, or guidelines regulate the decision?
Step IV: Who are involved stakeholders?
Step V: What are the stakeholders' potential burdens or benefits?
Step VI: What and whose interests may be in conflict?
Step VII: What are the values and principles at stake?
Discuss what is most important in the case, clarify trade-offs, and suggest acceptable solutions.

Box from Paper III.

In Paper III, we wished to analyze the dilemma between concerns for newborn health and family welfare identified in Papers I and II. Drawing upon our empirical findings from Paper I and II, we used a stylized and anonymized case to illustrate the dilemma between financial risk and newborn health benefits (Box 9.B). My initial discovery of gaps between theoretical discussions and real-life priorities made it pertinent to focus on an empirically derived dilemma and a case similar to what families and health workers experience in their everyday lives. We explicitly chose to focus on the health-welfare dilemma, though there were other ethical issues present.

Box 9.B: Summary of case: An ill newborn in a poor family in rural Ethiopia

A two-day-old newborn is brought to a health center, as she has still not taken the breast. The health worker suspects neonatal sepsis, a severe condition that requires treatment and referral to the hospital. The father is in distress about high hospital costs. “We cannot afford. If I sell our seeds to pay for treatment, how will I get food for her brothers and sister?” The health worker is afraid the baby will die if not taken to the hospital. She asks herself, “Should I convince them to go? Will I force them into economic ruin?”

Text in box adapted from Paper III.

In our analysis, we framed the ethical dilemma as follows: Is it ethically acceptable to limit treatment[17] for the ill newborn to protect the family against financial risk? (Step 1). We gathered empirical evidence on consequences for prognosis, costs, and financial burden if limiting treatment (Step 2), and on the rules and regulations involved (Step 3). Further, we identified affected parties and their perceived burdens and benefits (Steps 4 and 5). We discussed what and whose interests and which ethical principles were at stake (Steps 6 and 7). In our discussion of relevant principles (169), we used the WHO framework, Making fair choices on the path to universal health coverage. The framed the discussion with regards to the substantive criteria: health maximization, priority to the worse-off, and financial risk protection (6) (Box 7.A). While other frameworks or criteria would have been of interest, this framework explicitly considers financial risk protection, which was central in the decision making of families and health workers and at the core of the analyzed dilemma.

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[17] Limiting treatment was understood as not receiving recommended antibiotics and supportive treatment at the referral hospital.

10 RESULTS

10.1 Synopsis of Paper I

Newborn illness and deaths were common events in Butajira, and health care seeking was delayed. This study showed how health care decision making for ill newborns was shaped by local understandings, which were contingent on the structural conditions that form preferences and choices made at the household level. This study illustrated a mismatch between families' priorities when newborns fell ill and attention to newborns in medical literature and health policies. Though ill newborns were known to be at risk, families waited before seeking health care. When newborns fell sick, discussions within the family centered around the newborn's need for care, perceived benefits and burdens of seeking health care, and concerns for other needs of the family. Care-seeking could be delayed, and mothers were told that they could take the baby to the hospital later. The newborn's survival was uncertain, and costs for health care services put the whole family at risk. Where older children and adults were perceived as necessary for the survival of the household, newborns were not yet seen as useful to the family. The social recognition of a baby evolved gradually during the time after birth. Whereas many people gathered to express sorrow and respect after an older person died, newborn deaths were surrounded by silence, and public expression of mourning was not expected. While mothers grieved privately after losing a newborn, they were told to move on, and that the baby could be replaced by a new child within nine months. These local understandings were also visible in different burial rituals and support from *iddirs* (traditional financial associations), where limited financial and social support were provided after newborn deaths.

10.2 Synopsis of Paper II

While improving neonatal health is prioritized in policies and planning in Ethiopia, this study highlighted how health care seeking for newborns is closely tied to the family's economic situation. Expenses related to health care seeking were funded mainly by OOP payments. With limited money at hand and high direct health care costs, families balanced conflicting concerns for newborn health and the welfare of the family, particularly in poor households. High costs for drugs, equipment, admission, and other services led families to difficult choices (Figure 10.A). First, should they seek care? Second, should they spend their limited resources? Third, should they follow medical advice?

Figure 10.A: Family health care decision making for a sick newborn

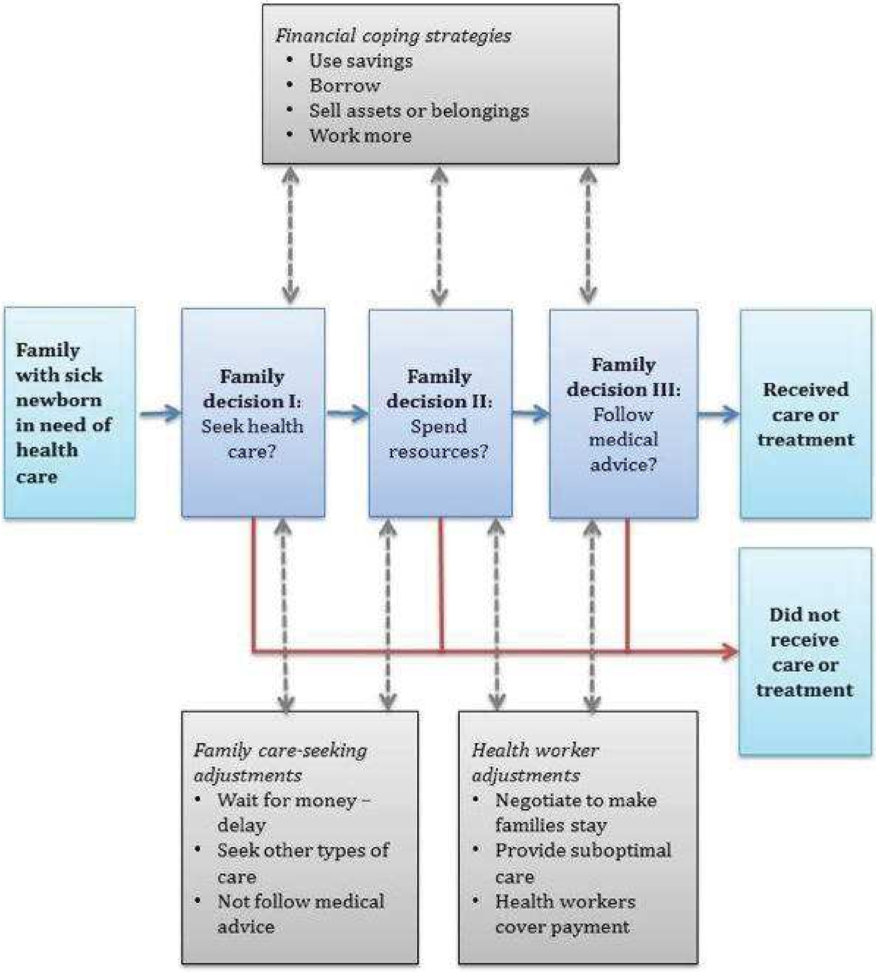

Figure from Paper II.

Consequences of health care decision making could be harmful to the ill newborn or family welfare when acting to answer these questions. If the baby did not get treatment, the baby could get worse or even die. If the baby received treatment, the family's economic situation was often in danger. In managing these choices, households made use of different financial coping strategies such as working more, borrowing, and selling their assets. However, poor families could not rely on the same coping strategies. They did not have anything to sell and could not depend on borrowing from others, and, in turn, families adjusted their care-seeking strategies. They delayed going to the health center or hospital when waiting for money, or preferred traditional medicines or other less-costly options, with dangerous and even deadly consequences for the ill newborns. Health workers made adjustments to influence the families' decisions and care-seeking strategies by negotiation to convince families to stay, or by covering payments themselves.

10.3 Synopsis of Paper III

Based on our finding of the dilemma between concerns for newborn health and family welfare, we examined a stylized real-life dilemma of an ill newborn in a poor family in rural Ethiopia. We outlined ethical concerns and normative implications of limiting treatment for an ill baby to protect against financial risk. The micro-level case was discussed with reference to the WHO criteria for priority setting (health maximization, priority to the worse-off, financial risk protection) (6).

In our seven-step analysis, we first assessed the available information on potential health outcomes and consequences for costs and financial burden. We examined relevant laws and regulations, affected parties, and burdens and benefits to these stakeholders. We then evaluated interests and principles in conflict when one cannot both improve health and protect against financial risk. Concerns for health maximization and that the newborn is worst-off from a lifetime health perspective may indicate that limiting treatment is not acceptable. Conversely, concerns for financial risk protection will give weight to avoiding high costs to protect the household's welfare. One may then accept that newborn health will be compromised. While limiting treatment can improve the family's financial well-being, sizeable potential health gains for the newborn – who is worst off – are foregone. In an all-things-considered judgment, we lean towards it not being acceptable to restrict treatment.

While the ethical analysis highlighted that both options could be perceived as acceptable, we argue that both alternatives are unacceptable and unfair. There is reason to believe that the most affected parties (the newborn, the family members, and the health worker) would value treating the newborn while avoiding financial ruin. However, they do not have the opportunity to do so. The analyzed dilemma occurs under unjust circumstances but could have been avoided. Newborn health care services are cost-effective and target patients that are worst-off in terms of lifetime health gains. When paying OOP, lower-level decision makers are left to choose between health benefits and financial risk. We claim that we cannot accept the ethical dilemma and its premises, as we then accept deprivations of people's basic capabilities and substantive freedoms.

11 DISCUSSION

In this section, I discuss major findings (11.1) and methodological issues related to the qualitative study and ethical analysis (11.2).

11.1 Discussion of major findings

In this thesis, I have attempted to provide new empirical knowledge on real-life priorities for newborn health in Ethiopia and to discuss normative issues related to these findings. With an emphasis on our most important results, I discuss mismatches between local realities and global and national policy attention and links between our findings and literature on adaptive preferences.

11.1.1 Global and local: Diverging understandings and priorities for newborn health

Paper I described how health care decision making for newborns was influenced by local socio-cultural perceptions and structural factors that delayed health care seeking. In Paper II, we reported that health care was known to be costly, and families' choices centered around concerns for the newborn versus other household needs. While health policies and literature have given attention to newborn health, these do not always resonate with the local realities in which micro-level decision making occurs. Using relevant literature, I reflect upon mismatches between local and global understandings and priorities and how these are relevant for efforts to improve newborn health.

To simplify, I argue that health goals and policies present newborn mortality as an avoidable problem, where newborn deaths are conceptualized as lives that can and should be saved through medical intervention. An illustrative example can be SDG Target 3.2.2. that aims to "end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births [by 2030].” The ambitious global strategy for women’s, children’s and adolescents’ health (2016–2030) (10) is “a roadmap for ending preventable deaths of women, children [including newborns] and adolescents by 2030… helping them achieve their potential for and rights to health and well-being in all settings.” The MDGs and SDGs, global actors, and newborn networks play important roles in agenda-setting and norm-setting, which influence financial resources and national strategies. These initiatives have highlighted intrinsic and instrumental reasons to support newborn health and tools in which this can be achieved. Emphasis has been given to newborns’ potential, the right to health, and newborn deaths as preventable tragedies: events that can be avoided by scaling up and investing in health care services (1, 3, 11, 170). At the national level, the Ethiopian newborn and child survival strategy document (2015-20) presents key steps to reduce NMR from 28 to 11 deaths per 1,000 live births (149). Though the strategy notes that the Federal Ministry of Health “will work with regional governments and health bureaus to scale up the Community Based and Social Health Insurance schemes,” financing is not among the ten guiding principles of the strategy, and OOP expenses or private health expenditures are not mentioned (149).

The understanding of newborn deaths as preventable events outlined in these strategies contrasts our findings from Butajira, where newborn illness and death were seen as part of life. Though a mother may have grieved in private when her newborn died, community perceptions and practices did not consider the newborn as a person yet, and emotional experiences of sorrow were not to be expressed. The status of the newborn was ambiguous; health care seeking was risky, and in sayings and practices, the newborns were not yet acculturated into the community. From the initial question of whether newborns were prioritized, we conclude that community perceptions and norms did not give priority to ill newborns. High costs and concerns for household needs further delayed care-seeking, in particular in poor families living on the margin.

Our findings are discussed in light of anthropological studies on how health care seeking and decision making are shaped by local cultural ideas embedded in social and economic resource constraints. Earlier studies from poverty-affected settings have described how care-seeking for ill children may put the family's and household's survival at risk (48, 171). In her study from Brazil, Scheper-Hughes discussed how shared experiences of common infant deaths and known vulnerability of infants made mothers detach from very ill babies and show little grief when they died (43). However, her thesis on the selective neglect of weak infants has been questioned (44, 45). Findings from Ethiopia, South Africa, and Tanzania describe a private but often hidden grief among mothers facing early child death (46, 47, 172). This is in line with studies on how emotional experiences of sorrow may differ from social practices and responses (42). Jewkes and Wood outlined how personhood was understood as a process, gradually developed as children became parts of families and communities in South Africa (47). As seen in a study on stillbirth and newborn deaths in the Amhara and Oromiya region in Ethiopia, newborn deaths were surrounded by silence (46), and the newborn was unknown to the community in Butajira. After surviving the first vulnerable period, newborns were introduced to others and took part in regular routines and practices. This understanding of personhood as a social process departs from the newborn health literature, where a newborn is seen as a person at birth.

While child, infant, and newborn death have long been common events (19), the progress and attention regarding child and newborn mortality is a recent phenomenon. Our findings illustrate that the attention to ill newborn and children as a priority in policies and literature does not necessarily resonate with household priorities. The burden of newborn mortality is highest in LMICs, and coverage is lowest in poorer parts of the population (5, 173). While the potential for life-saving interventions presents promising options in these settings, divergences between global and local priorities may require further scrutiny. In real life, decisions regarding health care seeking are made in families living in poverty, where the newborns' needs are balanced against other priorities. A study conducted after a health crisis in Niger described how health care seeking posed a risk for the whole family and how malnourished children became “victims of non-discrimination” when families did not give priority to the ill child over the other children in the family (48). The families’ choices in rural Niger contrasted with international and humanitarian efforts that focused on the malnourished children and saving individual lives (48). The authors noted a mismatch of worldviews between the humanitarian initiatives’ emphasis on immediate health improvements and the poverty-affected realities of families where care-seeking puts the household at risk (48). Along this line, biomedical approaches to improve global health have been criticized for their focus on evidence-based policies and technical interventions, which might overlook underlying vulnerabilities of those suffering from poor health (174).

A study of a World Bank nutrition project in India is relevant for our discussion on care seeking (175). The project aimed to promote behavioral change among mothers to improve the children’s nutrition. However, as Sridhar notes, the project was based upon some underlying assumptions that can be questioned:

> The first [assumption] is that inappropriate caring practices are a major cause of malnutrition. The second is that inappropriate caring practices are due to carers’ knowledge, attitudes, and practices. The third is that households have the capacity to change their behavior. The fourth assumption is that women are the household decision makers (175).

As Sridhar explains, malnutrition was understood as a product of “culture and behavior.” Efforts to combat malnutrition centered on overcoming women’s attitudinal barriers and ignorance. Contrasting these explanations, interviews with community members revealed that poverty, women’s limited decision-making power, and alcoholism caused malnutrition, not women’s lack of knowledge or care for children. The study showed how institutional norms and perceptions in the World Bank shaped the team’s understanding of hunger and nutrition, where malnutrition was seen as cultural and attitudinal problems with less attention to broader determinants (175).

Even though care seeking for children varies largely within studies and between countries (126, 127), I argue that it is often assumed that primary caretakers will seek care if there is an identified need, and she (or rarely, he) has bargaining power and resources to do so. By relying on primary caretakers – often mothers – as decision makers, health plans, and programs do not acknowledge the context in which health care decision making occurs. Our study showed that it was common, despite recognition of signs of illness, to wait before seeking health care. Primary caretakers were told to wait, and mothers rarely had money at hand. In policies, but also many community-based health care models, it is often assumed that a caretaker will seek care as long as she (he) has enough knowledge. These approaches do not address how gendered decision-making power, competing intra-household priorities, or underlying causes of poverty affect caretakers' real opportunities to seek care (176, 177).

This discussion has focused on contrasts between global plans and local realities and limitations of the biomedical presentation of newborn health. However, some of benefits of global and national attention to newborn health should be noted. Knowledge from the medical and public health fields has provided an evidence-based informed platform to improve newborn survival. This is relevant for the work of intergovernmental organizations, national governments, as well as non-governmental organizations. Scientific findings and normative framing of newborn health as an important area may have been instrumental in drawing attention to the issue and in promoting accountability (35, 36). The Every newborn action plan report 2017 describes progress on newborn health where countries with high burdens of neonatal deaths have set national targets, made national plans for newborn health and educated more health workers (11). Global and policy attention to newborn health also provides resources for scaling up newborn health care services. Still, our findings demonstrate that the presentation of newborn deaths as avoidable events may not always be practical, as it did not resonate with the families' real opportunities to seek health care in Butajira. In order to make it possible to seek health care, affordability of services is critical. Unless global and national stakeholders take local understandings, priorities, and lived realities seriously (178) and address underlying structural factors, it seems difficult to meet the goals of improving newborn health and UHC.

11.1.2 Empirical and normative interlinkages: Reflections on adaptive preferences

Our empirical studies describe delays in care-seeking for ill newborns. The newborn's interests competed against needs of the whole family, and the ill newborn could not always be the priority. These empirical findings contrast arguments for giving priority to newborn health. Ill newborns can be seen as worst-off from a lifetime health perspective[18] (priority to the worse off). Newborn health care interventions are cost-effective (health maximization) (3, 179), and families' financial burdens can be eased (financial risk protection) (152, 153, 180). This mismatch in priorities not only gives attention to diverging global-local understandings; it raises the normative question about whether to "accept" people's preferences and that local priorities may diverge from global priorities. In this section, I reflect upon the topic more generally and link these questions to our empirical findings (Papers I and II) and normative discussion (Paper III).

Should we accept that ill newborns are not given priority and accept the trade-off between newborn health and financial risk? One view argues that we should accept local values, norms, and perceptions and that moral truths and judgments will differ in different cultures and societies (181). A contrasting view claims that there are universal and cross-cultural values and that defining and understanding these values provides a basis for criticizing moral traditions of different societies (181). Nussbaum argues for certain universal norms of human capability but acknowledges that values and practices may differ with cultural diversity (182). As discussed earlier, we hold that decision making and care seeking for newborns were embedded in cultural

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[18] A newborn that dies prematurely suffers the largest individual lifetime health loss (DALYs lost).

perceptions and practices, and that people's opportunities to make choices were shaped by circumstances. I reflect upon what philosophers have called the problem of adaptive preferences, which is relevant for how we look upon – and accept – perceptions, practices, and preferences about care seeking for ill newborns in Butajira.

The literature on adaptive preferences discusses how people's preferences and desires may change based on the choices that are available to them (183, 184). Nussbaum writes, "people adjust their aspirations to what they actually can achieve" (183). In her work on women's empowerment in India, she discusses how women's aspirations in their everyday lives are shaped in response to the circumstances they live in "rather than the result of deliberate character formation" (183). These preferences are formed as adaptations to difficult or unfavorable circumstances – such as when poor people come to accept living in deprivation – and philosophers have argued that adaptive preferences should not have the same standing as preferences developed under what we may call just conditions (183, 184). Sen described how deprived people might come to accept what others might consider unfair:

> The most blatant forms of inequalities and exploitation survive in the world through making allies out of the deprived and exploited. The underdog learns to bear the burden so well that she overlooks the burden itself. Discontent is replaced by acceptance, hopeless rebellion by conformist quiet, and... suffering and anger by cheerful endurance (184).

Sen's capabilities approach was in part a response to the problem of adaptive preferences, where he has given emphasis to people's actual freedoms to live the kind of lives they "have reason to value," thereby going beyond what they do value (70).

Discussions about adaptive preferences are relevant for our empirical findings from Butajira and normative discussions of these. Should we accept the perception that newborns are not considered persons yet? Should we accept that some newborns will not survive? Should we accept that the interests of the ill newborn are traded against the needs of the family? A relativistic moral standpoint may argue for accepting these perceptions and practices (181). In our papers, we discuss how decision making delayed care-seeking and how families' choices were shaped by shared experiences of poor newborn health and costly and unavailable health care services[19]. From an impoverished context, the strategy "wait and see" can be seen as an adaptation to their (lack of) opportunities to seek health care. Understanding newborn deaths as the will of God can be interpreted as an expression of how people had come to accept that some newborns would not survive.

In our study, perceptions and norms related to the status of newborns and delays in health care-seeking are understood to depend on families' (limited) opportunities to seek care. In Paper I, we argued that structural barriers are internalized in families' everyday reasoning, which can be seen as adapting to resource constraints. This relates to Nussbaum's reflections of how circumstances influence not only people's available options but also their beliefs and preferences (185). Further, the underfunded health care system and lack of health insurance limit families' actual opportunities to seek health care, which we have argued that they would have reason to value (70). Interestingly, people's preferences are not fixed but are being molded and modified. Recent developments such as health extension workers and access to information about newborn health care services may contribute to re-shaping perceptions and practices. Participants residing in urban areas brought up the benefits of hospital care, and in wealthy families, it was perceived useful to seek health care for ill newborns.

This section has highlighted how underlying deprivations inform and shape perceptions, practices, and preferences and should be taken into account when discussing our empirical findings. The normative questions also links to anthropological writings. In her study on the selective neglect of vulnerable infants in an impoverished shantytown in Brazil, Scheper-Hughes argued that their neglect was a result of the selective neglect of mothers in this area in the first place (43).

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[19] Families often lived far away from hospitals. Health posts were physically available, but were often not open during nights or in the weekends. Ambulances were difficult to get and could be costly.

Considering adaptive preferences and the capabilities approach, delays in care seeking and balancing between health and welfare in our study must be understood in the context of high mortality and impoverishment. Rather than depicting delayed health care seeking as an end product of “culture” and “local context,” I argue that we need to examine people’s decisions and preferences at the micro level, but relate these to power structures and macro-level decisions about the distribution of resources, as discussed in Paper III.

Anthropologists and philosophers highlight how circumstances shape our worldviews. As an empirical and normative field, priority setting may play a role in exposing unfair premises and factors that make these injustices persist. In Paper III, we analyzed and discussed a micro dilemma families and health workers face between concern for health benefits and financial risk protection. In assessing criteria highlighted in the WHO framework (6), the newborn can be seen as worst-off in terms of lifetime health, and treatment is likely to maximize health. However, concerns about financial risk protection may point towards limiting treatment for the ill newborn. We incline towards it being unacceptable to limit treatment but understand that concerns for financial risk protection may be perceived more important for families living on the margin. However, as argued in Paper III, it seems unfair to leave micro-level decision makers to weigh an ill newborn’s survival against the family’s survival. Nussbaum’s and Sen’s works on the capabilities approach bring our attention to what kind of lives people have reason to value (70). I argue that, as a society, we should not accept this dilemma; lower-level decision makers do not have real choices to seek health care when they are deprived of basic capabilities and substantive freedoms.

11.2 Methodological considerations

In this section, I discuss methodological issues related to the three studies conducted. I first raise some general concerns before I reflect upon methods used in the qualitative study and ethical analysis.

11.2.1 General concerns

Our findings are based on a case study from Butajira in Ethiopia and may not be generalizable beyond the study area. Still, our results indicate that micro-level decision making and intra-household resource allocation are essential to understanding health care seeking in resource-constrained settings. While our study intended to present a view from below, we have discussed our results with regards to higher-level priorities and relevant literature. We acknowledge that our focus may have given unprecedented attention to micro-level priorities, which may have overlooked important bottlenecks and supply-side factors such as quality of services and physical accessibility (3, 186). Emphasis on improvements in coverage, quality, and equity of care will be needed to accelerate progress to reduce newborn deaths and stillbirth (29). Further, our study focused on the neonatal period, which is a biomedical category, and may differ from local understandings. Studies on stillbirth and late-missed pregnancies have found similar features of hidden grief and stigma (46, 172, 187).

