

Chronic disease among women in a resource-constrained setting

The case of pelvic organ prolapse in rural Ethiopia

Janne Lillelid Gjerde

Thesis for the Degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
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Scientific environment

This PhD project is a follow-up study of my Master of Philosophy in International Health conducted at the Centre for International Health (CiH), University of Bergen (UoB), from 2010-12. During my PhD period I have been a member of the Research School for International Health and of the Research Group for Global Health Anthropology located at the CiH, the Department of Global Public Health and Primary Care, UoB. From Sept 2016 I have been a member, as well as a board member, of the Norwegian Research School for Global Health (NRS GH).

I have throughout the PhD period been affiliated to and employed by the Department of Obstetrics and Gynecology at the Haukeland University Hospital, with three year full-time funding for the PhD scholarship from the Western Norway Regional Health Authority.

During the fieldwork in Ethiopia I have collaborated closely with research partners at the Department of Obstetrics and Gynecology, College of Medicine and Health Sciences, University of Gondar. In order to obtain temporary residency throughout the fieldwork period I moreover became affiliated to the Institute of Ethiopian Studies at the Addis Ababa University, Ethiopia from February 2015-16.

Main supervisor: Professor Astrid Blystad, Centre for International Health,
Department of Global Public Health and Primary Care,
University of Bergen, Norway

Co-supervisors: Professor Guri Rørtveit, Department of Global Public Health and
Primary Care, University of Bergen, Norway

Dr. Mulu Muleta, Department of Gynecology, Obstetrics and
Urogynecology, Jimma University, Jimma, Ethiopia

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When I entered the world of global health, I had no idea that women's health would be my field of interest, not only as a researcher but also as a nurse. More than anything, my numerous personal meetings with women in rural Ethiopia, who were suffering from treatable chronic pelvic floor disorders, have made me feel passionate about this field. I am truly grateful to each one of them, who, despite their embarrassment, shared their stories with me. I can only hope that this thesis gives their stories justice and somehow contributes needed attention to their struggles.

It is difficult to find the right words to explain how grateful I am to my supervisory team, who have followed me closely over so many years. Astrid, I will surely keep the experience of working closely together with you as one of the most precious memories. I learn so much from you. Your generosity and your genuine care, despite having a million things on your schedule, never stops to impress me. Thank you so much for always believing in me, for your optimism and constant follow-up throughout my studies. Guri, thank you for encouraging me to continue the research track and for always being supportive and caring. You have always helped me to keep focused and structured, especially in my writing, and for that I am so grateful. Our talks over delicious Ethiopian macchiatos and early morning walks up the hillsides of Gondar when you both visited me in the field I keep as truly memorable times. Dr. Mulu, thank you for our short, but valuable, meetings in Gondar and Addis Ababa during the project, and for opening doors and introducing me to important people in the field. I have deep respect for your work on women's health in Ethiopia.

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Summary in English

Background: Pregnancy and childbirth are major risk factors for pelvic floor disorders worldwide. Many of the affected women live in resource-constrained settings with high fertility rates, early-age deliveries and limited access to obstetric care. For women with advanced stages of symptomatic pelvic organ prolapse living in impoverished contexts, the lack of knowledge of and access to surgical treatment may severely affect practical, social and emotional aspects of their lives and may lead to many years of suffering.

Objectives: This study aims to enhance the understanding of how women with pelvic organ prolapse in rural parts of the Amhara region in Ethiopia experience living with the condition, their search for improvement of the condition, the recovery and the reintegration into their communities after having been provided with (free) surgical treatment.

Methods: The study has an explorative qualitative design. The data material was collected through fieldwork at hospital and community levels in the Amhara region of Northern Ethiopia in 2015 and 2016. The fieldwork implied participant observation, in-depth interviews and focus group discussions. The main informants included a total of 32 women with pelvic organ prolapse ranging from 24 to 70 years with various lengths of suffering and stages of the condition. A total of 18 additional informants took part in the study; health care providers, local healers and people from the local health authorities and non-governmental organisations.

Results: *Paper I* describes the women's explanation of pelvic organ prolapse as caused and aggravated by physical strains on their body, such as childbirth, food scarcity or hard physical work. It describes the daily challenges that the affected women faced and their attempts to deal with these in order to manage their work, meanwhile striving to keep the condition a secret from people around them in fear of embarrassment and discrimination.