11.2.2 Qualitative study

For all research, it is crucial to ask whether the results are worth paying attention to and whether we can trust the findings (142, 188). Quantitative research has put emphasis on validity – how research measures what it was intended to measure and reliability – whether the results are replicable and repeatable. These concepts raise important questions but are based on positivistic research traditions which focus on objectivity and may not directly apply to qualitative research where the role of the researcher herself is emphasized (142, 143). To evaluate if, and how, we can believe in our results, different concepts have been suggested for qualitative research (142, 189). I use reflexivity, trustworthiness, and saturation, as they seemed relevant to this study.

11.2.2.1 Reflexivity

Reflexivity can be understood as “an attitude of attending systematically to the context of knowledge construction” throughout the research process (143). While I touched upon relevant aspects such as choice of study area and recruitment strategy in previous sections and Papers I and II, here I highlight how my background and preconceptions may have shaped the questions asked and affected data collection and analysis.

Prior to data collection, my clinical experience was mostly from Norwegian hospitals, general practice and nursing home, a high-income setting where high-quality care is provided at no or low costs. Outside of Norway, I specialized in global health and had spent time in the health care systems in southern India (2008) and Ethiopia (2011, 2015). These impressions shaped my preunderstanding and what I paid attention to during fieldwork and analysis. Additionally, my earlier research on child and reproductive health in Ethiopia (31, 190) and interest in priority setting informed my research questions about how newborns were prioritized at the micro level. At the outset of data collection, I was trained in and had taken part in smaller qualitative research projects, but I was not experienced in interviews and observation.

My clinical experiences in and outside of Ethiopia were beneficial. Similarities in routines in hospitals made it easier to follow daily activities. Knowledge of treatment, routines, and guidelines within the field of newborn health was useful and enabled me to talk with health care workers and obtain overall impressions of ill newborns. Though my professional background had similarities to those of the health care workers, I was highly visible as a foreigner, which likely influenced access to information and data collection. While I, as a young, female foreigner and “outsider,” could ask different questions than an “insider” could, participants may have changed their answers or behavior in response to my presence. A researcher who was already known in Butajira and at the hospital is likely to have captured other aspects than I did. As I spent time at the hospital over a period of one month, I got to know some health care professionals better through continued conversations and interest in their work. This might have taken away some of the “outsider” effects. However, this was not possible in the community. When conducting IDIs and FGDs in rural locations, the arrival of the team – which included the CR, a BHRP representative, a driver (at times), and me – caught people’s attention. Our arrival sometimes presented itself as an event that received interest from the participant’s family or neighbors. Though this might have influenced participants’ responses, BHRP research in Butajira over the past 30 years has exposed the community to researchers’ activities and questions. In reflecting upon my role in the research process, collaboration with the CR during data collection and analysis made it possible to discuss and identify relevant issues related to the insider-outsider view. Also, a complete “outsider” might be considered as less bound by local structures and power relations and more independent from the authoritarian regime in Ethiopia (191).

While the medical language in the Ethiopian health care system is English, health workers often communicated in Amharic and local languages, and family members and community members rarely spoke English. As I do not speak Amharic beyond greetings and simple everyday exchanges, the close collaboration with the CR was crucial. I guided the discussions and the CR translated. In the two IDIs conducted in English, I was able to be more specific, and focus my questions in a different way. Whereas preliminary analysis started during data collection, in-depth reading of the material provided new understandings. In thorough reading, emphasis was – as far as possible – on what the participants had said. Yet, not knowing the language remains a significant limitation.

11.2.2.2 Trustworthiness

Different concepts have been suggested to evaluate trustworthiness, whether we can trust our findings and the research process (164, 188, 192). I focus on the four criteria credibility, dependability, transferability, and confirmability (164).

Credibility is concerned with how confident we are that data collection and analysis "address the intended focus of the study" (164). Prolonged engagement, persistent observation, and triangulation are suggested to improve credibility (188). In this study, we attempted all, but the short data collection period is a weakness of the study (October-November 2015). However, all researchers had worked in Ethiopia over several years, and two authors had done research in Butajira earlier. We tried to compensate for this weakness by triangulation in sources of participants (primary caretakers, health workers, community members) and data collection methods (IDIs, FGDs, observation), which we believe enhanced the findings' trustworthiness.

Dependability refers to the evaluation of how data may change over time and account for changes made in the analysis process (164, 188). Based on pre-study objectives, we prepared interview guides with a focus on key research objectives. These guides were modified during data collection, such as when we found that our question on potential gender differences and preferences for care seeking was not found relevant by any participants[20]. Along this line, we discovered early in data collection that the wording in our questions about giving priority to ill newborns did not make sense.

Transferability refers to whether findings can be applicable in other settings (143, 164). The study setting is described in Papers I and II and in section 9.2.1-9.2.2. Empirical findings are inherently context dependent. Yet, also other studies describe vulnerability of young children in resource-constrained settings (43, 44, 46-48, 172). Further, our results on coping mechanisms relate to studies on how families manage high OOP expenses (85, 87, 193, 194). Though our results may not be directly transferable, we believe our findings are relevant beyond Butajira, and particularly in Ethiopia.

Confirmability refers to whether or how the findings are shaped by study participants or researcher(s)' interests. The CR and I conducted data collection as a team, and the Ethiopian PhD supervisors did random checks of the first interviews. The material

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[20] Studies from Southeast Asia indicate gender preferences, e.g. Miljeteig et al., 2010 or Robitaille et al, 2016.

was discussed and read by different co-authors following data collection, which may enhance the reliance on our interpretations. In reading the transcripts, I used field notes and discussions with my co-authors to understand the material with a focus on participants' views. In presenting and discussing our results, key stakeholders acknowledged our findings on delays in health care seeking, the ambiguous status of the newborn, and experiences of high health care costs, which enhance confirmability.

11.2.2.3 Saturation

Saturation can be understood as data adequacy, and "operationalized as collecting data until no new information is obtained" (163). In practice, it remains a challenge to define saturation. In this study, data collection ended when new aspects or topics with regards to study questions were no longer revealed in interviews or observation. Data collection was relatively short (< two months) compared to ethnographic research, and longer and more in-depth exploration might have enriched our understanding. Still, as there will always be new stories and people, it can be asked whether saturation ever is possible. Time and resources may be just as reliable criteria for ending a recruitment process as data saturation.

11.2.3 Ethical analysis

Paper III studied the ethical dilemma between concerns for newborn health and family welfare and analyzed the ethical acceptability and normative implications of limiting treatment to provide financial risk protection. Although context matters, we hope the ethical issues highlighted are relevant for discussions on fairness and financial risk protection in other settings or with regards to other health benefits. Previous discussions on UHC have pointed at high OOP expenditures (83) and trade-offs concerning financial risk protection (6, 137). Few have looked at how these concerns are relevant for micro-level decision making (91, 195).

Studies I and II showed that decision making and care seeking involved different trade-offs. We explicitly focused on the trade-off between newborn health and family welfare, as diverging concerns for health benefits and financial risk protection represented an underlying ethical issue not yet assessed from a micro perspective. If we had emphasized the potential lower value of newborns, the philosophical debate on the badness of death could have been of interest for our analysis (196). We assume that every life year counts equally (from birth), and follow the Global Burden of Disease 2010 where one does not discount or age-weight when valuing the badness of death in estimating DALYs (197). When each DALY lost counts equally, newborns that die prematurely will suffer from the largest health loss.

The ethical dilemma was analyzed using a method developed for case-analysis which draws upon both bottom-up and top-down approaches (146). The systematic and evidence-informed seven-step method made the analysis more transparent (114). Some important considerations with regards to our analysis should be noted. While the systematic approach aimed to make the analysis less partial, we cannot claim that our empirical findings were “neutral facts.” Our questions, analysis, and interpretation were influenced by experiences from data collection and earlier work in Ethiopia[21]. We chose to focus explicitly on an empirically identified dilemma identified in study II. As our findings were presented and discussed with stakeholders in Butajira, we believe the case analyzed – though informed by our preunderstandings - is of relevance for those experiencing such dilemmas. Only Norwegian authors wrote the paper, but the dilemma was discussed with Ethiopian colleagues that have studied OOP payments and financial risk protection. Yet, our moral intuitions, earlier work on health care priority setting, and backgrounds as health care professionals might have influenced our conclusion towards not accepting to limit treatment for the ill newborn.

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[21] We have aimed to be transparent about this, but there was less room for explicit discussion of this in paper III due to word limits set by the journal.

Step two of the ethical analysis assessed prognosis, costs, and financial burden. These data were gathered through scoping searches, but a systematic review was not conducted. Particularly on financial risk protection empirical data was limited and uncertain, which questions the reliability of the empiric evidence. There is a need for better and contextualized data, in particular on actual costs, financial burden and poverty-cases (averted) to inform these challenging discussions (180, 194, 198, 199).

Step seven looked at values and principles at stake. We discussed the substantive criteria in WHO framework: health maximization, priority to the worse-off and financial risk protection (6). Others might have found other principles, criteria or frameworks more relevant (56, 76-78, 169).

12 CONCLUSIONS

Despite knowledge of effective medical and public health interventions, many newborns die without accessing life-saving treatment. Most newborn deaths occur in low-income contexts, where health care and welfare systems are limited by resource constraints. While cost-effective interventions exist, and newborns can be seen as worst-off from a lifetime health perspective, this study showed that other concerns mattered for families experiencing newborn illness in Butajira. These findings deviate from the focus on ill newborns in policy and literature in several ways. In this setting, it was not only the survival of the newborn that was at stake but the survival and economic well-being of the family. This study revealed how the newborn's ambiguous status delayed caretakers' health care decision making. In everyday life, high health care costs imposed hard choices for families balancing concerns for newborn health and family welfare. The conflict between newborn health benefits and financial risk protection played out at a micro level, but the dilemmas faced by families and health workers cannot be understood without paying attention to priorities at higher levels. We argue that these dilemmas are unacceptable and unfair, and that essential high-priority services must be made affordable. The mismatches between local realities and global policy priority on newborn health must be taken into account and underpin policy-making and implementation. To improve newborn health and move towards UHC, health and welfare systems must ensure that families can use essential health care services without falling into poverty.

13 FUTURE PERSPECTIVES

13.1 Policy implications

The recent priority on newborn health may push for national accountability through goals, plans, and allocation of funding. In these efforts, some initiatives have promoted community engagement (200, 201). This study indicates that to improve newborn health, it must be recognized that illness and deaths occur in local contexts, where families' and communities' understandings of health, and choices about health care seeking, are impacted by a range of factors. Policies, plans, and implementation strategies must consider broader determinants, including socio-cultural and structural factors. To ensure that every newborn receives the needed care, the circumstances that shape primary caretakers' and health workers' opportunities must move to center stage.

This study demonstrated that priorities made at higher levels of the health care system, including financing and organization, affect families' opportunities to seek and pay for care. Essential newborn health care services are high-priority services, which is recommended to be made available to everyone without causing financial hardship (6). In Ethiopia, coverage for essential newborn health care is low, and families face high costs. This indicates that efforts must be accelerated to achieve national goals of UHC and newborn health (17, 149). To promote fairness on the path to UHC, it is crucial to reduce OOP payments for high-priority services (6). Although health care facilities and staffing are being scaled up, and health insurance initiatives are about to be rolled-out, the Ethiopian health system is underfunded (16, 83). Sustainable funding mechanisms – which rely less on donors and OOP payments – are needed to promote health care for the population. The country's health budget must increase substantially from current total health spending per capita (US $27) to offer the needed health care services for its population (16). Estimates of health care financing in LICs indicate that $86 per capita is needed to achieve universal access to primary services (150) or recommend $112 per person per year to achieve the health-related SDGs (150, 151). On Ethiopia's path to achieving the SDGs on UHC and newborn health targets, the overall health budget must be increased, and the most essential services should be prioritized (6).

13.2 Research implications

The literature on health care priority setting often addresses macro-level decisions, and meso- and micro-level studies have focused on health institutions and health care professionals. This study looked at resource allocation and decision making among families at the micro level and described how decisions made at the household level are essential for health care seeking and spending. Intra-household resource allocation is highly relevant for priority setting in health, and further exploration of how bargaining power and preferences affect decision making is needed. Our study focused on newborns in a rural part of Ethiopia, and future studies should assess how context matters.

This study highlighted how non-health factors are central in real-life priority setting at lower levels. When families pay OOP for health care services, decisions about care seeking and spending are made from one budget where health *and* non-health-concerns are at the center. At the micro level, decisions are not made within a separate health sphere. While there are theoretical and pragmatic arguments for keeping separate spheres (101, 102), our empirical findings and normative analysis illustrate aspects less covered in discussions of whether to include concerns for non-health outcomes (93, 101, 103). These are relevant for the important and much-needed normative discussion regarding if and how non-health concerns, such as financial risk protection, should play a role in priority setting.

14 LIST OF APPENDICES

Paper I

Paper II

Paper III

Ethical approval: Regional Committee for Medical and Health Research Ethics, Western Norway (REC Western Norway)

Ethical approval: Institutional Review Board (IRB), University College of Health Sciences, Addis Ababa University

Informed consent forms (available in Amharic upon request)

Interview and focus group discussion guides (available in Amharic upon request)

15 REFERENCES

1. United Nations. Transforming our world: the 2030 agenda for sustainable development. New York: United Nations; 2015. Contract No: December 13th.

2. Wang H, Bhutta ZA, Coates MM, Coggeshall M, Dandona L, Diallo K, et al. Global, regional, national, and selected subnational levels of stillbirths, neonatal, infant, and under-5 mortality, 1980-2013;2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet. 2016;388(10053):1725-74.

3. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? Lancet. 2014;384(9940):347-70.

4. Institute for Health Metrics and Evaluation. GBD Results Tool 2017 [Internet] from: http://ghdx.healthdata.org/gbd-results-tool.

5. Barros AJ, Ronsmans C, Axelson H, Loaiza E, Bertoldi AD, Franca GV, et al. Equity in maternal, newborn, and child health interventions in countdown to 2015: a retrospective review of survey data from 54 countries. Lancet. 2012;379(9822):1225-33.

6. World Health Organization. Making fair choices on the path to universal health coverage: Final report of the WHO consultative group on equity and universal health coverage. Geneva: World Health Organization; 2014.

7. Convention on the Rights of the Child. Sect Treaty Series, vol. 1577. 1989.

8. International Covenant on Economic, Social and Cultural Rights. 1966.

9. A/RES/55/2: United Nations Millennium Declaration. 2000.

10. Kuruvilla S, Bustreo F, Kuo T, Mishra CK, Taylor K, Fogstad H, et al. The global strategy for women's, children's and adolescents' health (2016-2030): a roadmap based on evidence and country experience. Bull World Health Organ. 2016;94(5):398-400.

11. World Health Organization. Every newborn action plan: reaching the every newborn national 2020 milestones: country progress, plans and moving forward. Geneva: World Health Organization; 2017.

12. Ottersen T. Lifetime QALY prioritarianism in priority setting. J. Med. Ethics. 2013;39(3):175-80.

13. Norheim OF. A note on Brock: prioritarianism, egalitarianism and the distribution of life years. J. Med. Ethics. 2009;35(9):565-9.

14. Daniels N. Four unsolved rationing problems: a challenge. The Hastings Center Report. 1994;24(4):27-9.

15. Brock D, Wikler D. Ethical issues in resource allocation, research, and new product development In: Jamison DT, editor. Disease Control Priorities in Developing Countries. Second ed: The World Bank and Oxford University Press; 2006.

16. Federal Democratic Republic of Ethiopia Ministry of Health. Ethiopia's fifth national health accounts; 2010/2011. Addis Ababa, Ethiopia; 2014.

17. Federal Democratic Republic of Ethiopia Ministry of Health. Health sector development programme V. Addis Ababa, Ethiopia; 2015.

18. Central Statistical Agency (CSA) [Ethiopia] and ICF. Ethiopia demographic and health survey 2016: key indicators report. Addis Ababa, Ethiopia, and Rockville, Maryland, USA: CSA and ICF; 2016.

19. Roser M. Child mortality. Published online at OurWorldInData.org.2017 [Available from: https://ourworldindata.org/child-mortality/.

20. World Bank. World bank open data 2017 [Available from: http://data.worldbank.org/.

21. World Health Organization. Infant, Newborn. World Health Organization; 2016. Contract No.: 11.11.

22. Lawn JE, Blencowe H, Pattinson R, Cousens S, Kumar R, Ibiebele I, et al. Stillbirths: Where? When? Why? How to make the data count? Lancet. 2014;377(9775):1448-63.

23. Kerber KJ, Mathai M, Lewis G, Flenady V, Erwich JJH, Segun T, et al. Counting every stillbirth and neonatal death through mortality audit to improve quality of care for every pregnant woman and her baby. BMC Pregnancy and Childbirth. 2015;15(2):S9.

24. Victora CG, Barros AJ, Axelson H, Bhutta ZA, Chopra M, Franca GV, et al. How changes in coverage affect equity in maternal and child health interventions in 35 Countdown to 2015 countries: an analysis of national surveys. Lancet. 2012;380(9848):1149-56.

25. Central Statistical Agency II. Ethiopia demographic and health survey, 2011. Addis Ababa. Ethiopia and Rockville, Maryland, USA: CSA and ICF; 2012.

26. Central Statistical Authority, ORC Macro. Ethiopia demographic and health survey, 2005. Addis Ababa, Ethiopia; 2006.

27. Liu L, Oza S, Hogan D, Chu Y, Perin J, Zhu J, et al. Global, regional, and national causes of under-5 mortality in 2000–15: an updated systematic analysis with implications for the sustainable development goals. Lancet. 2016;388(10063):3027-35.

28. Millard AV. A causal model of high rates of child mortality. Soc Sci Med. 1994;38(2):253-68.

29. Darmstadt GL, Shiffman J, Lawn JE. Advancing the newborn and stillbirth global agenda: priorities for the next decade. Arch Dis Child. 2015;100(Suppl 1):S13-S8.

30. Friberg IK, Kinney MV, Lawn JE, Kerber KJ, Odubanjo MO, Bergh AM, et al. Sub-Saharan Africa's mothers, newborns, and children: how many lives could be saved with targeted health interventions? PLoS Med. 2010;7(6):e1000295.

31. Onarheim KH, Tessema S, Johansson KA, Eide KT, Norheim OF, Miljeteig I. Prioritizing child health interventions in Ethiopia: modeling impact on child mortality, life expectancy and inequality in age at death. PLoS One. 2012;7(8):e41521.

32. Lawn JE, Kinney MV, Black RE, Pitt C, Cousens S, Kerber K, et al. Newborn survival: a multi-country analysis of a decade of change. Health Policy Plan. 2012;27(suppl 3):iii6-iii28.

33. Gakidou E, Cowling K, Lozano R, Murray CJ. Increased educational attainment and its effect on child mortality in 175 countries between 1970 and 2009: a systematic analysis. Lancet. 2010;376(9745):959-74.

34. Feng XL, Theodoratou E, Liu L, Chan KY, Hipgrave D, Scherpbier R, et al. Social, economic, political and health system and program determinants of child mortality reduction in China between 1990 and 2006: A systematic analysis. J Glob Health. 2012;2(1):010405.

35. Shiffman J. Issue attention in global health: the case of newborn survival. Lancet. 2010;375(9730):2045-9.

36. Shiffman J. Network advocacy and the emergence of global attention to newborn survival. Health Policy Plan. 2015.

37. United Nations Secretary-General. Global strategy for women's and children's health. New York: United Nations; 2010.

38. Knippenberg R, Lawn JE, Darmstadt GL, Begkoyian G, Fogstad H, Walelign N, et al. Systematic scaling up of neonatal care in countries. Lancet. 2005;365(9464):1087-98.

39. Lawn JE, Cousens S, Zupan J. 4 million neonatal deaths: When? Where? Why? Lancet. 2005;365(9462):891-900.

40. Dieleman JL, Schneider MT, Haakenstad A, Singh L, Sadat N, Birger M, et al. Development assistance for health: past trends, associations, and the future of international financial flows for health. The Lancet.

41. Every Woman Every Child. Global strategy for women's, children's and adolescents' health. 2015.

42. Cannon A, Cook K. Infant death and the archaeology of grief. Camb Archaeol J. 2015;25(2):399-416.

43. Scheper-Hughes N. Death without weeping: the violence of everyday life in Brazil. Berkeley: University of California Press; 1992.

44. Einarsdóttir J. Tired of weeping: mother love, child death, and poverty in Guinea-Bissau. Madison, WI, USA: University of Wisconsin Press 2004.

45. Nations M, Corlis J, Feitosa J. Cumbered cries: contextual constraints on maternal grief in northeast Brazil. Curr Anthropol. 2015;56(5):613-37.

46. Sisay MM, Yirgu R, Gobezayehu AG, Sibley LM. A qualitative study of attitudes and values surrounding stillbirth and neonatal mortality among grandmothers, mothers, and unmarried girls in rural Amhara and Oromiya regions,

Ethiopia: unheard souls in the backyard. J. Midwifery Women's Health. 2014;59 Suppl 1:S110-7.

47. Jewkes R, Wood K. Competing discourses of vital registration and personhood: perspectives from rural South Africa. Soc Sci Med. 1998;46(8):1043-56.

48. Hampshire KR, Panter-Brick C, Kilpatrick K, Casiday RE. Saving lives, preserving livelihoods: understanding risk, decision-making and child health in a food crisis. Soc Sci Med. 2009;68(4):758-65.

49. Hampshire K, Casiday R, Kilpatrick K, Panter-Brick C. The social context of childcare practices and child malnutrition in Niger's recent food crisis. Disasters. 2009;33(1):132-51.

50. Sacks E. Defining disrespect and abuse of newborns: a review of the evidence and an expanded typology of respectful maternity care. Reprod Health. 2017;14(1):66.

51. Ottersen T, Norheim O, Berhane F, Chitah B, Cookson R, Daniels N, et al. Making fair choices on the path to universal health coverage: final report of the WHO consultative group on equity and universal health coverage. Geneva: World Health Organization; 2014.

52. Daniels N. Just health: meeting health needs fairly. Cambridge University Press; 2008.

53. Norheim OF. Ethical priority setting for universal health coverage: challenges in deciding upon fair distribution of health services. BMC Medicine. 2016;14(1):75.

54. Glassman A, Chalkidou K, Giedion U, Teerawattananon Y, Tunis S, Bump JB, et al. Priority-setting institutions in health. Global Heart. 2012;7(1):13-34.

55. Ottersen T. Greater benefits and the worse off: Specifying and balancing priority-setting principles in health. Dissertation for the degree philosophiae doctor (PhD) at the University of Bergen; 2013.

56. Persad G, Wertheimer A, Emanuel EJ. Principles for allocation of scarce medical interventions. Lancet. 2009;373(9661):423-31.

57. Ham C, Roberts G. Reasonable rationing: international experience of priority setting in health care. Philadephia: Open University Press; 2003.

58. Ubel PA, Goold S. Recognizing bedside rationing: clear cases and tough calls. Ann Intern Med. 1997;126(1):74-80.

59. Ubel PA, Goold S. 'Rationing' health care: not all definitions are created equal. Arch Intern Med. 1998;158(3):209-14.

60. Chalkidou K, Glassman A, Marten R, Vega J, Teerawattananon Y, Tritasavit N, et al. Priority-setting for achieving universal health coverage. Bull World Health Organ. 2016;94(6):462-7.

61. Holm S. Important insights into the black box of priority setting. A response to: priority setting for new technologies in medicine: qualitative case study 2000 [Available from: http://www.bmj.com/rapid-response/2011/10/28/important-insights-black-box-priority-setting.

62. Baltussen R, Mitton C, Danis M, Williams I, Gold M. Global developments in priority setting in health. Int J Health Policy Manag. 2017;6(3):127-8.

63. Rumbold B, Baker R, Ferraz O, Hawkes S, Krubiner C, Littlejohns P, et al. Universal health coverage, priority setting, and the human right to health. Lancet. 2017.

64. Hauck K, Smith OC, Goddard M. The economics of priority setting for health care. A literature review. Washington D.C.: World Bank; 2003.

65. Stanford Encyclopedia of Philosophy. Theory and Bioethics. Stanford Encyclopedia of Philosophy. Online access; https://plato.stanford.edu/entries/theory-bioethics/ February 23rd 2016.