Paper II illustrates through three case stories the manner in which many women living with pelvic organ prolapse struggle to find remedies and a solution for their aggravating ailment. Strongly influenced by poverty, by lack of knowledge about the condition, by their religious and spiritual beliefs and by the shame and embarrassment related to the condition; the women navigate between various available healing options, both within and beyond the public health care sector. The paper further sheds light on the implications of introducing a free treatment initiative targeting women with pelvic organ prolapse in the present study context.

Paper III focuses on the recovery period and the experienced positive transformation taking place in many of the women's lives after having received free surgical treatment. Strong mobilizations of family network facilitated work-related- and social support during the immediate post-surgery period, and for some also on a long term basis. At the time of inquiry all the informants spoke openly to others about their health condition and several actively engaged in creating awareness about the condition in their communities.

Conclusions: The study highlights how symptomatic pelvic organ prolapse may, in quite severe ways, affect women's lives in a resource-constrained setting, and how a complex web of barriers commonly prevent them from gaining knowledge about the condition and from receiving quality health care. The study moreover illustrates how, in a highly vulnerable population, the provision of free quality medical service for a highly prevalent and readily treatable maternal morbidity may dramatically alter women's health, health-and illness-related health seeking strategies as well as degree of openness surrounding illness perceived as embarrassing and shameful.

Summary in Amharic

የጥናቱ ዳራ፡- እርግጠና እና ልጅ መሠለድ በአለም አቀፍ ደረጃ ለዳሴ ወስጥ ላሉ አካላት በሽታ ዋና አጋላጭ ሁኔታዎች ናቸው ይሁን እንጂ አብዛኞች ተጎጂ ሴቶች የሚኖሩት የሃብት ወሰንነት ባለባቸው ሁኔታዎች እንዲሁም ከፍተኛ የወልደት ማሸነፍ፣ ያለእድሜ መሠለድ እና ወሰን የሆነ የእርግጠና ክትትል ባለባቸው ሁኔታዎች ወስጥ ነው፡

የጥናቱ አላማ - የሚጠየቅ እና ተያያዥ አካላት ወደ ወጭ መወጣት ችግር ያለባቸው በአሜሪካ ክልል ገጠማዊ አካባቢዎች የሚገኙ ሴቶች ከችግሩ ጋር እየኖሩ የሚኾኑት ሁኔታ፣ ከችግሩ ለመወጣት የሚደርጉት ጥረት፣ ቀዶ ህክምና ከተደረገላቸው በኋላ የማገማገሚያ ጊዜያቸው እና ወደ ማህበረሰቡ የሚቀላቀሉበትን ጊዜ በተመለከተ ያለውን ግንዛቤ ማሻሻል ነው፡

የጥናቱ ዘዴዎች፡- ይህ ጥናት አሰሳዊ አሃዛዊ ያልሆኑ መረጃዎች ጥናት ንድፍን መሰረት አድርጎ የተሰራ ነው፤ የጥናቱ መረጃ የተሰበሰበው በአሜሪካ ክልል ሰሜን ክፍል በሚገኙ ሆስፒታሎችን እና በማህበረሰቡ ወስጥ የተደረጉ የመከከል ጥናቶች ነው፡ የመከከል ጥናቱ ተሳታፊ እይታዎችን ጥልቅ ቃለጥያቄዎችን እና የቡድን ወይይቶችን አካቷል፡፡ ዋና መረጃ ሰጪዎች የሚሆኑ እና ተያያዥ አካላት ወደ ወጪ የመወጣት ችግር ያባቸው እድሜዎች ከ24-70 ዓመት የሆኑ 32 ሴቶችን ይዟል፤ የሴቶቹ የስቃይ ሁኔታ እና ደረጃ ይለያያል፡፡ ባጠቃላይ 18 ተጨማሪ መረጃ ሰጪዎች ከህክምና ባለሙያዎች፣ ከባህሪ ህኪሞች፣ ከአካባቢው የጠፍቦ ለሚገኙት የሚጠላከታቸው አካላት እና መንግስታዊ ካልሆኑ ድርጅቶች ተካተዋል፡፡

ወጠዎች

አንደኛው ጥናት ፡- የሚሆኑ እና ተያያዥ አካላት ወደ ወጪ የመወጣት ችግርን የሚባብሱ ሁኔታዎች አካላዊ ወጥረቶች (ሜጅኒቅ) ለምሳሌ ልጅ መሠለድ ፡ የምግብ እጥረት ወይም ከፍተኛ የስራ ጭነት በሚሉት ላይ ሴቶቹ የሰጡትን ማህበራዊ ደገልጻል፡፡ በበሽታው የተጎዱ ሴቶች የሚጠየቁትን መሰናክሎችን፣ እነዚህን መሰናክሎች ተቋቋመው ስራቸውን ለመስራት የሚደርጉት መከራዎች እና በዚህ ሁኔታ ወስጥ ሆኖ በአጠባባቢው (በአካባቢያቸው) ባሉት ሰዎች የሚጠየቁትን ወርደት እና መጠለል በመፍራት ችግሩን በመጠጥር ለማቆየት የሚደርጉትን ጥረት ይገልጻል፡፡