66. Sen A. Utilitarianism and Welfarism. Journal of Philosophy. 1979;76:463-89.

67. Stanford Encyclopedia of Philosophy. Libertarianism. Stanford Encyclopedia of Philosophy. Online access; https://plato.stanford.edu/entries/libertarianism/ December 7th 2017.

68. Rawls J. A theory of justice. Revised edition. Original edition, 1971 ed. Cambridge, MA: Harvard University Press; 1999.

69. Parfit D. Equality or priority? . Kansas: University of Kansas; 1995.

70. Sen A. Development as freedom (1st ed.). New York: Oxford University Press; 1999.

71. Daniels N, Sabin JE. Accountability for reasonableness. In Setting limits fairly : can we learn to share medical resources? Oxford; New York: Oxford University Press; 2002.

72. Gibson JL, Martin DK, Singer PA. Priority setting in hospitals: fairness, inclusiveness, and the problem of institutional power differences. Soc Sci Med. 2005;61(11):2355-62.

73. Norges offentlige utredninger. Prioritering på ny – Gjennomgang av retningslinjer for prioriteringer innen norsk helsetjeneste.; 1997.

74. Prioriteringsutvalget. Prioriteringsutvalgets mandat 2014 [Available from: http://prioriteringsutvalget.stat.no/mandat/.

75. Kapiriri L, Norheim OF. Criteria for priority-setting in health care in Uganda: exploration of stakeholders' values. B World Health Organ. 2004;82:172-9.

76. Cookson R, Dolan P. Principles of justice in health care rationing. J Med Ethics. 2000;26(5):323-9.

77. Norheim OF, Baltussen R, Johri M, Chisholm D, Nord E, Brock D, et al. Guidance on priority setting in health care (GPS-Health): the inclusion of equity criteria not captured by cost-effectiveness analysis. Cost Eff Resour Alloc. 2014;12(1):18.

78. Marckmann G, Schmidt H, Sofaer N, Strech D. Putting public health ethics into practice: a systematic framework. Front Public Health. 2015;3:23.

79. World Health Organization. World Health Report 2010: Health systems financing: the path to universal coverage. Geneva: World Health Organization; 2010.

80. World Health Organization. World Health Report 2013: Research for universal health coverage. Geneva: World Health Organization; 2013.

81. Xu K, Evans DB, Carrin G, Aguilar-Rivera AM, Musgrove P, Evans T. Protecting households from catastrophic health spending. Health Aff (Millwood). 2007;26(4):972-83.

82. Xu K, Evans DB, Kawabata K, Zeramdini R, Klavus J, Murray CJL. Household catastrophic health expenditure: a multicountry analysis. Lancet. 2003;362(9378):111-7.

83. Dieleman JL, Templin T, Sadat N, Reidy P, Chapin A, Foreman K, et al. National spending on health by source for 184 countries between 2013 and 2040. Lancet. 2016;387(10037):2521-35.

84. Kruk ME, Goldmann E, Galea S. Borrowing and selling to pay for health care in low- and middle-income countries. Health Affair. 2009;28(4):1056-66.

85. Leive A, Xu K. Coping with out-of-pocket health payments: empirical evidence from 15 African countries. Bull World Health Organ. 2008;86(11):849-56.

86. Nguyen KT, Khuat OT, Ma S, Pham DC, Khuat GT, Ruger JP. Coping with health care expenses among poor households: evidence from a rural commune in Vietnam. Soc Sci Med. 2012;74(5):724-33.

87. Storeng KT, Baggaley RF, Ganaba R, Ouattara F, Akoum MS, Filippi V. Paying the price: the cost and consequences of emergency obstetric care in Burkina Faso. Soc Sci Med. 2008;66(3):545-57.

88. Dercon S, Krishnan P. In sickness and in health: risk sharing within households in rural Ethiopia. J. of Political Econ. 2000;108(4):688-727.

89. Dercon S. Income risk, coping strategies, and safety nets. World Bank Res Obs. 2002;17:141-66.

90. Nguyen KT, Khuat OT, Ma S, Pham DC, Khuat GT, Ruger JP. Effect of health expenses on household capabilities and resource allocation in a rural commune in Vietnam. PLoS One. 2012;7(10):e47423.

91. Defaye FB, Danis M, Desalegn D, Dessie E, Berhane Y, Norheim O, et al. Financial risk protection at the bedside: how Ethiopian physicians try to minimize out-of-pocket health expenditures (forthcoming, 2018).

92. Wagstaff A. Poverty and health sector inequalities. B World Health Organ. 2002;80:97-105.

93. Persad G, du Toit J. Non-health and indirect benefits. In: Emanuel EJ, Verguet S, Jamison D, Norheim OF, Ottersen T, Johansson KA, et al., editors. Global health priority-setting: beyond cost-effectiveness. Oxford: Oxford University Press; (forthcoming 2018).

94. Bloom DE, Canning D. The health and wealth of nations. Science. 2000;287:1207.

95. World Bank. World development report 1993: Investing in health. World Bank; 1993.

96. Jamison DT, Summers LH, Alleyne G, Arrow KJ, Berkley S, Binagwaho A, et al. Global health 2035: a world converging within a generation. Lancet. 2013;382(9908):1898-955.

97. Bloom D.E., Fink G. The economic case for devoting public resources to health. In: Farrar J, Hotez P, Junghanss T, Kang G, Lalloo D, White N, editors. Manson's Tropical Diseases. 23rd ed: Expert Consult; 2013.

98. Bloom D, Canning D, Weston M. The value of vaccination. World Econ. 2005;6(3):15-39.

99. World Health Organization, World Economic Forum. From burden to "best buys": reducing the economic impact of non-communicable diseases in low- and middle-income countries. World Economic Forum; 2011.

100. Onarheim KH, Iversen JH, Bloom DE. Economic benefits of investing in women's Health: a systematic review. PLoS One. 2016;11(3):e0150120.

101. Brock DW. Separate spheres and indirect benefits. Cost Eff Resour Alloc. 2003;1(1):4.

102. Brock DW. Ethical issues in the use of cost effectiveness ananlysis for the prioritization of health care resources. In: Anand S, Peter F, Sen A, editors. Public health, ethics, and equity. Oxford: Oxford University Press; 2004. p. 201-23.

103. Du Toit J, Millum J. Are indirect benefits relevant to health care allocation decisions? J Med Philos. 2016;41(5):540-57.

104. Førde R. How can empirical ethics improve medical practice? Camb Q Healthc Ethics. 2012(21[04]):517-26.

105. Dunn M, Ives J. Methodology, epistemology, and empirical bioethics research: a constructive/ist commentary. Am J Bioeth. 2009;9(6-7):93-5.

106. Bærøe K, Ives J, de Vries M, Schildmann J. On classifying the field of medical ethics. BMC Med Ethics. 2017;18(1):30.

107. Molewijk B, Stiggelbout AM, Otten W, Dupuis HM, Kievit J. Empirical data and moral theory. A plea for integrated empirical ethics. Med Health Care Philos. 2004;7(1):55-69.

108. Calabresi G, Bobbitt P. Introduction. Tragic choices. New York: W. W. Norton & Company; 1978. p. 15-28.

109. Klein R. Dimensions of rationing: who should do what? BMJ 1993;307(6899):309-11.

110. Kapiriri L, Norheim OF, Martin DK. Priority setting at the micro-, meso- and macro-levels in Canada, Norway and Uganda. Health Policy. 2007;82(1):78-94.

111. Clinton C, Sridhar DL. Governing global health: who runs the world and why? New York, NY: Oxford University Press; 2017.

112. Hipgrave DB, Alderman KB, Anderson I, Soto EJ. Health sector priority setting at meso-level in lower and middle income countries: lessons learned, available options and suggested steps. Soc Sci Med. 2014;102:190-200.

113. Klein R, Day P, Redmayne S. Managing scarcity: priority setting and rationing in the National Health Service. In: Ham C, editor. Buckingham: Open University Press; 1996.

114. Miljeteig I, Johansson KA, Sayeed SA, Norheim OF. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. J Med Ethics. 2010;36(8):473-8.

115. Miljeteig I, Norheim OF. My job is to keep him alive, but what about his brother and sister? How Indian doctors experience ethical dilemmas in neonatal medicine. Dev World Bioeth. 2006;6(1):23-32.

116. Johansson KA, Miljeteig I, Kigwangalla H, Norheim OF. HIV priorities and health distributions in a rural region in Tanzania: a qualitative study. J Med Ethics. 2011;37(4):221-6.

117. Defaye FB, Desalegn D, Danis M, Hurst S, Berhane Y, Norheim OF, et al. A survey of Ethiopian physicians' experiences of bedside rationing: extensive resource scarcity, tough decisions and adverse consequences. BMC Health Serv Res. 2015;15:467.

118. Thomas D. Intra-household resource allocation: an inferential approach. J Hum Resour. 1990;25(4):635-64.

119. Duflo E. Grandmothers and granddaughters: old-age pensions and intrahousehold allocation in South Africa. World Bank Econ Rev. 2003;17(1):1–25.

120. Ringdal C, Sjursen I. Household bargaining and spending on children - experimental evidence from Tanzania. Helsinki, Finland: UNU-WIDER; 2017. Report No.: 978-92-9256-354-7.

121. Fiala N, He X. Unitary or noncooperative intrahousehold model? Evidence from couples in Uganda. World Bank Econ Rev. 2017;30(Supplement 1):S77-S85.

122. Sen A. Economics and the family. Resources, values and development. Harvard University Press; 1984.

123. Robitaille M-C, Chatterjee I. Sex-selective abortions and infant mortality in India: the role of parents' stated son preference. The Journal of Development Studies. 2016:1-10.

124. Willis JR, Kumar V, Mohanty S, Singh P, Singh V, Baqui AH, et al. Gender Differences in perception and care-seeking for illness of newborns in rural Uttar Pradesh, India. J Health Popul Nutr. 2009;27(1):62-71.

125. Agarwal B. "Bargaining" and gender relations: within and beyond the household. Fem Econ. 1997;3(1):1-51.

126. Herbert HK, Lee ACC, Chandran A, Rudan I, Baqui AH. Care seeking for neonatal illness in low- and middle-income countries: a systematic review. PLoS Med. 2012;9(3):e1001183.

127. Noordam AC, Carvajal-Velez L, Sharkey AB, Young M, Cals JWL. Care seeking behaviour for children with suspected pneumonia in countries in Sub-Saharan Africa with high pneumonia mortality. PLoS ONE. 2015;10(2):e0117919.

128. Bhandari N, Bahl R, Bhatnagar V, Bhan MK. Treating sick young infants in urban slum setting. Lancet. 1996;347(9017):1774-5.

129. Nonyane BA, Kazmi N, Koffi AK, Begum N, Ahmed S, Baqui AH, et al. Factors associated with delay in care-seeking for fatal neonatal illness in the Sylhet district of Bangladesh: results from a verbal and social autopsy study. J Glob Health. 2016;6(1):010605.

130. Sauerborn R, Berman P, Nougtara A. Age bias, but no gender bias, in the intra-household resource allocation for health care in rural Burkina Faso. Health transition review: the cultural, social, and behavioural determinants of health. 1996;6(2):131-45.

131. Sauerborn R, Nougtara A, Latimer E. The elasticity of demand for health care in Burkina Faso: differences across age and income groups. Health Policy Plan. 1994;9(2):185-92.

132. Miljeteig I. End-of-life priorities in complex settings: An ethical analysis of decisions in Indian neonatal units. Dissertation for the degree philosophiae doctor (PhD) at the University of Bergen; 2010.

133. Walton NA, Martin DK, Peter EH, Pringle DM, Singer PA. Priority setting and cardiac surgery: A qualitative case study. Health Policy. 2007;80(3):444-58.

134. Maluka S, Kamuzora P, San Sebastian M, Byskov J, Olsen OE, Shayo E, et al. Decentralized health care priority-setting in Tanzania: evaluating against the accountability for reasonableness framework. Soc Sci Med. 2010;71(4):751-9.

135. Zulu JM, Michelo C, Msoni C, Hurtig A-K, Byskov J, Blystad A. Increased fairness in priority setting processes within the health sector: the case of Kapiri-Mposhi District, Zambia. BMC Health Serv Res. 2014;14(1):75.

136. Voorhoeve A, Edejer TTT, Kapiriri L, Norheim OF, Snowden J, Basenya Oea. Three case studies in making fair choices on the path to universal health coverage. Health Hum Rights. 2016.

137. Norheim OF. Ethical perspective: five unacceptable trade-offs on the path to universal health coverage. Int J Health Policy Manag. 2015;4(11):711-4.

138. Stein F. On the equal validity of methods in global health research Global Health Governance Program; 2017 [Available from: http://globalhealthgovernance.org/blog/2017/4/13/a-comment-on-the-equal-validity-of-research-methods-in-global-health].

139. Brannen J. Mixing Methods: The entry of qualitative and quantitative approaches into the research process. Int J Soc Res Methodology. 2005;8(3):173-84.

140. Green J, Thorogood N. Qualitative methodology and health research. In: Green J, Thorogood N, editors. Qualitative methods for health research. Los Angeles: SAGE; 2009.

141. Donmoyer R. The SAGE Encyclopedia of Qualitative Research Methods. 2008. June 15th 2017. Thousand Oaks, California: SAGE Publications, Inc. Available from: http://sk.sagepub.com/reference/research.

142. Golafshani N. Understanding reliability and validity in qualitative research. Qual Rep. 2003;8(4):597-606.

143. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet. 2001;358(9280):483-8.

144. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ. 1995;311(6996):42-5.

145. Malterud K. Kvalitative metoder i medisinsk forskning: en innføring. Oslo: Universitetsforlaget; 2003.

146. Beauchamp T, Childress J. Method and moral justification. Principles of biomedical ethics. 6 ed. New York: Oxford University Press; 2009. p. 368-402.

147. Stanford Encyclopedia of Philosophy. Reflective equilibrium. Stanford Encyclopedia of Philosophy. Online access; https://plato.stanford.edu/entries/reflective-equilibrium/ June 23rd 2017.

148. Federal Democratic Republic of Ethiopia Ministry of Health. Health sector development programme IV. Addis Ababa, Ethiopia: Federal Democratic Republic of Ethiopia Ministry of Health; 2011.

149. Federal Democratic Republic of Ethiopia Ministry of Health. National newborn and child survival strategy document brief summary: 2015/16-2019/20. Federal Democratic Republic of Ethiopia Ministry of Health, ; 2015.

150. McIntyre D, Meheus F, Røttingen JA. What level of domestic government health expenditure should we aspire to for universal health coverage? Health Econ Pol Law. 2017;12(2):125-37.

151. Stenberg K, Hanssen O, Edejer TT, Bertram M, Brindley C, Meshreky A, et al. Financing transformative health systems towards achievement of the health sustainable development goals: a model for projected resource needs in 67 low-income and middle-income countries. Lancet Glob Health. 2017.

152. Srivastava NM, Awasthi S, Agarwal GG. Care-seeking behavior and out-of-pocket expenditure for sick newborns among urban poor in Lucknow, northern India: a prospective follow-up study. BMC Health Serv Res. 2009;9(1):61.

153. Ekwochi U, Osuorah DC, Ndu IK, Ezenwosu OU, Amadi OF, Nwokoye IC, et al. Out-of-pocket cost of managing sick newborns in Enugu, Southeast Nigeria. Clinicoecon Outcomes Res. 2014;6:29-35.
154. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334-40.
155. Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health. 2010;33(1):77-84.
156. Berhane Y, Byass P. Butajira DSS Ethiopia. In: INDEPTH network, editor. Population and health in developing countries. Volume 1. Part III. INDEPTH DSS site profiles. International Development Research Centre; 2002.
157. Berhane Y, Wall S, Kebede D, Emmelin A, Enquselassie F, Byass P, et al. Establishing an epidemiological field laboratory in rural areas: potentials for public health research and interventions. The Butajira Rural Health Programme 1987-1999. Ethiopian Journal of Health Development 1999 (13 Special Issue): 1-47.
158. Mekonnen W, Worku A. Determinants of fertility in rural Ethiopia: the case of Butajira emographic surveillance system (DSS). BMC Public Health. 2011;11:782-.
159. Medhin G, Hanlon C, Dewey M, Alem A, Tesfaye F, Lakew Z, et al. The effect of maternal common mental disorders on infant undernutrition in Butajira, Ethiopia: The P-MaMiE study. BMC Psychiatry. 2010;10:32-.
160. Gizaw M, Molla M, Mekonnen W. Trends and risk factors for neonatal mortality in Butajira District, South Central Ethiopia, (1987-2008): a prospective cohort study. BMC Pregnancy Childbirth. 2014;14:64.
161. Dicicco-Bloom B, Crabtree BF. The qualitative research interview. Medical education. 2006;40(4):314-21.
162. Mays N, Pope C. Qualitative research: observational methods in health care settings. BMJ. 1995;311(6998):182-4.
163. Morse JM. The significance of saturation. Qual Health Res. 1995;5(3):147-9.
164. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105-12.

165. Molla M, Mitiku I, Worku A, Yamin A. Impacts of maternal mortality on living children and families: A qualitative study from Butajira, Ethiopia. Reprod Health. 2015;12 Suppl 1:S6.

166. Kymlicka W. Moral philosophy and public policy: the case of NRTs. Bioethics. 1993;7(1):1-26.

167. Førde R, Pedersen R. Manual for arbeidet i klinisk etikk-komiteer i spesialisthelsetjenesten. Senter for medisinsk etikk, Universitetet i Oslo; 2012.

168. Miljeteig I, Skrede S, Langørgen J, Haaverstad R, Jøsendal O, Sjursen H, et al. Skal rusmiddelavhengige pasienter tilbys hjerteklaffkirurgi for andre gang? Tidsskrift for Den norske legeforening. 2013(133):977-80.

169. Beauchamp T, Childress J. Principles of biomedical ethics. 6 ed. New York: Oxford University Press; 2009.

170. World Health Organization. Compilation of WHO recommendations on maternal, newborn, child and adolescent health: recommendations on newborn health. Geneva: World Health Organization; 2013.

171. Østergaard LR, Bjertrup PJ, Samuelsen H. “Children get sick all the time”: A qualitative study of socio-cultural and health system factors contributing to recurrent child illnesses in rural Burkina Faso. BMC Public Health. 2016;16(1):384.

172. Haws RA, Mashasi I, Mrisho M, Schellenberg JA, Darmstadt GL, Winch PJ. "These are not good things for other people to know": how rural Tanzanian women's experiences of pregnancy loss and early neonatal death may impact survey data quality. Soc Sci Med. 2010;71(10):1764-72.

173. Wang H, Naghavi M, Allen C, Barber RM, Bhutta ZA, Carter A, et al. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980-2013;2015: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet. 2016;388(10053):1459-544.

174. Roalkvam S, McNeill D. What counts as progress? The contradictions of global health initiatives. Forum for Development Studies. 2016;43(1):69-88.

175. Sridhar D. The battle against hunger: choice, circumstance, and the World Bank: Oxford University Press; 2008.

176. Yamin AE, Bazile J, Knight L, Molla M, Maistrellis E, Leaning J. Tracing shadows: how gendered power relations shape the impacts of maternal death on living children in sub Saharan Africa. Soc Sci Med. 2015;135:143-50.

177. Richards E, Theobald S, George A, Kim JC, Rudert C, Jehan K, et al. Going beyond the surface: gendered intra-household bargaining as a social determinant of child health and nutrition in low and middle income countries. Soc Sci Med. 2013;95:24-33.

178. Freedman LP. Implementation and aspiration gaps: whose view counts? Lancet. 2016;388(10056):2068-9.

179. Darmstadt GL, Bhutta ZA, Cousens S, Adam T, Walker N, de Bernis L. Evidence-based, cost-effective interventions: how many newborn babies can we save? Lancet. 2005;365(9463):977-88.

180. Memirie ST, Metaferia ZS, Norheim OF, Levin CE, Verguet S, Johansson KA. Household expenditures on pneumonia and diarrhoea treatment in Ethiopia: a facility-based study. BMJ Global Health. 2017;2(1).

181. Stanford Encyclopedia of Philosophy. Moral relativism. Stanford Encyclopedia of Philosophy. Online access; https://plato.stanford.edu/entries/moral-relativism/ July 7th 2017.

182. Nussbaum MC. In defence of universal values. Women and human development : the capabilities approach. Cambridge; New York: Cambridge University Press; 2000.

183. Nussbaum MC. Adaptive preferences and women's options. Women and human development : the capabilities approach. Cambridge; New York: Cambridge University Press; 2000.

184. Sen A. Rights and capabilities. Resources, values and development: Harvard University Press; 1984.

185. Nussbaum MC. Women and human development : the capabilities approach. Cambridge; New York: Cambridge University Press; 2000.

186. Dickson KE, Simen-Kapeu A, Kinney MV, Huicho L, Vesel L, Lackritz E, et al. Every newborn: health-systems bottlenecks and strategies to accelerate scale-up in countries. Lancet. 2014;384(9941):438-54.

187. Burden C, Bradley S, Storey C, Ellis A, Heazell AE, Downe S, et al. From grief, guilt pain and stigma to hope and pride: a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. BMC Pregnancy Childbirth. 2016;16:9.

188. Lincoln YS, Guba EG. Establishing Trustworthiness. Naturalistic inquiry. Beverly Hills, Calif: Sage Publications; 1985.

189. Leung L. Validity, reliability, and generalizability in qualitative research. J Family Med Prim Care. 2015;4(3):324-7.

190. Onarheim KH, Taddesse M, Norheim OF, Abdullah M, Miljeteig I. Towards universal health coverage for reproductive health services in Ethiopia: two policy recommendations. Int J Equity Health. 2015;14:86.

191. Østebø MT, Cogburn MD, Mandani AS. The silencing of political context in health research in Ethiopia: why it should be a concern. Health Policy Plan. 2017:czx150-czx.

192. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative Content Analysis. SAGE Open. 2014;4(1):2158244014522633.

193. Kruk ME, Mbaruku G, Rockers PC, Galea S. User fee exemptions are not enough: out-of-pocket payments for 'free' delivery services in rural Tanzania. Trop Med Int Health. 2008;13(12):1442-51.

194. Tolla MT, Norheim OF, Verguet S, Bekele A, Amenu K, Abdisa SG, et al. Out-of-pocket expenditures for prevention and treatment of cardiovascular disease in general and specialised cardiac hospitals in Addis Ababa, Ethiopia: a cross-sectional cohort study. BMJ Global Health. 2017;2(2).

195. Miljeteig I, Melkie A, Berhane F, Dessie E, Onarheim KH. Priorities at the bedside: experiences of catastrophic health expenditures in Ethiopia In: Emanuel EJ, Verguet S, Jamison D, Norheim OF, Ottersen T, Johansson KA, et al., editors. Global health priority-setting: beyond cost-effectiveness. Oxford: Oxford University Press; (forthcoming 2018).

196. Solberg CT, Gamlund E. The badness of death and priorities in health. BMC Medical Ethics 2016;17:(21).

197. Murray CJL, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2197-223.

198. Verguet S, Memirie ST, Norheim OF. Assessing the burden of medical impoverishment by cause: a systematic breakdown by disease in Ethiopia. BMC Medicine. 2016;14(1):164.

199. Verguet S, Memirie S, Taddesse M, Jamison D. Extended cost-effectiveness analysis. In: Emanuel EJ, Verguet S, Jamison D, Norheim OF, Ottersen T, Johansson KA, et al., editors. Global health priority-setting: beyond cost-effectiveness. Oxford: Oxford University Press; (forthcoming 2018).

200. World Health Organization. Working with individuals, families and communities to improve maternal and newborn health: a toolkit for implementation. Geneva: World Health Organization; 2017.

201. Every Woman Every Child. Implementation toolkit in support of the global strategy for women's, children's and adolescents' health 2017 [Available from: http://www.everywomaneverychild.org/h6-toolkit/.

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

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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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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.

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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.

References

Berhane, Y., et al., 1999. Establishing an epidemiological field laboratory in rural areas - potentials for public health research and interventions. The Butajira Rural Health Programme 1987–1999. Ethiop. J. Health Dev. 13, 1–47.

Bhutta, Z.A., et al., 2014. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? Lancet 384, 347–370.

Britto, P.R., et al., 2017. Nurturing care: promoting early childhood development. Lancet 389, 91–102.

Callaghan-Koru, J.A., et al., 2013. Newborn care practices at home and in health facilities in 4 regions of Ethiopia. BMC Pediatr. 13 (1), 198.

Cannon, A., Cook, K., 2015. Infant death and the archaeology of grief. Camb. Archaeol. J. 25, 399–416.

Central Statistical Agency [Ethiopia] and ICF, 2016. Ethiopia Demographic and Health Survey 2016: Key Indicators Report. Addis Ababa, Ethiopia, and Rockville, Maryland, USA).

Einarsdóttir, J., 2004. Tired of Weeping: Mother Love, Child Death, and Poverty in Guinea-Bissau, second ed. University of Wisconsin Press, Madison, WI, USA.

Federal Democratic Republic of Ethiopia Ministry of Health, 2014a. Ethiopia's Fifth National Health Accounts; 2010/2011. Federal Democratic Republic of Ethiopia Ministry of Health, Addis Ababa, Ethiopia.

Federal Democratic Republic of Ethiopia Ministry of Health, 2014b. Health Sector Development Programme IV: Annual Performance Report 2012/2013. Federal Democratic Republic of Ethiopia Ministry of Health, Addis Ababa, Ethiopia.

Gizaw, M., et al., 2014. Trends and risk factors for neonatal mortality in Butajira District, South Central Ethiopia, (1987–2008): a prospective cohort study. BMC Pregnancy Childbirth 14, 64.

Graneheim, U.H., Lundman, B., 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurs. Educ. Today 24, 105–112.

Hampshire, K.R., et al., 2009. Saving lives, preserving livelihoods: understanding risk, decision-making and child health in a food crisis. Soc. Sci. Med. 68, 758–765.

Herbert, H.K., et al., 2012. Care seeking for neonatal illness in low- and middle-income countries: a systematic review. PLoS Med. 9, e1001183.

INDEPTH Network, 2017. Butajira HDSS. Addis Ababa University. http://www.indepth-network.org/member-centres/butajira-hdss, Accessed date: 31 March 2017.

Jewkes, R., Wood, K., 1998. Competing discourses of vital registration and personhood: perspectives from rural South Africa. Soc. Sci. Med. 46, 1043–1056.

Kuruvilla, et al., 2016. The Global Strategy for Women's, Children's and Adolescents' Health (2016–2030): a roadmap based on evidence and country experience. B. World Health Organ 94, 398–400.

Mekonnen, W., Worku, A., 2011. Determinants of fertility in rural Ethiopia: the case of Butajira demographic surveillance system (DSS). BMC Public Health 11, 782.

Miljeteig, I., Norheim, O.F., 2006. My job is to keep him alive, but what about his brother and sister? How Indian doctors experience ethical dilemmas in neonatal medicine. Dev. World Bioeth. 6 (1), 23–32.

Millard, A.V., 1994. A causal model of high rates of child mortality. Soc. Sci. Med. 38, 253–268.

Noordam, A.C., et al., 2015. Care seeking behaviour for children with suspected pneumonia in countries in sub-Saharan Africa with high pneumonia mortality. PLoS One 10, e0117919.

Nordanger, D., 2007. Discourses of loss and bereavement in Tigray, Ethiopia. Cult. Med. Psychiatry 31, 173–194.

Onarheim, K.H., et al., Selling my sheep to pay for medicines - Household priorities and coping strategies in a setting without universal health coverage, in press.

Østergaard, L.R., et al., 2016. “Children get sick all the time”: a qualitative study of socio-cultural and health system factors contributing to recurrent child illnesses in rural Burkina Faso. BMC Public Health 16 (1), 384.

Pankhurst, A., Mariam, D.H., 2000. The iddir in Ethiopia: historical development, social function, and potential role in HIV/AIDS prevention and control. Northeast Afr. Stud. 7, 35–57.

Roalkvam, S., McNeill, D., 2016. What counts as progress? The contradictions of global health initiatives. Forum Dev. Stud. 43, 69–88.

Richards, E., et al., 2013. Going beyond the surface: gendered intra-household bargaining as a social determinant of child health and nutrition in low and middle income countries. Soc. Sci. Med. 95, 24–33.

Sacks, E., 2017. Defining disrespect and abuse of newborns: a review of the evidence and an expanded typology of respectful maternity care. Reprod. health 14, 66.

Sauerborn, R., et al., 1996. Age bias, but no gender bias, in the intra-household resource allocation for health care in rural Burkina Faso. Health Transit. Rev. 6, 131–145.

Scheper-Hughes, N., 1992. Death without Weeping: the Violence of Everyday Life in Brazil. University of california press, Berkeley, CA, USA.

Shaw, B., et al., 2016. Access to integrated community case management of childhood illnesses services in rural Ethiopia: a qualitative study of the perspectives and experiences of caregivers. Health Policy Plan. 31 (5), 656–666.

Sisay, M.M., et al., 2014. A qualitative study of attitudes and values surrounding stillbirth and neonatal mortality among grandmothers, mothers, and unmarried girls in rural Amhara and Oromiya regions, Ethiopia: unheard souls in the backyard. J. Midwifery Wom. Heal 59 (1), S110–S117.

Smørholm, S., 2016. Suffering peacefully: experiences of infancy death in contemporary Zambia. Ethos 44, 333–351.

Sridhar, D., 2008. The Battle against Hunger: Choice, Circumstance, and the World Bank. Oxford University Press, Oxford.

Wang, H., et al., 2016. Global, regional, national, and selected subnational levels of stillbirths, neonatal, infant, and under-5 mortality, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. Lancet 388, 1725–1774.

World Bank, 2016. World Bank Open Data – Ethiopia Data. Washington, D.C. http://data.worldbank.org/country/ethiopia, Accessed date: 25 September 2016.

II

Under review

Selling my sheep to pay for medicines – Household priorities and coping strategies in a setting without universal health coverage

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Abstract

Background: The first month of life is the period with the highest risk of dying. Despite knowledge of effective interventions, newborn mortality is high and utilization of health care services remains low in Ethiopia. In settings without universal health coverage, the economy of a household is vulnerable to illness, and out-of-pocket payments may limit families' opportunities to seek health care for newborns. In this paper we explore intra-household resource allocation, focusing on how families prioritize newborn health versus other household needs and their coping strategies for managing these priorities.

Methods: A qualitative study was conducted in 2015 in Butajira, Ethiopia, comprising observation, semi-structured interviews, and focus group discussions with household members, health workers, and community members. Household members with hospitalized newborns or who had experienced neonatal death were primary informants.

Results: In this predominantly rural and poor district, households struggled to pay out-of-pocket for services such as admission, diagnostics, drugs, and transportation. When newborns fell ill, families made hard choices balancing concerns for newborn health and other household needs. The ability to seek care, obtain services, and follow medical advice depended on the social and economic assets of the household. It was common to borrow money from friends and family, or even to sell a sheep or the harvest, if necessary. In managing household priorities and high costs, families waited before seeking health care, or used cheaper traditional medicines. For poor families with no money or opportunity to borrow, it became impossible to follow medical advice or even seek care in the first place. This had fatal health consequences for the sick newborns.

Conclusions: While improving neonatal health is prioritized at policy level in Ethiopia, poor households with sick neonates may prioritize differently. With limited money at hand and high direct health care costs, families balanced conflicting concerns to newborn health and family welfare. We argue that families should not be left in situations where they have to choose between survival of the newborn and economic ruin. Protection against out-of-pocket spending is key as Ethiopia moves towards universal health coverage. A necessary step is to provide prioritized newborn health care services free of charge.

Key words

Universal health coverage, catastrophic health expenditure, poverty, out-of-pocket expenses, intra-household decision making, resource allocation, newborn health, health care seeking, Ethiopia

Background

I had nothing and I sold the only sheep I had to get treatment for my child. Before my child got sick, I was planning for the future; if the sheep gave birth I could send my children to school. So after I sold my sheep, my plan will fail… When the sheep is not there, what would I do in the future?
(Focus group discussion, mother, rural Ethiopia)

In settings where user fees are high and patients and their families have to pay out-of-pocket for health care services, dilemmas arise regarding the use of available household resources: Should the family give priority to the needs of the sick patient, or the needs of the rest of the family?

Health care systems aim to improve the health and well-being of their populations. Closely tied to this objective is the need to avoid impoverishment when households use health care services. The interconnected relationship between health and financial risk protection has been framed as universal health coverage (UHC), which aims to ensure that everyone obtains the health care services they need without exposing them to financial hardship [1, 2]. The World Health Organization (WHO) recommends financial reforms of health care systems and incorporation of concerns for equity and fairness when countries move towards realization of UHC [1, 3]. UHC has affirmed its global importance as one of the Sustainable Development Goal (SDG) targets [2], and has received attention in national policy and planning. The promising momentum built around UHC needs to be translated into plans and implementation, and many countries have a long way to go. Despite the commitment to the ambitious goal of UHC, direct payments for using health care services, known as out-of-pockets (OOP) payments [4], contribute to half of total health expenditure in low income countries [5]. Without risk pooling through publicly financed health care systems, the economies of households remain vulnerable to illness. In health care systems that rely largely on OOP payments, health care costs can keep or push patients and their families into poverty [6, 7]. In response to high costs and limited health insurance options, households commonly rely on informal insurance through borrowing money and selling assets, known as financial *coping strategies* [7, 8]. In the short run, these strategies can work as buffers and make it possible for families to pay, but in the long run the effects can be damaging for the households and their resources [7, 9, 10]. When OOP payments exceed 40% of the household income after basic needs are met, they can be described as catastrophic [7]. A study from 2007 estimated that 150 million people globally suffer from catastrophic health spending every year [11], indicating the severity of the problem.

One country in which OOP payments are high is Ethiopia, where this study was conducted. Ethiopia is a low-income country in eastern Africa [12]. Remarkable development has been seen in an annual growth between 8 and 12% of gross domestic product (GDP) during the past five years [12], and through an increase of 9.1 years in life expectancy (from 56.1 to 65.2 years) between 2005 and 2015 [13]. While these trends are promising, one third of its population of almost 100 million lives below the poverty line [12].

(Table 1 here)

The total health expenditures per GDP – both public and private – increased from 2.8% in 1995 to 4.7% in 2013 [5] (see Table 1), but are still far from the Abuja Declaration's pledge to allocate 15% of the budget to health. The Ethiopian health care system is underfinanced in absolute numbers. In 2014, the health expenditure per capita was $27, which is substantially lower than what is recommended to uphold access to primary care services in low-income countries ($86) [14, 15]. Financing of health care services rely on OOP payments, and 34% of health care expenses are covered by households [15]. In this context, Ethiopia's ambitious commitment to UHC seems warranted. The national health care system, primary care services and preventive care have been scaled-up through investments in health centers and community health workers (health extension workers). Further, community-based health insurance and social health insurance programs have been piloted in a selection of *woredas* (districts) [16, 17]. However, the increase in utilization of health care services is slow and the majority of the population remains uncovered by health insurance [18, 19].

Every year, worldwide, 2.6 million newborns do not make it through their first 28 days of life [20, 21]. The major causes of neonatal deaths are preterm birth complications, intrapartum-related complications, and sepsis [23]. Despite the magnitude of the problem and knowledge of effective health care services for treating and preventing these conditions [23], the decline in mortality has been slower for newborns than for older children [20]. Although newborn mortality in Ethiopia declined from 47 to 29 newborn deaths per 1000 live births between 2005 and 2016 [18], neonatal disorders contributed to 14% of the burden of disease and 61600 newborns deaths [24]. Newborn health has been prioritized in Ethiopian health plans, which has put emphasis on upgrading the quality of child and maternal health services and facilities [25]. Increasing utilization of effective interventions could avert newborn deaths [23], but coverage of essential newborn health care services remains low and unequally distributed. A newborn from a poor family, rural area or which the mother has low education is less likely to receive health services than other newborns (see Table 2) [18, 19]. Ethiopian households pay a larger share of health expenditures for children (48%) than for adults (34%) [15], pointing to the importance of studying family priorities. Globally, the literature on user-fees and utilization of newborn health care services is limited, and there are no studies from Ethiopia. The few studies that exist on OOP payments of hospital care for sick newborns find that costs are high, in particular for inpatient services and longer stays, where payments often exceed family income in low income families [26, 27]. Beyond the problem of health service delivery, structural barriers and social norms influence health care seeking. Earlier studies have shown a delay in recognition of personhood in Ethiopia, with implications for newborn illness and death [28].

(Table 2 here)

In this setting without UHC, it becomes crucial to understand how families make choices about care seeking for newborns and health care spending. Decision making at the household level can be understood as intra-household resource allocation, where families make decisions about expenditures on health care, food, transportation, and other goods. Whereas the literature on UHC has identified dilemmas and trade-offs at the policy level [3], little is known about how households with limited resources prioritize between health and other needs. To understand more about intra-household resource allocation, family priorities regarding care seeking for newborns are of particular importance. Sick newborns require urgent care, and cannot make decisions themselves. In this study, we aim to explore intra-household resource allocation, focusing on how families prioritize newborn health and household needs in Ethiopia. Furthermore, we seek to explore coping strategies families use to manage these priorities.

Methods

Study setting

The study was conducted in the semi-urban town of Butajira and surrounding rural area. Butajira is situated in Gurage Zone three hours south of Addis Ababa. This area consists of farmland, in which the literacy levels are low and the poverty rate is high [29, 30]. The total fertility rate in the area is 5.3 [29]. The majority of the population are Muslims and Orthodox Christians.

Social and community-based health insurance schemes had not been implemented in Butajira at the time of data collection (October-November 2015). Butajira has one public and one private hospital to serve the population, with associated health centers in proximity of the town. The public hospital, as a part of the new three tier organization of the Ethiopian health care system, serves a population of 1–1.5 million. The hospital is open 24 hours a day, and there is a health care professional on call, but services such as laboratory and radiology are fully open only during office hours on weekdays. The hospital commonly has experienced shortages of drugs at the pharmacy and missing equipment. The pediatric unit consisted of 50 beds, and on weekdays one or two doctors were doing rounds at the ward.

In Butajira there is a health and demographic surveillance site: the Butajira Rural Health Program (BRHP). Established in 1987, BRHP registers and monitors births and deaths, and collects data on fertility and mortality in nine rural and urban kebeles (villages) [30, 31]. Information from BHRP facilitated data collection and identification of participants.

Data collection and analysis

We chose a qualitative study design to capture the nuances and complexities in household decision making.

Data collection methods comprised in-depth interviews (IDIs) and focus-group discussions (FGDs), as well as observation and registration of costs of drugs, diagnostics, and other health care services. We conducted 41 IDIs with focus on direct experiences of newborn illness and 7 FGDs with emphasis on community perceptions (4-8 participants per FGD). There were three categories of participants with the aim of understanding family priorities from different perspectives: 1) household members that were experiencing newborn illness or had experienced newborn deaths the previous year (IDIs), 2) health workers involved in newborn or child health care (IDIs and FGDs), and 3) community members (FGDs) (see table 3). The triangulation in methods and type of participants was intended to increase credibility of the study. Informants were recruited purposively by the primary investigator (PI; KHO) and research assistant (RA; MG) at the hospital, and community members and health workers were recruited through collaboration with the BRHP.

(Table 3)

The interviews focused on illness and care for the newborn, what costs the family had faced, and the impacts of seeking care for the newborn and the rest of the family. Attention was given to what was perceived as most important for the family when making decisions about care for the newborn.

By observation in the public hospital and in the participants' homes, we aimed to gain additional understanding about family priorities and impacts of health-care seeking on the newborns and their families. Daily notes were taken and used for early analysis. Data about costs of health care services and related costs were collected in the public hospital, health center, and pharmacies, including costs of stay, drugs [32], equipment, procedures, diagnostics, and transportation. Interviews were conducted by the PI and RA in Amharic or English, depending on the informants' preferences.

During data collection, the PI and RA discussed the topics that came up during daily debriefings. Interview guides and topic guides were revised based on impressions and insights from data collection, and issues of particular interest were given further attention in subsequent interviews and in observations. The data were transcribed and translated from Amharic to English, and the written material was analyzed drawing upon qualitative content analysis [33]. Following preliminary analysis from data collection, the material was read in detail, organized, and coded by the PI, assisted by NVivo11 (http://www.qsrinternational.com). Preliminary findings were discussed continuously by the team of authors during analysis and writing.

Ethical considerations

The study was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University, Ethiopia, and by the Regional Ethical Committee, Helse Vest, Norway. Informed consent (written or by fingerprint) was obtained from potential participants after they had received information about the study, the opportunity to take part, and indication that participation was voluntary. Participants received 100 birr (5 USD) to compensate for their time; this was a typical amount given to participants in previous studies in the area [34].

Availability of data and materials

The data material cannot be made publicly available or available upon request in order to protect the identity of the participants of the study.

Results

With limited money at hand, families had to strike between giving priority to long term economic security for the family on the one hand and taking the risk of spending scarce resources to save the life of the newborn on the other. The following section will describe how families faced tough choices between conflicting needs within the households. First, costs were perceived as a big burden, and families struggled to pay for health care and other expenses. Second, with limited money at hand, families faced hard choices, weighing concerns regarding survival of the newborn and damaging effects on the welfare of the family. Third, common coping strategies used to pay for drugs, diagnostics, transportation, and other costs were to borrow from others or sell their assets. Fourth, when these coping strategies failed or were not feasible, poor families waited before seeking care or did not seek care at all, with dangerous consequences for the sick newborns.

Figure 1 illustrates decisions families had to make in the process of seeking care, spending resources, and following health care professionals' advice. In making these decisions, families used financial coping strategies and made care-seeking adjustments, and health workers made adjustments aiming to influence families' decisions on care seeking.

(Figure 1)

Facing high costs: 'You have to pay for everything'

The costs of seeking care could be very high, and the costs troubled family members before, during, and after having used health care services. While delivery care was provided free of charge at the public hospital, families had to pay for services when the newborn was transferred to the neonatal unit in the same hospital. Community members noted that services were said to be provided for free, but in reality there were costs 'for everything'.
First you need money for card [the hospital's individual patient record], then for laboratory, after that you need money to buy medicine and if the disease is severe, you need money for bed/admission, IV, injection. There is nothing free at the hospital. You have to buy everything. (FGD, mothers, rural area)

Through observation at the hospital, we saw that for every new procedure or diagnostic test used, another amount was added to the bill. The families received information on how much they had to pay when they left the hospital. In addition to this bill, mothers or other household members were instructed by the doctors to buy drugs and other equipment, which could be bought at the hospital's pharmacy or outside when the drugs were not available. Services provided at health centers or by health extension workers were less expensive or for free, but mothers described that drugs and other treatment were often not available there, which made it necessary to go to the hospital to get treatment. Health workers explained how the worry about costs made some fathers prefer treatment at lower-level facilities.

In addition to the direct expenses, families faced increased spending on food or other goods while away from home. Husbands and other family members went back and forth bringing food, gathering more money, or taking care of children who remained at home. Costs for transportation to health facilities by horse, public transport or ambulance could be high. While ambulances were most often free of charge for mothers, they could be difficult to get hold of during night, and payments could be required for refueling after transportation to or from rural areas. Furthermore, long-distance travel to Addis Ababa for cases of referral could cost up to 1000 birr (45 USD) for the ambulance alone.

The families we met at the hospital and in follow-up interviews experienced high OOP payments, ranging from 600 (27USD) to 7000 birr (314 USD). These expenses included fees for health services, transportation, and other expenses related to seeking health care. Family and community members repeated how these expenses hampered care seeking, caused delay in seeking care, and burdened families with economic stress and worry.

Making hard choices: 'To treat the baby and let the family starve – or not"

When newborns fell ill, families faced a series of decisions about seeking care, paying for care, and whether to follow medical advice (Figure 1). Mothers and community members described the conflict between potential worsening of the baby's health on the one hand, and risking unbearable costs and consequences for the family when taking the newborn to hospital on the other.

Let us say a person has an ox with which he farms his land. If he sells this ox to be able to pay for treatment for his child, he will have nothing to fend his family with. In the end the family will be starved. They view this situation as a harmful thing. On the other hand, if he pays and treats his child, that is something you could call useful. (FGD, nurses and midwives, urban area)

Mothers and fathers who had experienced newborn illness or death, health workers, and community members all emphasized the challenges of making these choices, but had somewhat diverging opinions on how these concerns should be weighted.

What mattered most to many mothers was saving the baby. When the baby was born too early or would not suck or in some other way needed care, mothers explained that they would seek care even if that meant leaving other children back home or selling their belongings.

Human life and money are different things. Money is such a thing that we can get it if we work, but human life is irreversible if it's once lost… It is understandable to think about the money, but whatever the fee is, there is nothing more precious than life. So we decided to bring him to health facility and spent all our money. We try to balance based on what we have, but we are worried about the money. (Mother experiencing newborn illness 6, urban area,)

Fathers and community members expressed worry regarding other family members and the consequences that seeking health care for the newborn would have on them. They stated that they could not be concerned only about the newborn, but had to think about the rest of the family as well. Health workers explained that when newborns and older children were admitted for longer stays, and they faced high costs, but with little improvement, the fathers wanted to leave the hospital. As head of households, fathers expressed concerns about the family as a whole.

They don't want to spend a lot of money for one child when they have like seven or six back home. They are trying to find other ways to deal with the problems. (Health worker 12, urban area)

Aiming to convince the families to stay, health workers explained that they negotiated with the families concerning health care for the babies. Yet, some family members said that *"they won't sacrifice the whole family for only one child"*. At the same time, the nurses and doctors noted the lack of options for poor families, and how these families could not prioritize concerns for the baby over the family economy.

The mothers' presence at the hospital was difficult for those staying back home, as she was the primary care taker of the children and the one who managed cooking, feeding, and other needs. Mothers and family members at the hospital expressed worry about the rest of the household. Who would take care of the ones back home? Did the other children eat enough? If the parents were not at home or spent all the money on the sick newborn, the other children would suffer. One mother explained:

If I go to the hospital with my child, there is no one who can properly give food for the others, there is no one to wash them or send them to school properly. They will not go to school and also there will be no one to buy them books. (FGD, mothers, rural area)

Although the decisions and consequences for the newborns and the families varied, many families, and mothers in particular, found dealing with the burdens of illness and economic stress emotionally challenging, and experienced a sense of powerlessness. The ambiguous feelings related to the desire to take the sick baby to the hospital and the needs of the family as a whole caused worry during illness and admission. Some parents in urban areas were aware of medical treatment, and one father described the suffering when not managing to access adequate care in time. Their girl, who was born with fetal abnormalities, died while the family was mobilizing resources to go to Addis Ababa for referral.

We were planning to take her there, and we tried, but we didn't had enough money, and she died before I took her to Tikur Anbessa (tertiary hospital in Addis Ababa). I do cleaning in this city, which is how I live my life. If I stopped working to take care of *her (the sick baby), my children would starve to death. I sold two hundred kg of maize, which was a reserve for future consumption for 1000 birr (45 USD) because there wasn't any other option. I was trying to get 2000 birr (90 USD). Since I didn't have enough money, she died before I took her there. I feel sad for not getting her treated; I would have felt better if she died while getting treatment at Tikur Anbessa. I swear to God, I get a headache whenever she crosses my mind; she didn't get what she was supposed to get. The fact that I was unable to get her the treatment that she needed breaks my heart. (Father experiencing newborn death 2, urban area)*

Finding a way to pay for care: 'Selling my sheep'

After deciding to seek care for the sick newborns, families used different strategies to manage the high expenses they experienced. When a mother worried that her baby was sick, and wished to seek care, she needed money and had to mobilize resources. It was unusual to have cash available for care when someone fell sick, and the everyday economy depended on the families' resources and exchanges of food, animals, land or other goods and assets. Many fathers were day laborers, where job opportunities and income could change from one day to the next. In these circumstances, families often had no money at hand nor were they prepared for the high expenses when someone fell ill.

People living in the rural parts of the country do not save up money, which they could use as a health insurance. They don't think they need money as a back-up if their child becomes ill. They often pawn their land or sell their herd to seek medical treatment for their sick children. Sometimes they ask us to be patient for the payments at the hospital when the money doesn't arrive on time. (FGD, nurses and midwives, urban area)

When both parents worked or the family had money available, their savings were the first option for covering the costs. However, few families had savings available, and the common strategy was to borrow from family members, friends or contacts in the neighborhood. To earn the money for repayment, the parents – often the fathers – had to work more or sell their harvest, animals or other assets. Staying at the hospital could be particularly damaging when the father lost income during the harvest season. One husband explained how they found money, and had to pay it back:

Anyone who has the capacity will take money from home. A person who doesn't have the money will borrow from close relatives or friends. In this way people will take their children to the health facility. After the child is cured the parents are obliged to pay the money they borrowed. If he has a tree that is ready he might sell some of it and pay his dept. The person may have a property like an ox, calf, sheep or goat. If the debt is small, he might sell the sheep and pay his dept. If the debt is large, he might sell two or three calves. If it is more than that or if his wife is ill, he has to sell the ox. (FGD, husbands, rural area)

For some, paying back their debt was very difficult. There was less money for food or other resources, and one mother explained how her husband who was in debt had to leave his family for a while.

I got treatment for my first child from the hospital and they charged us a lot of money. We did not have anything left after, and my husband was hiding. After a long time we *were able to borrow money from a relative. Then we worked, and after some time we were able to pay the debt (FGD, mothers, rural area)*

At the hospital, mothers and families helped each other when they were out of money. They borrowed from each other, or gave money, drugs or food to mothers who did not have anything. Almost all mothers who had been in the hospital with their babies gave or received support from others in forms of money, drinks or medicines during their stay.

None of the families had made use of health insurance, nor did they mention it as a strategy to deal with high expenses. One family explained that they had heard about the introduction of a health insurance scheme. Health workers and religious leader described that the *kebele* (village) had a support system to aid poor people. Health workers explained that through this system, poor families could seek support to cover treatment costs. For care to be provided for free or at a reduced rate, a letter would have to be signed by leaders in the local kebele, based on a statement from one or more witnesses about the deprived economic status of the household. The husbands noted that this could be a time-consuming process at a time where urgent care was needed.

When there are no assets to mobilize: 'If the mother doesn't have money, how can she take the child to the health facility?'

The poorest households or families with small networks could not rely on the previously described coping strategies. Neighbors and acquaintances were hesitant to lend them money, worrying that they would not be able to pay them back. Thus, poor families altered and adjusted their care seeking in accordance with the available resources. These strategies became visible through delays in health-care seeking, use of other types of care, or inability for families to follow the given medical advice.

Only when the men have cattle, sheep and goat they will borrow – then they will be confident to receive their money by selling those assets. If someone doesn't have any assets, no one is willing to give credit. Rather, they recommend different types of traditional medicine, saying it is better to give him some plant leaves, or explaining that it might be the devil and smoke some plastic sheets – (this advice is given) because of the fear that if I give him credit, he may not return (the money). But if the person has assets they are easily willing to give. (FGD, religious leaders, urban area)

When families did not have money, they were advised by friends or neighbors to use traditional medicine, which was substantially cheaper, or that the illness was caused by evil spirits or by bad spirit possessions. Health workers experienced that poor families came late, or with complicated cases, as they had waited a long time, even days, to get money. Mothers, community members and health workers noted that this deferral resulted in complications of illness.

There were some exceptions of mothers who left home with no money to seek care for their children. However, when they did so, they were aware of a way to recover the costs later. Families without money or support from others were not able to go to the

hospital in the first place. They waited and hoped for the baby to get better, or were trying to get money to seek care. While waiting, some sick newborns did not make it to hospital, and did not survive. Further, families with some money faced similar challenges when they had borrowed or sold what they had, then struggled to follow the advice from the doctor and nurses about further treatment or referral. Newborns that needed care that was not available at the hospital were referred to higher level care, for tests at private health clinics or to hospitals in Addis Ababa. For referrals to Addis Ababa, the expected expenses for treatment and transportation were very high, and with limited resources families could not follow the recommendations. Health workers and household members described families who had been saving money, but in the meantime the condition of the baby worsened and became critical.
The mother didn't have the means to take her baby to Tikur Anbessa (central referral and teaching hospital), and she was forced to see her baby die at home. (FGD, nurses and midwives, urban area)

Health care providers modified their recommendations in various ways if they recognized that costs were high and the fathers, or both parents, were hesitant or unable to pay. They tried to convince the family to seek care or to stay at the hospital, but if unsuccessful they suggested and provided some sort of treatment. Health workers repeatedly explained how they made use of leftover medications or tried to find alternative treatment options. These could include out-patient instead of in-patient services, fewer diagnostic tests or second-best medications. For very poor families or the rare cases of abandoned children, they even paid for drugs themselves.

Discussion

The health-welfare choices

This study illustrates families' real-life dilemmas when newborns fall ill in a setting without UHC. In this deprived area, high health care costs and related expenses left families in situations where they had to choose between conflicting needs: Should the family sell their sheep to seek treatment for the baby? In other words, should individual health gains be compromised for concerns for family welfare? These hard choices between the newborn and the welfare of the family played out in every decision made, illustrated by three central decision steps for families (Figure 1). First, should the family seek care? Second, should the family spend money on health care, and if so, how should they pay for services? Third, should they follow medical advice, and if so, how would they deal with the costs? The answers to these questions and the decisions made had implications for the whole family and their future. In intra-household resource allocation, families made compromises with effects on welfare and health outcomes. On welfare, families used financial coping strategies, such as borrowing or selling. On health, families adjusted the ways in which they sought health care. For the very poor living on the margin, the informal financial support mechanisms were not available, and through waiting for money and seeking other types of care, families made compromises affecting the health of the newborn.

Methodological concerns

Some important methodological concerns should be noted. While this study focused on affordability, services must also be available, accessible, and appropriately and equitably delivered. Bottlenecks in the health workforce, financing, and service delivery create barriers to ensure essential maternal and newborn health care [35]. Families explained that health posts or health centers were not always effective or even open. The low quality of care at some facilities is another important reason as to why families do not seek care [36]. Beyond these barriers, we believe that this in-depth study has extended our understanding through descriptions of the role that family priorities and coping strategies play in care seeking.

The key informants in the study were primary care takers that had experienced newborn illness or death, which brought unique and rich descriptions of intra-household resource allocation in these families. Community and health worker perspectives, observations, and knowledge of health service prices enabled triangulation of the sources of information. The results were presented and discussed with key stakeholders in Butajira (April 2017), which further strengthens the trustworthiness of the study. We chose deliberately to study families' priorities and the trade-off between health and welfare in families from the perspective of newborn health. It should be noted that newborn deaths and stillbirths receive less attention than deaths of older children and adults [28], which might delay care seeking for newborns, as compared to adults. Further study on intra-household resource allocation between family members is needed [37].

We aimed to establish confidence in the discussion of sensitive issues through IDIs at the hospital and follow-up interviews at homes, and felt privileged but saddened to hear about these families' hard choices and dilemmas. The PI is a Norwegian medical doctor, and her understanding has shaped research questions, data collection, and analysis. Her earlier clinical experiences are mainly from settings where high quality health care services are provided for free. Her background and values may have made her particular attentive to the role of costs in care seeking, and potentially giving less emphasis to other important aspects of seeking health care for newborns. To better understand the local setting and perceptions, norms, and values, the data collection and analysis was conducted in close collaboration with MG and MM, who have extensive experience doing research in the area. While the 'outsider' view might have limited our understanding, it also made it possible to explore questions that an 'insider' could not have asked, such as *why* they would give priority to the health of the newborn or to the welfare of the household.

Household priorities in poverty settings

Banerjee and Duflo's important work on the complex economic lives of the poor describes how people living in poverty have higher risks of unfortunate events, and how changes in income or high expenses have relatively larger impacts on their already limited expenditures [38]. High health care expenses can be a burden, or even a catastrophe, for patients and their families, and can lead to impoverishment. In Butajira, as seen elsewhere [7, 9–11], financial coping strategies, such as borrowing money and selling assets, were used as a source of informal insurance that enabled families to seek care. However, the poor cannot rely on the same coping mechanisms, and are not protected against catastrophic health expenditure through these informal community-based strategies [38-40]. This study described how families experiencing illness in a setting without social and community-based health insurance faced large economic stress and high OOP expenses. This seemed to be in particular damaging for the poor, who did not have access to financial coping strategies and made adjustments when choosing if and when to seek care.

The circumstances in Butajira – with high poverty, low literacy, and varying quality and availability of care – shaped families' abilities to make choices. Despite aspirations and expressed wishes to seek care, the unbearable costs of care and concern for the family's future represented a persistent challenge. From a societal perspective, we argue that these families and patients – and in particular poor families – did not have the opportunity to seek health care and be healthy. Amartya Sen, in his capabilities approach, argues that policies should be judged based on the freedoms or capabilities people have to 'lead the kind of lives they value – and have reason to value' [41]. Therefore, when studying household priorities, we must also look at their capacity to make free choices [41, 42]. Families' decisions that directly or indirectly delayed care seeking in Butajira can be understood as a choice between family welfare and newborn health, where poor families gave priority to family welfare over newborn health. Others could claim that the repeated efforts by family members to seek care, despite harmful consequences, imply that they might have chosen to seek care if they had money, but were limited by actual opportunities. We argue that the ability to pay was decisive for the actual opportunity to seek health care, and that families, and in particular the newborns, do not have the capability to lead the kinds of lives we assume they would have reason to value. Building on Sen's approach, we argue that, from a societal perspective, this injustice must be addressed by policies that secure families actual opportunities to seeking- and paying for care.

UHC, financial risk protection, and newborn health care services in Ethiopia

Child and maternal health services are supposed to be provided free of charge at the health center level, but families struggled with high expenses for newborn care at the hospital. Formal health insurance was not available in Butajira, and the ability to seek care, pay, and follow medical advice depended on the economic situation of the household. This finding illustrates the reality of patients and their families in a health care system that relies on OOP spending [5], and is in line with other studies describing the large burden of OOP costs in Ethiopia [43, 44]. In realization of UHC, WHO recommends that national policy makers set priorities regarding which services to cover, who should be covered, and how to proceed from OOP spending towards prepayment systems [1, 3]. OOP cannot be eliminated for all services at once, and WHO recommends eliminating co-payments on high-priority services [3], which can be promoted through prepayment and risk pooling by using health insurance schemes and reimbursement systems. The burden of newborn mortality remains high, and if newborn health care is a continued priority towards UHC in Ethiopia [25], efforts to reduce or eliminate co-payments of these and other priority services is necessary.

Although there are limitations in the quality of published studies, removal of user fees has generally been associated with increased utilization of health care services [45, 46]. However, studies have shown disruptive effects when user-fee removal is implemented in unstable health systems [47], and the varying impact on health outcomes highlights the importance of quality of care [48]. The removal of user fees may have positive effects on welfare, seen in the reduction of OOP expenses and catastrophic health expenditure [40, 49]. One year after abolishing user fees for children in Burkina Faso, the risk of households experiencing expenses at health facilities was reduced by two-thirds [49]. In Ethiopia, a pilot community-based health insurance scheme was introduced in 13 *woredas* (districts) in 2011. The pilot found increases in outpatient health care utilization and reductions in the need to borrow [16, 17]. Current efforts under the Ethiopian Health Insurance Agency to introduce voluntary community-based health insurance to individuals and families in the informal sector, and compulsory social health insurance through the formal sector, are promising steps in accelerating progress towards UHC [50]. However, these initiatives are not scaled-up nationwide, and leaving 95% of the population without health insurance [18]. Further, coverage of high priority newborn health services remains low, as seen in slow increase of postnatal care from 7% in 2005 to 17% in 2016 [18, 19]. With this as a backdrop, our findings illustrates that the reality is far from the ambitious goal of UHC, and efforts must be accelerated to realize UHC.

Conclusions

When countries move towards UHC, financial risk protection from catastrophic spending on health care is essential for improved health and in avoiding harmful effects on family welfare. This study describes how families in Butajira, without risk pooling and prepayment systems in place, faced hard choices when their newborns fell ill. In intra-households resource allocation families balanced conflicting concerns to newborn health and family welfare. To manage and cope with the high costs, families borrowed money, sold assets and adjusted their care seeking. From a societal perspective, we argue that families should not be left in situations where they have to choose between health and welfare, between the survival of the newborn and selling their sheep. Steps towards UHC and efforts to secure financial risk protection through implementation of community-based health insurance and social health insurance are promising. Prioritized essential child-health services, including neonatal health care services, should be delivered free of charge to protect against financial catastrophe and to improve newborn survival.

Declarations

Ethics approval and consent to participate

The study was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University, Ethiopia, and by the Regional Ethical Committee, Helse Vest, Norway. Informed consent (written or by fingerprint) was obtained from potential participants after they had received information about the study, the opportunity to take part, and indication that participation was voluntary. In obtaining informed consent, participants were informed that it would not be possible to identify the participant and his or her family in the presentation of the results of the study.

Consent to publish

Not applicable.

Competing interests

The authors declare not to have any financial and non-financial competing interests.

Authors' contributions

KHO, IM, OFN, MM and KMM developed the idea for the study. KHO, MG and MM collected the data. KHO analyzed the data in collaboration with IM, OFN, KMM, MM, and MG. KHO prepared the first draft of the manuscript. All authors read and approved the final manuscript.

Availability of data and materials

The data material cannot be made publicly available or available upon request in order to protect the identity of the participants of the study.

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Abbreviations

FGD – focus-group discussions
GDP – gross domestic product
IDI – in-depth interviews
OOP – out-of-pocket
PI – primary investigator
PPP – purchasing power parity

RA – research assistant
SDG – sustainable development goal
SSA – sub-Saharan Africa
UHC – universal health coverage
WHO – World Health Organization

References

1. World Health Organization. **The World Health Report 2010: Health systems financing: The path to universal coverage.** Geneva: World Health Organization; 2010.
2. United Nations. **Transforming our world: the 2030 Agenda for Sustainable Development. vol. 2016**. New York: United Nations; 2015.
3. World Health Organization. **Making fair choices on the path to universal health coverage: Final report of the WHO consultative group on equity and universal health coverage.** Geneva: World Health Organization; 2014.
4. World Health Organization. **Out-of-pocket payments, user fees and catastrophic expenditure**, vol 2017. World Health Organization; http://www.who.int/health_financing/topics/financial-protection/out-of-pocket-payments/en/ [accessed 18 Jun 2017]
5. Dieleman JL, Templin T, Sadat N, Reidy P, Chapin A, Foreman K, et al. **National spending on health by source for 184 countries between 2013 and 2040.** Lancet. 2016;**387:**2521-35.
6. McIntyre D, Thiede M, Dahlgren G, Whitehead M. **What are the economic consequences for households of illness and of paying for health care in low- and middle-income country contexts?** Soc Sci Med. 2006;**62:**858-65.
7. Xu K, Evans DB, Kawabata K, Zeramdini R, Klavus J, Murray CJL. **Household catastrophic health expenditure: a multicountry analysis.** Lancet. 2003;**362:**111-7.
8. Leive A, Xu K. **Coping with out-of-pocket health payments: empirical evidence from 15 African countries.** B World Health Organ. 2008;**86:**849-56.
9. Kruk ME, Goldmann E, Galea S. **Borrowing and selling to pay for health care in low- and middle-income countries.** Health Aff. 2009;**28:**1056-66.
10. Flores G, Krishnakumar J, O'Donnell O, van Doorslaer E. **Coping with health-care costs: implications for the measurement of catastrophic expenditures and poverty.** Health Econ. 2008;**17:**1393-412.
11. Xu K, Evans DB, Carrin G, Aguilar-Rivera AM, Musgrove P, Evans T. **Protecting households from catastrophic health spending.** Health Aff. 2007;**26:**972-83.
12. **Ethiopia - Country profile.** The World Bank Group, Washington, D.C.. 2016. http://data.worldbank.org/country/ethiopia [accessed 25 Sept 2016]
13. Wang H, Naghavi M, Allen C, Barber RM, Bhutta ZA, Carter A, et al. **Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015.** Lancet. 2016;**388:**1459-544.

14. McIntyre D, Meheus F, Røttingen J-A. **What level of domestic government health expenditure should we aspire to for universal health coverage?** Health Economics, Policy and Law. 2017;**12**(2):125-37.
15. Federal Democratic Republic of Ethiopia Ministry of Health. **Ethiopia's fifth national health accounts; 2010/2011.** Addis Ababa, Ethiopia: Federal Democratic Republic of Ethiopia Ministry of Health; 2014.
16. Mebratie AD, Sparrow R, Yilma Z, Abebaw D, Alemu G, Bedi A. **Impact of Ethiopian pilot community-based health insurance scheme on health-care utilisation: a household panel data analysis.** Lancet. 2013;**381 Suppl 2:**S92.
17. Yilma Z, Mebratie A, Sparrow R, Dekker M, Alemu G, Bedi AS. **Impact of Ethiopia's Community Based Health Insurance on Household Economic Welfare.** The World Bank Economic Review. 2015;**29 Suppl_1:**S164-S73.
18. Central Statistical Agency (CSA) [Ethiopia] and ICF. **Ethiopia Demographic and Health Survey 2016.** Addis Ababa, Ethiopia, and Rockville, Maryland, USA: CSA and ICF; 2016.
19. Central Statistical Agency (CSA) [Ethiopia] and ICF. **Ethiopia Demographic and Health Survey 2011.** Addis Ababa, Ethiopia, and Rockville, Maryland, USA: CSA and ICF; 2011.
20. Wang H, Bhutta ZA, Coates MM, Coggeshall M, Dandona L, Diallo K, et al. **Global, regional, national, and selected subnational levels of stillbirths, neonatal, infant, and under-5 mortality, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015.** Lancet. 2016; **388:**1725-1774.
21. World Health Organization. **Infant, Newborn, vol. 2016**: World Health Organization; 2016. http://www.who.int/topics/infant_newborn/en [accessed 12 Oct 2016]
22. Liu L, Oza S, Hogan D, Perin J, Rudan I, Lawn JE, et al. **Global, regional, and national causes of child mortality in 2000–13, with projections to inform post-2015 priorities: an updated systematic analysis.** Lancet. 2015;**385**:430-40.
23. Bhutta ZA, Das JK, Bahl R, Lawn JE, Salam RA, Paul VK, et al. **Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost?** Lancet. 2014;**384:**347-70.
24. **GBD Results Tool.** Global Health Data Exchange, Institute of Health Metrics and Evaluation, Seattle. 2016. http://ghdx.healthdata.org/gbd-results-tool [accessed 7 Dec 2016]
25. Federal Democratic Republic of Ethiopia Ministry of Health. **Health Sector Development Programme IV: Annual Performance Report 2012/2013.** Addis Ababa, Ethiopia: Federal Democratic Republic of Ethiopia Ministry of Health; 2014.
26. Srivastava NM, Awasthi S, Agarwal GG: **Care-seeking behavior and out-of-pocket expenditure for sick newborns among urban poor in Lucknow, northern India: a prospective follow-up study**. BMC Health Services Research 2009, **9**(1):61.
27. Ekwochi U, Osuorah DC, Ndu IK, Ezenwosu OU, Amadi OF, Nwokoye IC, Odetunde OI: **Out-of-pocket cost of managing sick newborns in Enugu, southeast Nigeria**. Clinicoecon Outcomes Res 2014, **6**:29-35.

28. Sisay MM, Yirgu R, Gobezayehu AG, Sibley LM. **A qualitative study of attitudes and values surrounding stillbirth and neonatal mortality among grandmothers, mothers, and unmarried girls in rural Amhara and Oromiya regions, Ethiopia: Unheard souls in the backyard.** J Midwifery Wom Heal. 2014;**59 Suppl 1:**S110-17.
29. Mekonnen W, Worku A. **Determinants of fertility in rural Ethiopia: the case of Butajira Demographic Surveillance System (DSS).** BMC Public Health. 2011;**11:**782.
30. Berhane Y, Byass P. **Butajira DSS Ethiopia. In: Population and health in developing countries. Volume 1. Part III. INDEPTH DSS site profiles.** Ottawa: International Development Research Centre; 2002. pp. 135-42.
31. Berhane Y, Wall S, Kebede D, Emmelin A, Enquselassie F, Byass P, et al. **Establishing an epidemiological field laboratory in rural areas - potentials for public health research and interventions. The Butajira Rural Health Programme 1987-1999.** Ethiop J Health Dev. 1999;**13:**1-47.
32. World Health Organization: **WHO Model List of Essential Medicines for Children, 4th list.** Geneva: World Health Organization; 2013.
33. Graneheim UH, Lundman B. **Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness.** Nurs Educ Today. 2004;**24:**105-12.
34. Molla M, Mitiku I, Worku A, Yamin A. **Impacts of maternal mortality on living children and families: A qualitative study from Butajira, Ethiopia.** Reprod Health. 2015;**12 Suppl 1:**S6.
35. Dickson KE, Simen-Kapeu A, Kinney MV, Huicho L, Vesel L, Lackritz E, et al. **Every Newborn: health-systems bottlenecks and strategies to accelerate scale-up in countries.** Lancet. 2014;**384:**438-54.
36. Kruk ME, Leslie HH, Verguet S, Mbaruku GM, Adanu RMK, Langer A. **Quality of basic maternal care functions in health facilities of five African countries: an analysis of national health system surveys.** Lancet Glob Health. 2016;**4:**e845-55.
37. Sauerborn R, Berman P, Nougtara A. **Age bias, but no gender bias, in the intra-household resource allocation for health care in rural Burkina Faso.** Health Transit Rev. 1996, **6:**131-145.
38. Banerjee AV, Duflo E. Poor economics: a radical rethinking of the way to fight global poverty. 1st ed. New York: PublicAffairs; 2011.
39. Chuma J, Maina T. **Catastrophic health care spending and impoverishment in Kenya.** BMC Health Serv Res. 2012;**12:**413.
40. Masiye F, Kaonga O, Kirigia JM. **Does user fee removal policy provide financial protection from catastrophic health care payments? Evidence from Zambia.** PLoS ONE. 2016, **11:**e0146508.
41. Sen A. Development as freedom. 1st ed. New York: Oxford University Press; 1999.
42. Sridhar D. The battle against hunger: choice, circumstance, and the World Bank. Oxford: Oxford University Press; 2008.
43. Taddesse MT, Norheim OF, Verguet S, Bekele A, Amenu K, Abdisa SG. **Out-of-pocket expenditure for prevention and treatment of cardiovascular**

disease in general and specialized hospitals in Addis Ababa, Ethiopia: a cross-sectional study. Under review.

44. Verguet S, Memirie ST, Norheim OF. **Assessing the burden of medical impoverishment by cause: a systematic breakdown by disease in Ethiopia.** BMC Med. 2016;**14:**164.
45. Ridde V, Morestin F. **A scoping review of the literature on the abolition of user fees in health care services in Africa.** Health Policy Plann. 2011;**26:**1-11.
46. Lagarde M, Palmer N. **The impact of user fees on health service utilization in low- and middle-income countries: how strong is the evidence?** B World Health Organ. 2008;**86:**839-48.
47. Ridde V, Robert E, Meessen B. **A literature review of the disruptive effects of user fee exemption policies on health systems.** BMC Public Health. 2012;**12:**289.
48. Hatt LE, Makinen M, Madhavan S, Conlon CM. **Effects of user fee exemptions on the provision and use of maternal health services: a review of literature.** J Health Popul Nutr. 2013;**31:**S67-80.
49. Abdou Illou MM, Haddad S, Agier I, Ridde V. **The elimination of healthcare user fees for children under five substantially alleviates the burden on household expenses in Burkina Faso.** BMC Health Serv Res. 2015;**15:**313.
50. Ashenafi N. **Ethiopia: Social Health Insurance to Be Applied.** allAfrica, Addis Ababa. 2015. http://allafrica.com/stories/201512071289.html [accessed 12 Oct 2016]
51. Lakner C, Milanovic B. **Global Income Distribution: From the Fall of the Berlin Wall to the Great Recession.** World Bank Policy Research Working Paper 6719 2013, Washington, DC.

Tables and figures

Table 1: Economic development, poverty and health care financing

	Ethiopia	World
Annual GDP growth[12]	9.6%	2.6%
Gini index[16,51]	33.2	70.5
Population living below the poverty line (<$1.90 a day (2011 PPP)[12]	33.5%	12.7%
Tax revenue (of GDP in 2011)[12]	9.2%	12.9%
OOP expenses for health care covered by households[15]	General: 34% Children: 48%	
OOP per total health expenditure[5]	42.9%	20.6% (31.3% SSA)
Total health expenditure per GDP[5]		
1995	2.8%	6.0% (4.5% SSA)
2013	4.7%	7.1% (5.5% SSA)
Total health expenditure per capita 2014 (US$)[5]	27	1061

Gross domestic product (GDP), purchasing power parity (PPP), out-of-pocket (OOP), sub-Saharan Africa (SSA)

Table 2: Use and inequality of health care services in Ethiopia

Background characteristics	**Delivery in a health facility (%)**	**Postnatal checkup in the first two days after birth (%)**
National average	26	17
Average by wealth quintile		
Highest quintile	65	41
Lowest quintile	12	9
Average by residence		
Urban	79	45
Rural	19	13
Average by mother's education		
Mother more than secondary education	92	54
Mother no education	16	9

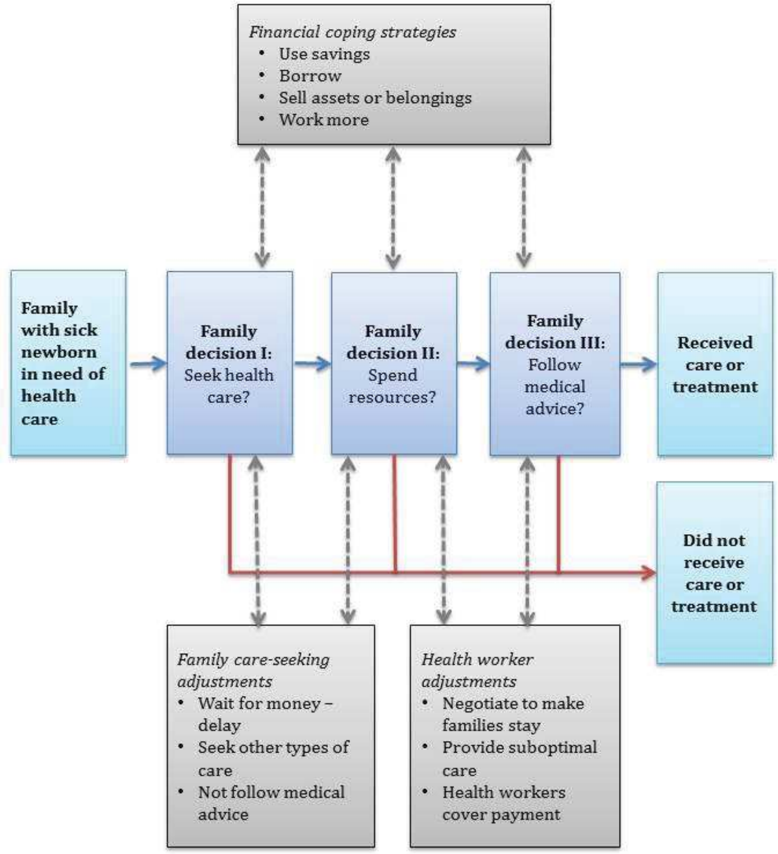
Data from the Ethiopian Demographic and Health Survey, 2016 [18].

Table 3: Participants of in-depth interviews and focus group discussions

Type of participants	**Recruitment of participants**
Household members experiencing newborn illness or death (18-35 years) Mother or primary caretaker of sick newborn: 11 IDIs at hospital during illness, *9 follow-up IDIs* Mother or primary caretaker who faced newborn death: 5 urban IDIs, 5 rural IDIs	Sick newborn identified during hospital admission (>1 day) by PI Recruited through Butajira Rural Health Program (BHRP)
1 IDI with key informant from health bureau	From health bureau
Health workers involved in newborn health care (20-35 years) 3 IDIs with Medical Doctors 7 IDIs with nurses and midwifes 1 FGD with nurses and midwifes 1 FGD with health extension workers (HEWs)	From hospitals and health centers From hospital, health center and kebeles, HEWs through BHRP
Community members (20-73 years) 1 FGD with women in reproductive age with child <1 year (urban) 1 FGD with women in reproductive age with child <1 year (rural) 1 FGD with husbands with wife with child <1 year (rural) 1 FGD with grandmothers (rural) 1 FGD with religious leaders and elders (urban)	From communities in three selected kebeles, recruited through BHRP

Figure 1: Family decisions on health care seeking for a sick newborn

Families made decisions about seeking health care (I), spending resources (II) and following medical advice (III). In these decision making processes, families used financial coping strategies and made care-seeking adjustments. Health workers made adjustments to influence the families' decisions and care seeking for sick newborns.



III

Under review

Newborn health benefits or financial risk protection? An ethical analysis of a real-life dilemma in a setting without universal health coverage

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Abstract

Introduction

High health care costs make illness precarious for both patients and their families' economic situation. Despite the recent focus on the interconnection between health and financial risk at the systemic level, the ethical conflict between concerns for potential health benefits and financial risk protection at the household level in a low-income setting is less understood.

Methods

Using a seven-step ethical analysis, we examine a real-life dilemma faced by families and health workers at the micro-level in Ethiopia and analyse the acceptability of limiting treatment for an ill newborn to protect the family against financial risk. We assess available evidence and ethical issues at stake and discuss the dilemma with respect to three priority setting criteria: health maximization, priority to the worse-off, and financial risk protection.

Results

Giving priority to health maximization and lifetime health loss suggests that limiting treatment is not acceptable. Conversely, if financial risk protection is perceived as most important, then more weight is assigned to the welfare of the household. There are problematic aspects with the premise of this dilemma. The most affected parties– the newborn, family members and health worker–cannot make free choices about whether to limit treatment or not, and we thereby accept deprivations of people's substantive freedoms.

Conclusion

In settings where health care is financed largely out-of-pocket, families and health workers face tragic trade-offs. As countries move towards universal health coverage, financial risk protection for high-priority services is necessary to promote fairness, improve health, and reduce poverty.

Introduction

Worldwide, neonatal mortality is decreasing, but still 2.6 million newborns die annually within their first month of life.[1] Contributing to 8% of disability adjusted life years (DALYs) lost globally every year, this largely avoidable burden mainly affect babies in low- and middle-income countries.[1] Seventy-one percent of newborn deaths, mostly caused by prematurity, intrapartum complications and sepsis,[1] could be prevented or treated with effective interventions.[2] From a global perspective, one can argue that ill newborns are worse-off for different reasons. They have large and urgent immediate health needs and will suffer from the largest individual lifetime health loss if they die prematurely. Among ill newborns, some are worse-off than others, as there are inequalities in use of services across socioeconomic groups (Figure 1), rural/urban location, and gender.[3]

(Figure 1)

Limited health care budgets challenge current initiatives to secure access to health care services for all neonates. In particular in low income countries, where public spending on health often is low[4] discussions about health-care priority setting and newborn health become important.

Fairness in priority setting

In general, several criteria have been suggested to support the fair allocation of scarce resources. While there is disagreement on how to balance these, two principles form the basis for much of the discussion[5]. The *greater benefit principle* can be understood as giving priority to interventions with greater health benefits. The *worse-off principle* is concerned with giving priority to those who are worse-off initially. These principles are often applied with a focus on direct health benefits, but some claim we should consider indirect or non-health benefits and burdens as well.[6]

The high economic burden of health-care expenses makes it relevant to consider financial risk protection in priority setting at macro and meso levels.[3] In health systems that largely depend on out-of-pocket (OOP) payments, health-care costs put patients and their families at risk of poor health outcomes and impoverishment.[3] Globally, 21% of total health expenditures are paid OOP, increasing up to 50% in low-income countries.[7] As a part of the United Nations *Sustainable Development Goals*, all 193 member states have committed to achieving universal health coverage (UHC), which includes protection against financial risk when using health-care services.[8] As countries move towards achieving this goal, they will face priority setting dilemmas. The WHO framework, *Making fair choices on the path to universal health coverage,* suggests three substantive criteria to guide policy makers in defining priority services.[3] The *health maximization* criterion gives priority to cost-effective interventions. The *priority to the worse-off* criterion prioritizes interventions that benefit individuals or groups that are worse-off[i]. The *financial risk protection* criterion prefers interventions that protect against high OOP expenses. The criteria may all point in one direction, or

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[i] In the WHO framework, the worse-off in terms of health as is understood as those with the largest individual disease burden.[3]

concerns may conflict. If so, the WHO framework suggests that concerns should be carefully balanced. Decision makers may disagree on how to evaluate lives saved versus poverty cases averted.[3] Further, while priority setting discussions often focus on trade-offs at the policy and macro-level,[3] few have analysed diverging concerns for financial risk protection and health benefits at the micro-level.[9]

Financial risk protection at the micro-level

In previous studies of families' and health-care workers' ethical dilemmas in Ethiopia, we found that concerns about financial risk protection were central in micro-level decision making. In a setting without universal health coverage, families with ill newborns struggled to pay OOP for health care; they had to borrow and sell their assets. Facing high costs, families and health workers made decisions that required balancing the needs of ill newborns versus other household needs. Families' opportunities to seek care, obtain services, and follow medical advice depended on their social and economic assets.[10] Some families had no option but to delay care-seeking, which had tragic consequences. One father explained, "Since I didn't have enough money, she died before I took her there (referral hospital)."*[10]* When living on the margin, the worry did not only concern the ill newborn but impacted the whole family. One mother was concerned about the future of her other children. "I had nothing, and I sold the only sheep I had to get treatment for my child. When the sheep is not there, what will I do in the future?"*[10]*

In an Ethiopian survey, 83% of physicians regularly withheld recommended treatment because patients could not afford services. They often protected patients against high costs by limiting prescription of drugs or diagnostics and compromised by offering suboptimal care.[11] In their daily practice, physicians often had to choose between two evils, either poorer health outcomes for the patient or harmful economic consequences for the family.[9]

As these studies describe, families' and health workers' decisions on care seeking often involve choices between diverging concerns for individual health and family welfare. Whereas priority setting trade-offs at macro-level fortunately receive academic and policy attention[3], we find that there is a need to further scrutinizethe common dilemma between financial risk and health benefits faced by families and health workers at micro-level. By analysing a stylized case (Box 1), our aim is to outline ethical concerns and normative implications of limiting treatment for an ill newborn to protect against financial risk. The micro-level dilemma in Box 1 is discussed with reference to criteria for priority setting proposed in the WHO framework (health maximization, priority to the worse-off, financial risk protection).[3] Though this framework was developed for priority setting by policy makers and technical advisors, we could in our search not find any other systematic framework that explicitly considers financial risk, which we found to be at the center of families' and health workers' everyday dilemmas.[9 10 12]

(Box 1)

It should be noted that our discussion is grounded in the specific case from Ethiopia (Box 1). We do not aim to provide a general conclusion on the inherent trade-off between health and welfare, which occur in different settings and at different levels.

Methods

Drawing upon earlier empirical work on micro-level priority setting in Ethiopia, we present an anonymized and stylized case in Box 1.[9-12] The micro-level dilemma was analyzed using a modified version of Kymlica's ethical case analysis as described by Miljeteig et al.[13] In a seven-step analysis, we assess available evidence, clarify options for concerned parties, identify conflicts between interests and ethical principles, and suggest acceptable solutions (Box 2). The analytic tool cannot in itself offer guidance for how to reconcile competing interests of stakeholders or how to balance conflicting values or ethical principles. However, it is used to structure relevant information and ethical concerns at stake in the dilemma. This systematic approach supports a discussion on what matters most, the acceptability of the tradeoffs, and what are potential legitimate solutions.

(Box 2)

Ethical analysis

1: What is the ethical dilemma and alternative actions?

Is it ethically acceptable to limit treatment[ii] for the ill newborn, in this case to protect the family against financial risk? Alternative responses are; yes, it is acceptable or no, it is not acceptable.

2: What do we know about the outcomes of alternatives?

We evaluated evidence on the possible outcomes of both alternatives (limiting treatment for the newborn or not) and looked at health outcomes, costs and financial burden with and without treatment (Table 1).

Health outcomes

The burden of neonatal sepsis and infections contributes to 0.1%, and 2.9% of DALYs lost in high- and low-income countries, respectively. In Ethiopia, neonatal sepsis and infections account for 3.1% of DALYs lost and 14,600 deaths annually.[1]

WHO guidelines for neonatal sepsis recommend antibiotic treatment (ampicillin and gentamicin).[14] When skilled attendance is 0% and 100%, the case fatality rate is predicted to be 30% and 10%, respectively.[15] In the ethical dilemma analysed, the health worker identified the ill newborn in need of inpatient care, and we

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[ii] Limiting treatment is understood as not receiving recommended antibiotics and supportive treatment at the referral hospital.

conservatively assumed the case fatality rate without treatment to be more than 50% [16]. A Delphi consultation indicated that hospital-based management, including IV antibiotics and supportive care, could reduce sepsis-specific and pneumonia-specific mortality by 80% and 90%, respectively.[15]

Average life expectancy at birth in Ethiopia is 65 years.[1] Even if the newborn survives from sepsis, a systematic review found that 49% of septic premature neonates developed long-term sequels.[17] Though less is known about subsequent effects of sepsis in term babies, it is likely that some encounter physical, neurological and cognitive impairment.[16 17] Thus, in this case we assume that also if the newborn survives septicaemia, she is at increased risk of morbidity, increased health and welfare support, and lower life expectancy (<<65 years[iii]).

Being poor relate to poorer health outcomes, lower care seeking and relatively higher burden of high health care costs.[18] If the family falls into poverty due to high OOP expenses - after paying for advanced treatment, household members may be of risk of worse health later. Current choices about health care seeking hereby influence the future health (as well as welfare, see next paragraph) of the newborn and the family.

Costs

A facility-based study from Ethiopia found that the mean OOP cost of admission for severe pneumonia was US $64 per inpatient visit (0-59 months).[19] While the relative burden of these costs may differ between poor and less well-off families, we - for simplicity -, assume that the cost of treatment is similar for newborn sepsis. Bhutta et al. estimated that a package of interventions to address stillbirth, neonatal and maternal deaths could be provided at US $60 per DALY averted.[2] Since the 2015 gross domestic product (GDP) per capita in Ethiopia was US $619,[20] treatment of the ill newborn can be considered highly cost-effective.

Financial burden

In the case analysed, the father expressed that costs of seeking health care are too high, and was worried about the welfare and food supply for the family if he has to sell their seeds.

Health systems that largely depend on OOP payments rather than prepayments expose households to great financial risk and poor health.[3] In Ethiopia, 48% of health-care costs for children are covered OOP.[21] We assume that neonatal sepsis and infections account for 20% of all deaths from respiratory infections.[1] Extrapolating from Verguet et al.'s study on the burden of medical impoverishment in Ethiopia, we estimate that neonatal pneumonia and sepsis cause 11,800 poverty cases per year.[22]

[iii] Data on long-term outcomes of sepsis in term newborns in resource-constrained settings is limited [16 17]

Thirty-four percent of the Ethiopian population lives on less than \$1.90 a day (2011 PPP).[20] When we adjust the cost of treatment for purchasing power, the OOP expenditure of US \$64 equals about \$175 (current international Purchasing Power Parities (PPP)).[19] The family in the case is likely to live below the poverty line, and we estimate the relative impact of treatment to be close to three months' spending (\$175/\$1.90 = 92 days).[20] These estimates indicate that the consequences for family welfare are severe. The financial wellbeing of the household is likely to influence the future of the family and the newborn. Yet, the monetary value in our estimates may not fully reflect the real loss for the family. If they sell their seeds, there will be an immediate loss as well as an impact on future sources of food and income. This may influence other family members, where the newborn and other children may get less food or can no longer go to school, or the parents must find additional sources of income.

(Table 1)

3: What laws, rules or guidelines regulate the decision?

Ethiopia ratified the *United Nations Convention on the Rights of the Child* in 1991. The Convention recognizes the right of children to have the highest attainable standard of health, and the obligation of the state to pursue implementation.[23]

For this analysis, two strategies by the Federal Ministry of Health are of particular relevance. The *National Strategy for Newborn and Child Survival in Ethiopia* focuses on goals and plans to ensure coverage of high-impact neonatal interventions with an emphasis on marginalized populations.[24] In the *Health Sector Transformation Plan V,* Ethiopia has committed to moving towards UHC, where necessary services are to be made accessible for everyone while providing protection against financial risk.[21] However, there is limited guidance on how to incorporate concerns about financial risk in decision making.

WHO guidelines and national treatment guidelines on neonatal illness and sepsis clearly state that the newborn in this case should be treated.[14]

4: Who are the involved stakeholders?

The most-affected parties are the ill newborn, the parents, other children in the family, the health-care worker, other ill newborns, community members, society, policy makers, and international stakeholders.

5: What are the stakeholders' potential burdens/benefits?

We consider benefits and burdens of affected parties if treatment for the ill newborn is withheld to protect against financial risk (Table 2).

(Table 2)

The largest benefits will be for other family members. By restricting treatment, the family avoids devastating costs in their already-vulnerable economic situation. The costs of treatment may push them into the vicious circle of poverty and ill health. The most severe burden will be on the ill newborn, who will lose out on better survival chances when not receiving medical treatment. Health workers might experience moral and professional stress if the newborn is not treated.

If it is perceived as acceptable to give priority to household needs over newborn health in the community, this might delay seeking care for other ill newborns.[12] Although policy makers and international stakeholders will not be directly affected by one additional newborn death or one additional poverty case, general trends in OOP expenses and mortality are of relevance in their work.

6. What interests are in conflict?

The direct interests of the newborn, the parents, and other children of the family are in conflict. Without treatment, the newborn's chances of survival are lower, and the newborn may die. It is in the economic interest of the parents and siblings to not sell their assets, in this case, their seeds, to avoid financial ruin. At the same time, the loss of a newborn is an emotional burden and a future productivity loss for the family.

Indirectly, the interests at stake and conflict between the newborn and the family's interests affect the health worker. From a professional view, the health worker's obligations concern the patient. However, in handling the dilemma, the physician is likely to be challenged by concerns for family welfare.[9]

7. What are the values and principles at stake?

There are several values and principles at stake in this dilemma, such as respecting patient autonomy, the health care worker's duty to care, and the principles to do good (beneficence) and do no harm (non-maleficence).[25] Following a non-consequentialist approach, the health care worker's duty to provide a life-saving treatment may very well override all other concerns for the wellbeing of other family members. Yet, the purpose of our analysis was to discuss the ethical acceptability of prioritizing health versus welfare, which we discuss with regards to the criteria in the WHO framework. In our discussion of justice and fairness, we pay particular attention to health maximization, priority to the worse-off, and financial risk protection.[3]

Maximizing health

The newborn, if treated, can expect to live up. Though she has an increased risk of long-term complications,[16 17] the most likely outcome is survival without complications. Limiting highly cost-effective treatment would not maximize health.[2] The newborn will most likely die.

Priority to the worse-off

The WHO framework identifies the worse-off in terms of health as those with the largest individual disease burden.[iv][3 26] The ill newborn is worse-off in terms of potential lifetime health loss, and benefits to the newborn should, therefore, have extra weight. Even if we include non-health outcomes, no other person in the family is as badly off as the ill newborn, although the financial burden in total may be larger.

Protecting against financial risk

At the micro-level[v], concerns for financial risk protection for all family members may favour limiting treatment for the newborn. Some may argue that improved wellbeing outcomes for the parents and older children, taken together, are more important than improved health outcome for the newborn. Protecting the family's wellbeing may be positive for the future health and survival of the family (as well as for the newborn if it survives without treatment), as being poor poses health risk. In addition, productive family members contribute more to the wellbeing of the household than the newborn, and their survival may be more important for the survival of the family.

We assess, however, that when the improved total wellbeing benefits for all family members are compared to the health and wellbeing gains for the newborn, and additional weight is assigned to the benefits for the worse-off, the latter outweighs the former. This is a judgment made by the authors, and we acknowledge that others may reach a different conclusion.

Discussion

Health benefits or financial risk protection?

The stakes are high in the micro-level dilemmas families and health workers face in settings without UHC. The empirically-derived case is constructed, but we have reason to believe that patients, next of kins and health care professionals face similar choices in settings where health-care is largely financed OOP. The ethical dilemma concerns what to do when parents or health workers cannot both improve health and protect against financial risk. For the father and mother: should they sell their seeds to pay for care, or not? For the health worker: should she advice the parents to seek care at the hospital, or not? At worst, their choices can cause newborn death, economic disaster, or both.

Central in this dilemma is the value judgement of whether to take wellbeing beyond health outcomes into account or not.[6 27] Should we consider only direct health benefits, or include non-health and indirect benefits? Brock has argued, "different activities have different distinct purposes".[27] The purposes of these activities, such as health-care services to improve health, should determine their "proper sphere," and goods and resources should be distributed based on the activities they produce.[27] While the

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[iv] The literature on badness of death discusses other ways to assess when it is worst to die.[26]

[v] It should be noted that financial risk protection at the macro-level would mean reduction in costs of treatment through pooling of resources.[3]

argument to separate allocation of health and non-health benefits may hold in an ideal world, the pragmatic reality seen in the real-life dilemmas illustrated in our case shows how spheres are not separated at household level. As long as patients pay OOP for health-care services, families' decisions are constrained by one budget, and both health and non-health concerns are taken into account in intra-household decisions. Persad and du Toit argue that relying on separate spheres through "tunnel-vision approaches" in health policies is a mistake.[6]

We agree and accept that wellbeing beyond health is relevant, and that health maximization, priority to the worse-off, and financial risk protection are ethically relevant criteria for priority setting. However, it is not clear what to do when these concerns conflict.[3] Depending on which outcome one values most, and for whom, one may conclude that it is either acceptable or unacceptable to limit treatment. Though limiting treatment can secure three months of daily expenses and the aggregated total wellbeing gain for the whole household, the baby has a high chance if dying and is clearly worse-off than the others (Table 1). In our all-things-considered judgment, where gains to the worse-off are given additional weight, we incline towards the option that limiting treatment is not acceptable.

Unacceptable real-life dilemmas

Our case highlights a real-life dilemma between promoting health benefits and reducing financial risk that plays out in health-care systems worldwide. However, from a normative perspective, there are problematic consequences of accepting this situation and treating it merely as a dilemma to be resolved. Even if we could accept that it is (for the parents or the health professional), permissible to limit treatment for the ill newborn in this particular case, we as a society should not accept that the worst-off newborn dies from a disease that could have been easily avoided with cost-effective interventions. The unfair choices imposed on the family and health worker is caused by priorities and choices made at the health system level.

In their reflections on distributive justice, it is relevant to consider how people's preferences, beliefs and choices are shaped by underlying conditions.[28 29] Following Sen's capabilities approach, being poor and ill – as seen in the case analysed - can be understood as deprivations of freedoms.[28] Both as means and ends, poverty and ill health may restrict people's capabilities to "live the kind of life they have reason to value."[28] Conceptualized as *adaptive preferences*, Sen and Nussbaum discuss how individuals adjust their preferences based on the choices that are available to them.[30 31] In the dilemma analysed, the most-affected parties–the newborn, family members and health worker–cannot make free choices about whether to limit treatment or not. There is reason to believe that they would value treating the newborn without ending in financial ruin, but without money, this is not a real option.[10] We argue that the situation in which the ethical dilemma plays out is unacceptable and unfair. Worldwide, health care is often financed by patients and their families, and opportunities to survive and enjoy lives without poverty often depend on economic factors. Our discussion demonstrates that the resource-constraints settings in which these dilemmas occur, compromise people's substantive freedoms and could have been avoided by pooling resources for high-priority health services.

Micro-dilemmas and macro-decisions

Policy-level questions on UHC typically centre on which services to include, to whom they should be provided, and how to protect against financial hardship.[3] Organization and implementation of health and welfare systems, closely connected to macro-decisions, influence micro-level practices and opportunities. Dilemmas faced by families and health workers (Box 1) are shaped by policy choices at higher levels of the system. In Ethiopia, life expectancy increased by nine years between 2005 and 2015,[1] and in 2013, total health spending was 4.7% of GDP.[7] An essential healthcare package is being implemented, and advanced medical treatments such as renal transplants and cancer care are about to be implemented in selected hospitals.[21] Although the new services seem promising, expanding access to low- and medium-priority services when larger parts of the population cannot access or afford high-priority services is problematic.[3 32] From a fairness perspective, reducing OOP payments for essential services, such as antibiotic treatment for neonatal infections, is more important than ensuring access to expensive and less-effective services, such as advanced cancer treatment.[21] If basic newborn healthcare services were provided at no or low cost, the unacceptable ethical dilemma analysed in this study would not be present. Trade-offs between health and welfare may always be present, but examples such as the case analysed is particularly problematic. For cost-effective services for a group that is worse-off in terms of health and well-being, lower-level decision makers should not be left to choose between health benefits and financial risk protection. Progressive realization of UHC can make care-seeking without falling into poverty a reality, which may intrinsically and instrumentally enhance people's capabilities.[3] Ethiopia's rollout of community-based and social health insurance represents promising steps away from financing models based on OOP payments and voluntary mechanisms. Yet, to progressively realize UHC here and in countries worldwide, it is urgent to make high-priority services affordable.

Methodological concerns

A better understanding of real-life dilemmas is relevant for health policies, and for normative discussions to illuminate what justice–and injustice–means. As far as we know, this is one of the first attempts to explicitly analyse a micro-level ethical dilemma where concerns for health benefits and financial risk protection diverge. Some important methodological considerations should be noted. We chose the WHO framework for our analysis, which included financial risk, a criteria that has received little attention in the medical ethics literature. However, it did not take bedside rationing considerations, such as health professionals' duty to care, into account.[9 11] While this may have left out relevant principles or values, it was a deliberate choice on our part as we aimed to focus on financial risk. Further discussion of the health-welfare trade-off, whether these concerns are incommensurable, and the role of professional duties, are of great interest, but are beyond the aim of this study.

The strength of evidence on outcomes can be questioned. In the analysis, we simply assumed that the baby suffered from neonatal sepsis and could be saved. In real-life health-outcomes may depend on additional factors such as quality of treatment, appropriate care and the aetiology of illness.[16 17] This may also hold for our assumptions on financial risk, where data is even more limited. To address these challenges and research gaps, further empirical studies on financial burdens and indirect costs and benefits,[19 22] and normative discussion on how to weigh health and non-health concerns are needed.[6]

Studies show that health care financing in low income countries is particularly dependent on OOP payments[4 7]. Though our analysis deliberately focused on one case from Ethiopia, it is likely that similar tragic dilemmas are seen in other settings, and especially in underfinanced health-care systems. While essential newborn health services are cost-effective, other services or treatment of other diseases may challenge the balance in the health welfare trade-off.

Although context always matters, we still believe the ethical issues highlighted are relevant for discussions on fairness and financial risk protection.

Concluding remarks

By analysing an ethical dilemma in a resource-constrained setting, we have seen that non-health factors challenge our views about which principles matter in priority setting and how conflicting concerns should be balanced. Families' and health workers' choices about health benefits or protection against financial ruin play out at micro level, but are influenced by macro-level decisions and priorities, If we neglect the fact that non-health factors affect real-life priority setting, in particular the health and welfare of the poor, this neglect may perpetuate and reinforce inattention to underlying structural issues that shape health and development.

Figure

Figure 1: Coverage of newborn health care services per wealth quintile (Data source: Ethiopia Demographic and Health Survey 2016 [18]

References

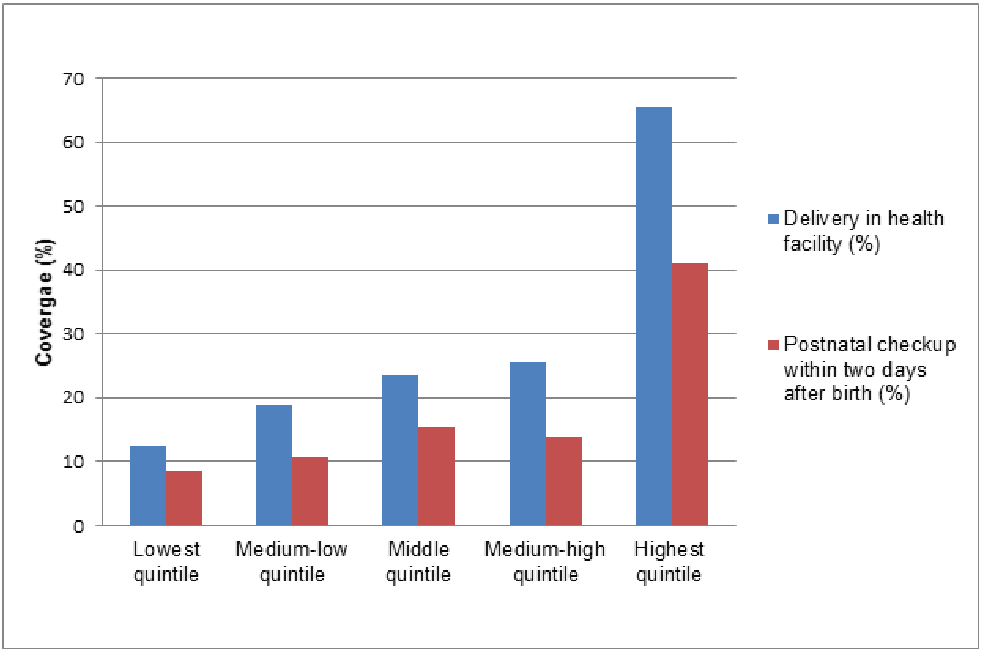
1. Institute for Health Metrics and Evaluation. GBD Results Tool 2017 [Available from: http://ghdx.healthdata.org/gbd-results-tool accessed April 12th 2017].
2. Bhutta ZA, Das JK, Bahl R, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *The Lancet* 2014;384(9940):347-70. doi: 10.1016/S0140-6736(14)60792-3

3. World Health Organization. Making fair choices on the path to universal health coverage: Final report of the WHO consultative group on equity and universal health coverage. Geneva: World Health Organization, 2014.
4. Stenberg K, Hanssen O, Edejer TT, et al. Financing transformative health systems towards achievement of the health Sustainable Development Goals: a model for projected resource needs in 67 low-income and middle-income countries. *Lancet Glob Health* 2017 doi: 10.1016/s2214-109x(17)30263-2 [published Online First: 2017/07/22]
5. Ottersen T. Lifetime QALY prioritarianism in priority setting. *Journal of Medical Ethics* 2013;39(3):175-80. doi: 10.1136/medethics-2012-100740
6. Persad G, du Toit J. Non-Health and Indirect Benefits. In: Emanuel EJ, Verguet S, Jamison D, et al., eds. Global health priority-setting: beyond cost-effectiveness. Oxford: Oxford University Press (forthcoming 2017).
7. Dieleman JL, Templin T, Sadat N, et al. National spending on health by source for 184 countries between 2013 and 2040. *Lancet* 2016;387(10037):2521-35. doi: 10.1016/S0140-6736(16)30167-2
8. United Nations. Transforming our world: the 2030 agenda for sustainable development. New York: United Nations, 2015.
9. Defaye FB, Danis M, Desalegn D, et al. Financial risk protection at the bedside: how Ethiopian physicians try to minimize out-of-pocket health expenditures (forthcoming, 2017)
10. Onarheim KH, Sisay MM, Gizaw M, et al. Selling my sheep to pay for medicines – Household priorities and coping strategies in a setting without universal health coverage. *BMC health services research* (in press, 2017)
11. Defaye FB, Desalegn D, Danis M, et al. A survey of Ethiopian physicians' experiences of bedside rationing: extensive resource scarcity, tough decisions and adverse consequences. *BMC health services research* 2015;15:467. doi: 10.1186/s12913-015-1131-6 [published Online First: 2015/10/16]
12. Onarheim KH, Sisay MM, Gizaw M, et al. What if the baby doesn't survive? Health-care decision making for ill newborns in Ethiopia. *Social Science & Medicine* 2017;195(Supplement C):123-30. doi: https://doi.org/10.1016/j.socscimed.2017.11.003
13. Miljeteig I, Johansson KA, Sayeed SA, et al. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. *J Med Ethics* 2010;36(8):473-8. doi: 10.1136/jme.2010.035535 [published Online First: 2010/07/29]
14. World Health Organization. Compilation of WHO recommendations on maternal, newborn, child and adolescent health: Recommendations on newborn health. Geneva: World Health Organization, 2013.
15. Zaidi AKM, Ganatra HA, Syed S, et al. Effect of case management on neonatal mortality due to sepsis and pneumonia. *BMC Public Health* 2011;11(3):S13. doi: 10.1186/1471-2458-11-s3-s13
16. Seale AC, Blencowe H, Zaidi A, et al. Neonatal severe bacterial infection impairment estimates in South Asia, sub-Saharan Africa, and Latin America for 2010. *Pediatric research* 2013;74 Suppl 1:73-85. doi: 10.1038/pr.2013.207 [published Online First: 2013/12/25]
17. Mwaniki MK, Atieno M, Lawn JE, et al. Long-term neurodevelopmental outcomes after intrauterine and neonatal insults: a systematic review. *The Lancet* 2012;379(9814):445-52. doi: https://doi.org/10.1016/S0140-6736(11)61577-8

18. Central Statistical Agency (CSA) [Ethiopia] and ICF. Ethiopia Demographic and Health Survey 2016: Key Indicators Report. Addis Ababa, Ethiopia, and Rockville, Maryland, USA: CSA and ICF, 2016.
19. Memirie ST, Metaferia ZS, Norheim OF, et al. Household expenditures on pneumonia and diarrhoea treatment in Ethiopia: a facility-based study. *BMJ Global Health* 2017;2(1) doi: 10.1136/bmjgh-2016-000166
20. World Bank. World Bank Open Data 2017 [Available from: http://data.worldbank.org/ accessed 10.08 2017.
21. Federal Democratic Republic of Ethiopia Ministry of Health. Health Sector Development Programme V. Addis Ababa, Ethiopia, 2015.
22. Verguet S, Memirie ST, Norheim OF. Assessing the burden of medical impoverishment by cause: a systematic breakdown by disease in Ethiopia. *BMC Medicine* 2016;14(1):164. doi: 10.1186/s12916-016-0697-0
23. United Nations General Assembly. Convention on the Rights of the Child. In: United Nations, ed., 1989.
24. Federal Democratic Republic of Ethiopia Ministry of Health. National Newborn and Child Survival Strategy Document Brief Summary: 2015/16-2019/20: Federal Democratic Republic of Ethiopia Ministry of Health, , 2015.
25. Beauchamp T, Childress J. Principles of Biomedical Ethics. 6 ed. New York: Oxford University Press 2009.
26. Solberg CT, Gamlund E. The badness of death and priorities in health. *BMC Medical Ethics* 2016;17:(21)
27. Brock DW. Separate spheres and indirect benefits. *Cost Eff Resour Alloc* 2003;1(1):4.
28. Sen A. Development as freedom (1st ed.). New York: Oxford University Press 1999.
29. Nussbaum MC. Women and human development : the capabilities approach. Cambridge ; New York: Cambridge University Press 2000.
30. Sen A. **Rights and capabilities**. Resources, values and development: Harvard University Press 1984.
31. Nussbaum MC. **Adaptive preferences and women's options**. Women and human development : the capabilities approach. Cambridge ; New York: Cambridge University Press 2000:xxi, 312 p.
32. Norheim OF. Ethical perspective: five unacceptable trade-offs on the path to universal health coverage. *Int J Health Policy Manag* 2015;4(11):711-4. doi: 10.15171/ijhpm.2015.184

Tables and illustrations

Figure 1: Coverage of newborn health care services per wealth quintile



Box 1: An ill newborn in a poor family in Ethiopia

A mother and father have brought their two-day-old newborn to a health centre in rural Ethiopia. Two days after a difficult 24-hour birth at home, the baby has still not taken breast. The health worker recognizes that the newborn is in respiratory distress, and suspects neonatal sepsis. From a medical perspective, the condition is severe, and the baby should be referred to the hospital, as the health centre does not offer intravenous treatment with antibiotics and supportive treatment. The father, who is a daily labourer, is in distress about the expenses for drugs and the hospital stay. He states, “How can we afford? We used everything we had and have no money. If I sell our seeds to pay for treatment, how will I get food for her brothers and sister? Can they go to school? Now, they will suffer.” The health worker is afraid the baby will not be taken to the hospital, and may die. She asks herself, “Should I try to convince them to go? Will I force them into economic disaster? How should I negotiate?”

Box 2: Seven-Step Ethical Analysis [13]

Gather information. If insufficient, ask for more.

Step I: What is the ethical dilemma and alternative actions?

Step II: What do we know about the outcomes of alternatives?

Step III: What laws, rules or guidelines regulate the decision?

Step IV: Who are the involved stakeholders?

Step V: What are the stakeholders' potential burdens and benefits?

Step VI: What interests are in conflict?

Step VII: What are the values and principles at stake?

Discuss what is most important in the case; clarify trade-offs and suggest acceptable solutions.

Table 1: Potential outcomes of alternative actions

	Option I: Limit treatment to provide protection against financial risk	**Option II: Provide treatment, which contributes to financial risk**
Medical prognosis of newborn[vi] Case fatality rate Life expectancy	0.50 <1 month	0.1 << 65 years
Costs of treatment for family Cost of treatment	≈0	$64 (absolute) $175 (PPP adjusted) (Additional costs for newborn with sequel)
Financial risk Impact on available resources[vii]	≈0	3 months of spending (Additional impacts of spending on newborn with sequel)

[vi] Assuming that the newborn with severe neonatal sepsis has low chances without treatment.

[vii] Assuming that the family lives below the poverty line (below $1.90/day, 2011 PPP).

Table 2: The benefits and burdens of limiting treatment to protect against financial risk

	Benefits	**Burden**
The ill newborn	No direct benefit	The chance of survival decreases, and the newborn is likely to die
The parents	Avoid selling their harvest/seeds Avoid risk of catastrophic health expenditures More resources for food and other necessities	Emotional burden of losing a baby. Future productive loss of losing a child Immediate cost of funeral, etc. Long-term lost income if the child lived
The other children	More resources for other children: improved nourishment, opportunity to go to school, improved health	Emotional and productive burden of losing a sibling
The health worker	Protecting the family against high costs and financial risk	Moral destress of not providing treatment to ill newborn Professional stress when not following medical guidelines
Other ill newborns	Indirect: More room and public resources for other ill newborns in the hospital	Indirect: Shape perceptions and practices of (not) seeking treatment for ill newborns
Community members	Friends and neighbours have to lend money to family with ill newborn	Loss of a new child Fear that high costs of treatment might delay care seeking for others
Society	Avoid further poverty	Loss of one citizen
Policy makers	Less families experiencing high OOP payments Success in financial risk protection outcomes	Higher newborn mortality rate Lack of success in newborn mortality
International stakeholders	Less poverty cases due to high OOP payments Success in financial risk protection outcomes	Higher newborn mortality rate: Lack of success of newborn health programs or funding

IV

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Executive officer:	Telephone:	Our date:	Our ref.:
REC Western Norway	Trine Anikken Larsen	55978497	08.04.2015	2015/327/REK vest
			Your date:	Your ref.:
			24.02.2015	

Ingrid Miljeteig
Kalfarveien 31

2015/327 Prioritering av nyfødtes helsebehov i Etiopia

Institution responsible: University of Bergen
Project manager: Ingrid Miljeteig

With reference to your application to the Regional Committee for Medical and Health Research Ethics, Western Norway (REC Western Norway), reviewed the application in meeting, 2015-03-19, pursuant to the Health Research Act.

Project description

Despite a high priority in health policies, newborns in Ethiopia continue to have a high mortality rate (37 per 1000 live births). Little is known about the families' decision making with regards to newborn health. This study aims to gain a better understanding of intra-household resource allocation and care seeking among families with sick newborns in Butajira, Ethiopia. The research group will explore the research question through a qualitative design using in-depth interviews, focus group discussions and observations. This project is expected to provide empirical knowledge about family decision making and barriers to newborn health and survival. This will be of high relevance for health policy and for discussions about priority setting. 20 cases of newborn illness will be identified, and their mothers or significant others will be recruited into the study. 10 cases of newborn deaths the last year will be identified and the research group will recruit the mother or significant other of diseased new born. 24 health workers and 32 community members will be recruited from the hospital and health centres, and via key informants in the Butajira Rural Health Programme.

Ethical review

Application/study protocol
The Committee finds this project important, and has no objections to the research questions, the purpose of the project or the implementation of the project.

Compensation
The Committee discussed if soap is a sufficient and adequate compensation to give to the participants in this study. The Committee presupposes that there is an adequate compensation for their participation and points out that the ethics committee in Ethiopia is the right body to determine this question.

Contingency
The research group wants to recruit mothers who lost their sick newborn. Losing a newborn may be very sensitive to talk about, especially to strangers. The Committee misses a reflection on the implementation of a contingency against these women who have lost a newborn. The Committee set as a condition that the research group initiates a contingency to safeguard the interests of the women who have lost their newborn.

Besøksadresse:
Armauer Hansens Hus (AHH), Tverrfløy Nord, 2 etasje. Rom 281. Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

Condition

- The research group must initiate a contingency towards the women who have lost their newborn child.

Decision

REC Western Norway approves the project in accordance with the submitted application as long as the aforementioned conditions are met.

Final Report and Amendments

The project manager shall submit a final report to the REC Western Norway according to Health Research Act § 12. The project manager shall submit an application of approval to REC Western Norway if there is significant changes in the project protocol, according to Health Research Act § 11.

Appeal

The project manager may appeal the committee's decision, see the Administration Act § 28. The appeal must be sent to the REC Western Norway within three weeks of receiving this letter. If the decision is upheld by REC Western Norway, the appeal will be forwarded to the National Research Ethics Committee for Medical and Health Research for a final assessment.

Yours sincerely,

Marit Grønning
Prof. Dr.med
Vice chairman

Trine Anikken Larsen
Executive officer

Copy: postmottak@uib.no

V

UNIVERSITY COLLEGE OF HEALTH SCIENCES (IRB)
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Institutional Review Board

ANNEX 3
Form AAUMF 03-008

IRB's Decision

Meeting No: 007/2015 Date: September 09, 2015
Protocol number: 025/15/SPH Assigned No..................

Protocol Title: Accessibility and utilization of newborn care services: A qualitative study on intra-household resource allocation among Ethiopian families experiencing neonatal illness	
Principal Investigators:	Dr. Mitike Mola
Institute:	SPH-CHS-AAU
Elements Reviewed (AAUMF 01-008)	☑ Attached ☐ Not attached
Review of Revised Application ☐ Yes ☐ No	Date of Previous review:
Decision of the meeting:	☑ **Approved** ☐ Approved with Recommendation ☐ Resubmission ☐ Disapproved

I. Elements approved-
1. Protocol Version No. ...2..................................
2. Protocol Version Date...................................
3. Informed consent Version No. ...2.......................
4. Informed Consent Version Date ....

II. Obligations of the PI-
1. Should comply with the standard international & national scientific and ethical guidelines
2. All amendments and changes made in protocol and consent form needs IRB approval
3. The PI should report SAE within 10 days of the event
4. End of the study, including manuscripts and thesis works should be reported to the IRB

III. **TO NERC** ☐

Institution Review Board (IRB) Approval: Period from 05/10/15 to 04/10/16

Follow up report expected in
3 Months ___ 6 months ___ 9 months____√___one year____

Chairperson, IRB
Dr. Yimtubezinash Woldeamanuel
Signature____________
Date: 05/10/15

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Institutional Review Board Office
(IRB)
Faculty of Medicine
ADDIS ABABA UNIVERSITY

VI

Consent form *September 24th 2015*
In-depth interview - family member

Accessibility and utilization of newborn health care services: A qualitative study on intra-household resource allocation among Ethiopian families experiencing neonatal illness

Background and purpose
This is a request for you to participate in study at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn about sick babies and health care services, with a particular interest in how what families do when a baby falls ill. We would like to invite to participate in this study.

What does the study entail?
To learn about illness of babies, we will talk to family members who have been involved with care of sick babies. If you choose to participate in the study, we will ask questions about the health of your baby, care seeking and how you and your family decided what to do. If there are some questions you do not want to answer you do not have to, and you can stop at any time. The interview will take from 30 to 90 minutes. We will take notes and audio record the interview.

Potential advantages and disadvantages
There are no direct benefits or harms for you to participate in the study. As a compensation for the time lost, we will give you a soap. We will cover you transportation costs if necessary. To participate in this study will not have any consequences for treatment for you and your family at a later stage.

What will happen to the research about you?
After the interviews the material will be analyzed by the researchers. The material will be processed without your name, ID number or other any information that makes it possible to recognise you. Any information about you will be kept confidential and will be anonymous in the reporting of the results. It will not be possible to identify you when we present the results of the study.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent in the study at any time and without stating any particular reason.

If you wish to participate, sign the declaration of consent.

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

If you later on wish to withdraw your consent or have questions concerning the study, you may contact dr. Mitike Molla (Telephone: 0911131805) or dr. Kristine Onarheim (Telephone: 0946597034).

Consent form *September 24th 2015*
Health worker – in-depth interview

Accessibility and utilization of newborn health care services: A qualitative study on intra-household resource allocation among Ethiopian families experiencing neonatal illness

Background and purpose
This is a request for you to participate in study at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn about sick newborns and health care services, with a particular interest in families' decisions around health care seeking. We would like to invite to participate in this study.

What does the study entail?
To learn about newborn illness, we will talk to health care workers who have been involved with care of sick newborns. If you choose to participate in the study, we will ask questions about newborn health, health care and family decision making. If there are some questions you do not want to answer you do not have to, and you can stop at any time. The interview will take from 30 to 90 minutes. We will take notes and tape record the interview.

Potential advantages and disadvantages
There are no direct benefits or harms for you to participate in the study. As a compensation for the time lost, we will give you a soap. We will cover you transportation costs if necessary. To participate in this study will not have any consequences for your work at this health facility.

What will happen to the research about you?
After the interviews the material will be analyzed by the researchers. The material will be processed without your name, ID number or other directly recognisable type of information. Any information about you will be kept confidential and will be anonymous in the reporting of the results. It will not be possible to identify you when we present the results of the study.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent in the study at any time and without stating any particular reason.

If you wish to participate, sign the declaration of consent.

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

If you later on wish to withdraw your consent or have questions concerning the study, you may contact dr. Mitike Molla (Telephone: 0911131805) or dr. Kristine Onarheim (Telephone: 0946597034).
IRB contact: Addis Ababa University, College of Health Sciences, IRB (Telephone: 0118961396).

Consent form *September 24th 2015*
Health worker – focus group

Accessibility and utilization of newborn health care services: A qualitative study on intra-household resource allocation among Ethiopian families experiencing neonatal illness

Background and purpose
This is a request for you to participate in study at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. In this study we hope to learn about sick newborns and health care services, and particularly families' decisions and community values. We would like to invite you as health care professionals to participate in a group discussion.

What does the study entail?
To learn about newborn illness, we will ask you to participate in a group discussion. We will ask health care workers to take part in group discussions lead by a moderator. If you choose to participate, we will ask questions about newborns, health care and how families make decisions about seeking care and adhering to your advice. If there are questions you do not want to answer you do not have to, and you can stop at any time. The discussion will take 60 to 90 minutes. We will take notes and audio record the discussions.

Potential advantages and disadvantages
There are no direct benefits or harms for you to participate in the study. As a compensation for the time lost, we will give you a soap. We will cover you transportation costs.

What will happen to the research about you?
After the group discussions, the material will be analyzed by the researchers. The material will be processed without name, ID number or other directly recognisable type of information. Any information about you will be kept confidential and will be anonymous in the reporting of the results. It will not be possible to identify you when we present the results of the study.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent in the study at any time and without stating any particular reason.

If you wish to participate, sign the declaration of consent.

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

If you later on wish to withdraw your consent or have questions concerning the study, you may contact dr. Mitike Molla (Telephone: 0911131805) or dr. Kristine Onarheim (Telephone: 0946597034).
IRB contact: Addis Ababa University, College of Health Sciences, IRB (Telephone: 0118961396).

Consent form *September 24th 2015*
Community members – focus group

Accessibility and utilization of newborn health care services: A qualitative study on intra-household resource allocation among Ethiopian families experiencing neonatal illness

Background and purpose
This is a request for you to participate in study at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. In this study we hope to learn about sick babies and health care services, and particularly families' decisions on seeking care for babies and community values. We would like to invite to participate in a group discussion.

What does the study entail?
To learn about illness of babies, we will ask you to participate in group discussions, and are interested in the views in this community. We will ask community members will take part in group discussions lead by a moderator. If you choose to participate, we will ask questions about babies, health care for babies and how families decides to seek care. If there are questions you do not want to answer you do not have to, and you can stop at any time. The discussion will take 60 to 90 minutes. We will take notes and audio record the discussions.

Potential advantages and disadvantages
There are no direct benefits or harms for you to participate in this discussion. As a compensation for the time lost, we will give you a soap and we will cover you transportation costs. To participate in this study will not have any consequences for treatment of you and your family at any later point.

What will happen to the research about you?
After the group discussions, the material will be analyzed by the researchers. The material will be processed without your name, ID number or other directly recognisable type of information. Any information about you will be kept confidential and will be anonymous in the reporting of the results. It will not be possible to identify you or your family when we present the results of the study.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent in the study at any time and without stating any particular reason.

If you wish to participate, sign the declaration of consent.

I am willing to participate in the study.

(Signed by the project participant, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

If you later on wish to withdraw your consent or have questions concerning the study, you may contact dr. Mitike Molla (Telephone: 0911131805) or dr. Kristine Onarheim (Telephone: 0946597034.)

VII

INTERVIEW AND FOCUS GROUP GUIDES

Interview guide: Family members at health facility

Site:

Date and time:

Name of interviewer:

Introduction

Thank you for agreeing to speak with us today. My name is ___________ and my colleague's name is ________. We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick babies and the use of health care services. We hope that this study will give important knowledge to improve health care services to newborns.

Since you recently experienced that your baby was ill, we would like to invite you to participate in this study. If you are willing to participate in the study we would like to interview you today about your experiences related to your baby's illness (at discharge from hospital) and then at home after two weeks.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. Before we begin, I would like to read aloud the informed consent form.

[Interviewer reads the informed consent and asks the participant whether he/she has any questions. The participant will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our conversation. I would like to emphasise again that the information you provide, will be confidential. Any information we use from your interview will be combined with other information and it will not be possible to identify what you said. Is this acceptable?

Do you have any questions before we start the interview?

Before we start with some questions, can you tell us about yourself?
Potential areas to be included:

- Interviewee : Age, Gender, Work, Religion
- Size of household, Marital status
- Number of pregnancies, Number of live children
- Wealth measure: Parabol? Radio? Roofs? Smart telephones?
- Gender, Age and Delivery place of newborn that has been ill

Question 1: I'm very sorry to hear that your baby has been sick. Can you please tell me what happened from the time your child was born and up to now?
Probing:

- How did you come to understand that your baby was sick? (Own observation, information from doctor, child not sucking well, child not crying, febrile, breathing problem, etc.)
- What happened next?
- Did you have any thoughts about what kind of sickness the baby had?

Question 2: What did you do when you realized that she/he was sick?
Probing:

- Treated him/her at home?
- Did you seek help? Where? (Relative? Religious leader? Holy water? Health extension worker? Health development army? Health center?)
- What were the reasons for seeking care…?

Question 3: What advice or treatment was given from the persons you sought help from?
Probing:

- What did you think of the advice you got?
- What did you think of the advice you got here (at health facility)?
- Did you follow the advice? Why/why not?

Question 4: How did you decide to seek care at this health facility?
Probing:

- Advice from HEWs, other health care workers?
- Who were involved in making the decision? Mother, father, older siblings, mother in law, grandmothers, others?
- If there was disagreement, what was it about? How did you agree?

Question 5: Do you have any earlier experiences with seeking care for sick babies?

- In your family? Among you friends?
- How was this of relevance when your newborn got sick this time?

Question 6: What was important when you decided to [to seek care at health facility/stay at home/go to traditional practitioner]?
Probing:

- Money, transport, food while in hospital?
- Hope of survival, lack of confidence in survival, other priorities in the household?

Question 7: How did potential costs of care for treatment for the sick baby influence your decision to seek help?
Probing:

- How much were the costs? How did you manage to mobilize/get the money needed?
- If another family member had fallen sick and you had to choose, would you bring the baby or {other family member} to the hospital? Why/why not?
    - Imagine that your mother has stomach pain. She has experienced stomach pain from time to time the last months, but it has now gotten worse and she cannot help out in the house anymore. At the same time, your baby is not sucking well

and is very sleepy. What do you do? What kind of expectations will other people have on this? Should you take your mother to the hospital? The baby?

Question 8: Do you have any earlier experiences of high costs of treatment when family members have fallen sick?
Probing:

- What happened? Loan? Selling? Borrowing from relatives? Health insurance?
- How do you think these experiences may have influenced your decision this time?

Question 9: How has the illness of the baby influenced the everyday life for you and the rest of the family?
Probing:

- Did you have any additional expenses?
- E.g. missing school, missing to work, use of family resources, food, time spent on other activities, other children, savings?
- Did you have to spend resources differently; Less spending on food/education/transportation? Selling something?

I have now asked you several questions about illness of your baby. I have a general question which you might have some thoughts on:

Question 10: Some say that newborns are less important than adults, while others say that newborns are more important than adults: How is illness of newborns perceived versus illness of adults in your community?
Probing:

- How does your opinion differ from this?

Question 11: Do you have anything that you would like to add that we have not talked about?

Thank you for your participation and time.

Interview guide: Family members – follow-up interview

Site:

Date and time:

Date and time of interview I (at health facility):

Name of interviewer:

Introduction

Thank you for agreeing to speak with us again today. We met {two} weeks ago, but I would like to introduce myself and the project again. My name is ___________ and my colleague's name is ________. We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick babies and the use of health care services. We hope that this study will give important knowledge to improve health care services to babies.

Today, we would like to conduct a follow-up interview after we met in the hospital about {two} weeks ago, as we also are interested what happened after you left the hospital.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. Before we begin, I would like to read aloud the informed consent form.

[Interviewer reads the informed consent and asks the participant whether he/she has any questions. The participant will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our conversation. I would like to emphasise again that the information you provide, will be confidential. Any information we use from your interview will be combined with other information and it will not be possible to identify what you said. Is this acceptable?

Do you have any questions before we start the interview?

Question 1: I was very concerned that your child was sick when we met two weeks ago. Can you please tell me how you and the baby are doing?
Probing:

- What happened from the day we spoke (at discharge) and up to now? How was the travel home? How has it been to staying at home?
- Did the condition of the baby improve or worsen after arriving at home? How did you understand that he/she was doing better/worse (own observation, information from health care worker, baby not sucking, baby not crying, febrile, breathing problem)? What did you do? Consulted other practitioners, relatives, neighbors, took the baby back to health facility?)

Question 2: What did they do in hospital/health center [to make him/her better?]
Probing:

- What did you think of this?
- How long did you stay in the health facility?
- How was it for you to be admitted to the hospital/health center?

Question 3: What advice or treatment was given from the health personnel you got help from?
Probing:

- What did you think of the advice you got?
- Did you trust the advice you got? From the doctor? From the nurse? Others at the hospital/health center?
- Did you seek help from other? Relatives? Religious leader? Health extension worker? Health development army? Health center?

Question 4: What was important when you made the decision to follow the recommendations from the doctor/not follow the recommendations?
Probing:

- If there was disagreement, what was it about?
- How did money, transport, food while in hospital play a role?

Question 5: Who were involved in making the decision to stay at/leave the hospital?
Probing:

- What were the roles of the mother, father, older siblings, mother in law, grandmothers, others?

Question 6: What costs did you experience related to the stay in the health facility?
Probing:

- What consequences did these costs have for your family budget after discharge?
- *Did these costs influence how you spend your resources (savings, valuables, etc)?* Less spending on food/education/transportation? Did you have to sell something?
- Now looking back, how do you consider the decision to spend the money on health care for the baby?

Question 7: How has the illness of the baby influenced the everyday life of the rest of the family after you left the hospital?
Probing:

- What were the consequences for the other children in the family? Use of family resources, food, time spent on other activities, savings of the family?

Question 8: Last time, I brought up a statement, I would like to hear your thoughts on again: Some say that newborns are less important than adults, while others say that newborns are more important than adults. Given your experience with your sick baby, what do you think of the statement?
Probing:

- What is the understanding in the community about this? In your family?
- How has the experience of having a sick baby shaped your thinking about this?

Question 9: Do you have anything to add that you would like to add that we have not talked about?

Thank you for your participation and time.

Interview guide: Family members experiencing newborn death

Site:
Date and time:
Name of interviewer:

Introduction

Thank you for agreeing to speak with us today. My name is ___________ and my colleague's name is ________. We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick babies and the use of health care services.

We would like to invite you to participate in this study as we have understood that you recently experienced that your baby got sick, and passed away. We are very sad to hear about this. We hope that this study will give important knowledge about health care for ill babies, and that it can help preventing deaths for other babies that fall sick in the future.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. We are very sorry to hear that you baby passed away. We understand that this must be a very difficult time for you. We appreciate that you agree to talk to us, but would like to emphasize that you at any time can stop this interview.

Before we begin, I would like to read aloud the informed consent form.

[Interviewer reads the informed consent and asks the participant whether he/she has any questions. The participant will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our conversation. I would like to emphasise again that the information you provide, will be confidential. Any information we use from your interview will be combined with other information and it will not be possible to identify you. Is this acceptable?

Do you have any questions before we start the interview?

Before we start with some questions, can you tell us about yourself?
Potential areas to be included:

- Interviewee : Age, Gender, Work, Religion
- Size of household, Marital status
- Number of pregnancies, Number of live children
- Wealth measure: Parabol? Radio? Roofs? Smart telephones?
- Delivery place of baby
- Gender of baby
- Age of baby at illness, Age of baby at death

- Question 1: Can you please tell me what happened from the time your baby was born and until he/she became sick and died?
  Probing:
    - How did you come to understand that your baby was sick? (own observation, information from doctor, child not sucking well, child not crying, etc)
    - What happened next?
    - Did you have any thoughts about what kind of sickness the baby had?

  Question 2: What did you do when you realized that she/he was sick?
  Probing:
    - Treating him/her at home?
    - Did you seek help? Where? Traditional healers? Relative? Religious leader? Health extension worker? Health development army? Health center?
    - Why did you seek care…?

  Question 3: What advice or treatment was given from the persons you got help from?
  Probing:
    - What did you think of the advice you got?
    - Did you follow the advice? Why/why not?

  Question 4: How did you decide to seek care at health facility /stay at home/go to traditional practitioner?
  Probing:
    - Who were involved in making the decision? Mother, father, older siblings, mother in law, grandmothers, others?
    - If there was disagreement, what was it about? Did you agree? How did you agree?

  Question 5: What were the reasons for you to seek care/stay at home/go to traditional practitioner?
  Probing:
    - Why?
    - Belief that the outcome was in the hands of God, costs of treatment, transport or food while in hospital?
    - Hope of survival, lack of confidence in survival, other priorities in the household?

  Question 6: Do you have any earlier experiences with seeking care for sick babies?
    - If so, to what extent did your experiences help you when your baby got sick this time?

  Question 7: How did costs of care influence your decision to seek care when your baby fell sick?
  Probing:
    - How much did you pay for…?
    - Which other costs did you have?
    - What costs have you had after the baby died? Funeral? Other costs?

  Question 8: Do you have any earlier experiences of high costs of care when a family member has fallen sick?
  Probing:
    - What happened? Loan? Borrowing from relatives? Health insurance?

- How do you think these experiences may have influenced your/your family's decision this time?

Question 9: What was in your greatest challenge in connection with the death of your baby?
- Personal loss, reputation as a mother, blame from family members, rumours, loss of self-esteem?
- Expenses? Funeral costs?
- How are you coping with this now?

Question 10: How has the illness and later death of the baby influenced the everyday life for you and the rest of the family?
Probing:
- Did you have any additional expenses?
- What were the impacts on other family members, e.g. going to school, going to work, use of family resources, food, time spent on other activities, other children, savings?
- Did you have to spend resources differently; Less spending on food, education, transportation? Funeral costs? Are you working as you used to do before?

I have now asked you several questions about illness of your child. I have a general question which you might have some thoughts on:

Question 11: Some say that newborns are less important than adults, while others say that newborns are more important than adults: How is illness of newborns perceived versus illness of adults in your community?
Probing:
- How does your opinion differ from this?

Question 12: Do you have anything you would like to add to what we have talked about?

Thank you for your participation and time.

Interview guide: Health care workers

Site:
Date and time:
Name of interviewer:

Thank you for agreeing to speak with us today. My name is ___________ and my colleague's name is ________ We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick babies and the use of health care services. We also seek to understand the social and economic consequences for families with sick babies. We hope that this study will give important knowledge to improve health care services to newborns.

We would like to invite you to participate in this study and will ask your permission to interview you as a health professional with experience in caring for sick newborns.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. Before we begin, I would like to read aloud the informed consent form.

[Interviewer reads the informed consent and asks the participant whether he/she has any questions. The participant will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our conversation. I would like to emphasise again that the information you provide, will be kept confidential. Any information we use from your interview will be combined with other information and it will not be possible to identify you. Is this acceptable?

Do you have any questions before we start the interview?

Before we start with some questions, can you tell us about yourself?
Potential areas to be included:

- Interviewee : Age, Gender,
- Profession, Role at health facility
- Years of experience at health facility, Year of graduation
- Marital status, Number of children, Size of household,
- Religion

Question 1: We have previously talked about some cases of newborn illness in the ward, and we would like to discuss with you the challenges you meet in caring for sick newborns in the hospital/health centers. Can you tell me about the challenges you have to handle when you are treating sick newborns?

Probing:

- What kind of health problems among the newborns do you see?
- Can you tell me about a sick newborn you met lately?

Question 2: Based on your experience, when and possibly for what conditions do the families seek care at health facilities if a newborn is ill? When do the families *not* seek care?

Probing:

- Why do you think it is like this?
- Do they seek help from others? Traditional healers? Relatives? Religious leader? Health extension worker? Health development army? Why?

Question 3: How do you think earlier experiences with health care seeking (for sick newborns, other family members) influence their care seeking when their newborn is ill?
Probing:

- Why is earlier experience(s) relevant to the families?
- Can you given an example?

Question 4: How do families adhere to medical advice that you give when the baby is ill?
Probing:

- Can you give an example where they did not follow you advice? E.g. not taking treatment, leaving the hospital against your advice, etc.?
- Can you give an example where they did not follow you advice? Why do you think they (this family) followed your advice?
- Why do they (not) adhere?

Question 5: How would you as a health care professional respond to a family that does not follow the advice you give them?
Probing:

- E.g. leaving the hospital against you advice, not taking treatment, etc?
    - Do you play a role in protecting the interests of the baby? The interests of other family members?

Question 6: Have you ever experienced that a baby has been left behind in the hospital? What did you do?
Probing:

- Why do you think the family / parents left the baby at the hospital/health center?
- What happens to these babies?
- Who are responsible for taking care of these babies? At the hospital? In the community?
- In the case you just described… Did you recognize that they were leaving the hospital? If so, how did you understand that they were leaving?

We will now discuss difficult decisions the family might have to make when a newborn is ill.
Question 7: Based on your experiences from the hospital/health center, which concerns are (most) important for the family when a newborn fall ill?
Probing:

- Is the newborn the key priority? Why/why not?
- Can you give an example from the ward?
- What if one of the older brothers, the mother, the father, or the grandmother (father's mother) also has fallen sick. If they have to choose, do you think they treat the baby or the others?
- Why? How are these concerns balanced?

Question 8: Do you think gender play a role when families make decisions?
Probing:

- Is it different if it is a boy or a girl that falls sick? Why?

Question 9: Services for children are supposed to be provided for free, but many don't seek care. How have you seen that high costs influence the families' decisions to seek care?
Probing:

- How have you experienced this in your practice?
- How do other factors play a role? Do you know of an example…

Question 10: How does illness of the newborns influence the rest of the family?
Probing

- What are the benefits for the family? Baby survives?
- What are the burdens? Less spending on food? Less spending on education? Experiences of sales (of belongings), spending of savings, borrowing from others?
- Can you give an example from your practice?

Question 11: How are the different family members involved in decision making [to seek care/stay at home/go to traditional practitioner]?
Probing:

- Mother, father, older siblings, mother in law, grandmothers, others?
- If there is disagreement, what is it about? How do you think is agreement made?
- Who do you think has the final say? Why?
- How have you seen these processes been dealt with in the ward?

I have now asked you questions about ill newborns and how families make decisions about health care seeking. I have some general questions which you might have some thoughts on:

Question 12: Some studies from West Africa and Asia show that newborns are valued of less importance than adults: How is a newborn death perceived versus an adult death in this community?
Probing:

- How is a newborn death perceived versus a death of an older child?
- Why do you think it is like this?

Question 13: What do you think of the government's policies to address newborn health?
Probing:

- What must be done to give newborns a higher status? How can this be done?

Question 14: Do you have anything you would like to add to what we have talked about?

Thank you for your participation and time.

Topic guide – focus group discussions: Health care workers

Site:

Date and time:

Name of moderator:

Introduction

Welcome to this group discussion, and thank you for agreeing to speak with us today. My name is ___________ and my colleague's name is ________. We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick newborns and the use of health care services. We also seek to understand the social and economic consequences for families with sick babies. We hope that this study will give important knowledge for health care services to newborns.

We would like to conduct a group discussion today with you as health professionals with experience in caring for sick newborns.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. We would like to hear all points of view and encourage you to feel free to disagree with one another. All comments are welcome. To allow good discussions, we would ask you to not discuss details of this conversation after you leave this room. We also would like to encourage you to speak one at a time.

Before we begin, I would like to read aloud the informed consent.

[Interviewer reads the informed consent and asks the participants for questions. The participants will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our group discussion. I would like to emphasise again that the information you provided will be confidential. Any information we use from this group discussion will be combined with other information and it will not be possible to identify what you said.

Do you have any questions before we start?

Question 1: We will now discuss difficult decisions the family might have to make when a baby is ill.
Please tell us about a baby that was taken to your hospital after falling sick.
Probing:

- What happened to the baby?
- What happened to the family?

Question 3: What do you think the family consider when deciding to take a baby to the hospital/health center?
Probing:

- What do you think is important for the family members in their considerations (the family economy, the baby, the father's mother)?

- Why would go to the hospital?

Question 4: How would you as a health care professional respond if the family decides to leave the hospital?
Probing:

- What would you do if you think the family is about to leave the hospital against your advice?
  - Do you play a role in protecting the interests of the baby? Who plays a role? The other family members?

Question 5: Have you experienced that a newborn has been left in the hospital or a baby was brought to hospital without any parents or family? What did you do?

- Why do you think they left the baby?
- Who are responsible for taking care of these babies?
- How did you understand that they were leaving the hospital?

We will now discuss difficult decisions the family might have to make when a newborn is ill.
Question 6: What concerns are most important to the family if a newborn fall ill?

- Is the newborn a priority? Why/why not?
- Can you give an example from your clinical work?
- What if one of the older brothers, the father or the grandmother (father's mother) also has fallen sick. If they have to choose, should they treat the baby or the grandmother?

Question 7: Do you think gender of the newborn play a role when families make decisions?
Probing:

- Would it be different if it was a boy that fell sick? Why?

Question 8: Services for children are supposed to be provided for free, but we many don't seek care. How do you think high costs influence the families' decisions to seek care?
Probing:

- How have you experienced this in your practice?
- How are other factors important to health care seeking? Do you know of an example…

Question 9: What are the consequences for the families' of using their resources on ill babies?
Probing:

- What are the benefits for the family? Baby survives?
- What are the burdens? Less spending on food? Less spending on education? Experiences of sales (of belongings), spending of savings, borrowing from others?
- How have you experienced that in your practice?

Question 10 Some studies from West Africa and Asia show that newborns are valued of less importance than adults: How is a newborn death perceived versus an adult death in this community?
Probing:

- How is a newborn death perceived versus a death of an older child?
- Why do you think it is like this?

Question 11: What do you think of the government's policies to address newborn health?
Probing:

- What must be done to give newborns a higher status? How can this be done?

Question 12: Do you have anything you would like to add to what we have talked about?

Thank you for your participation. Your time is very much appreciated and your comments have been very helpful.

Topic guide – focus group discussions: Community members

Site:

Date and time:

Name of moderator:

Introduction

Welcome to this group discussion, and thank you for agreeing to speak with us today. My name is ___________ and my colleague's name is ________. We are researchers at the School of Public Health, Addis Ababa University, Ethiopia and the Department of Global Public Health, University of Bergen, Norway. We are doing a study to learn more about care of sick babies and the use of health care services. We hope that this study will give important knowledge to improve health care services to babies.

Procedure

We are interested in your thoughts and experiences, and there are no right or wrong answers. We would like to hear all points of view and encourage you to feel free to disagree with one another. All comments are welcome. To allow good discussions, we would ask you to not discuss details of this conversation after you leave this room. We also would like to encourage you to speak one at a time.

Before we begin, I would like to read aloud the informed consent.

[Interviewer reads the informed consent and asks the participants for questions. The participants will sign the form or withdraw from the study]

As I mentioned [in the informed consent], I would like to use a tape recorder to record our group discussion. I would like to emphasise again that the information you provided will be confidential. Any information we use from this group discussion will be combined with other information and it will not be possible to identify what you said.

Do you have any questions before we start?

Question 1: What do you think the family would do in this case?
Probing:

- Why would they respond in this way?
- What do you think is the family's opinion about the advice from the doctor?
- What are important for them (the family economy, the baby, the father's mother)?

We will now discuss difficult decisions the family might have to make when a baby is ill.
Question 1: Please tell us about your experiences when a baby has fallen sick. Probing:

- What happened to the baby?
- What happened to the family??
- Can you give me an example?

Question 2: What kind of difficult decisions do families in this community face when babies fall ill (like in the cases we just discussed)?

- Which concerns are (most) important to the family?

Question 3: In the cases you described, imagine that it is not only the baby that is sick. What if other family members become ill? Is it more important to care for the baby or the other family members?
Probing:

- Imagine that one of the older brothers also has fallen sick. If they have to choose, should they treat the baby or the brother? Why?
- Imagine that the mother also has fallen sick. If they have to choose, should they treat the baby or the mother? Why?
- Imagine that the father also has fallen sick. If they have to choose, should they treat the baby or the father? Why?
- Imagine that the grandmother (father's mother) also has fallen sick. If they have to choose, should they treat the baby or the grandmother? Why?

Question 4: How does the gender of a baby play a role?
Probing:

- Would it be different if it was a boy or a girl that fell sick? Why?

Question 5: Services for children are supposed to be provided for free, but many don't seek care. What are the costs you experience when going to the hospital or health facilities?
Probing:

- How do you think high costs influence the families' decisions to seek care for babies?
- How do you deal with the high costs?
- Do you know of an example…

Question 6: What are the consequences for the families' of using their resources on ill babies?
Probing:

- *What are the benefits for the family?* Baby survives?
- *What are the burdens?* Less spending on food? Less spending on education? Experiences of sales (of belongings), spending of savings, borrowing from others?

Question 7: What should the family choose, if the family has to sell a cow to take the baby to a facility?
Probing:

- What are most important if other family members also are in need of resources?
- How do think this is dealt with in practice?

Question 8: Some say that newborns are less important than adults: How is a newborn death perceived versus an adult death in your community?
Probing:

- Or a death of a newborn versus a death of an older child?
- How does your opinion differ from this? Do you agree with what he/she said?
- Why do you think newborns are perceived of lower/higher importance?

Question 9: Do you have anything to add that you we have talked about?

Thank you for your participation. Your time is very much appreciated and your comments have been very helpful.

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