ሁለተኛው ጥናት ፡ - ሶስት የችግሩ ባታሪኮችን መሰረት በማድረግ ሴቶቹ እየተባባሰ ለመጣው ሀመማቸው መጽህኒት እና መፍትሄ ለማግኘት ምን ያክሉ ሴቶች ጥረት እንደሚደርጉ ያብራራል፡፡ በደህነት፤ ስለችግሩ እወቅት ባለመኖር፤ በሀይማኖታዊ እና መንፈሳዊ እምነታቸው እንዲሁም በችግሩ በሜር እና በወርደት ስማት በከፍተኛ ሁኔታ ተፅእኖ ወስጥ በመገባታቸው ምክያት የተገኙትን የሀኪምና መስጫዎች ሁሉ ይጨምራል፡፡ ከዚህም በተጨማሪ ጥናቱ የሚገባውን እና ተያያዥ አካላት ወደ ወጪ የመወጣት ችግር ያለባቸው ሴቶች በነፃ ህኪምናውን የመስጠት ሂደት እና የሚመዘኙትን ጥያቄዎች ለማሳየት ሞክሯል ፡፡

ሶስተኛው ጥናት ፡ - የነፃ ቀዶ ህኪምና ከተሰጣቸው በኋላ በአብዛኞቹ ሴቶች የማገገሚያ ጊዜ እና አዎንታዊ ለውጦች ላይ ያለውን ሁኔታ ያብራራል፡፡ ጠንካራ የሆነ የቤተሰብ ንቅናቄ እና ትስስሮች ከስራ ጋር የተገናኙ እና ማህበራዊ ድጋፎችን (ከቀዶ ህኪምናው በኋላ) የተሳሰጡ አድርጓል፤ ለአንዳንዶቹ ይህ ድጋፍ ለረጅም ጊዜ ቀጥሏል፡፡ በቃለመጠየቁ ጊዜ ሁሉም ሴቶች ስላሉባቸው ችግሮች ለሌሎች በግልፅ ተናግረዋል፤ አብዛኞቹ በማህበረሰቡ ዘንድ ግንዛቤ ለመፍጠር በንቃት ተሳትፈዋል፡፡

መጸምጸሚያ፡ - ጥናቱ የሚገባውን እና ተያያዥ አካላት ወደወጪ የመወጣት ችግር ወስጥ የሃብት ወስንነት ባለባቸው በታዎች የሚኖሩ ሴቶችን ህይወት በተለያዩ መንገዶች እንዴት ሊጎዳ እንደሚችል እንዲሁም በተወሳሰቡ መስጫዎች ምክያት እነዚህ ሴቶች ስለችግሩ እወቅት እንዳይኖራቸው እና ጥራት ያለው ህኪምና እንዳያገኙ መሆናቸውን ያሳያል፡፡ ከዚህ በተጨማሪ ይህ ጥናት በከፍተኛ ሁኔታ ተጋላጭ በሆነ ማህበረሰብ ወስጥ በከፍተኛ ሁኔታ የተንሰራፋውን እና በቀላሉ ሊታከም የሚችለውን ይህን የእናቶች ህመም በነፃ እና በጥራት መብትም የሴቶችን ጠፎ፤ በጠፎ እና ህመም ላይ ያላቸውን አመለካከት እንዲሁም ከጠፎ ችግሩ ለመቀነስ የሚጠቀሙባቸው ስልቶችን ያሳያል፡፡

Summary in Norwegian

Bakgrunn: På verdensbasis er svangerskap og fødsel de viktigste risikofaktorene for kroniske bekkenbunnslidelser, som inkontinens og fremfall av urogenitalorganene (også kalt genitalt descens eller prolaps). Mange av dem som rammes av slike tilstander er kvinner som bor i områder preget av høy fødselsrate, lav alder ved første fødsel og liten tilgang til fødselshjelp. For fattige kvinner som lider av alvorlig grad av genitalt descens kan mangel på kunnskap bidra til redusert tilgang til behandling, som igjen kan ha og langvarige praktiske, sosiale og følelsesmessige konsekvenser.

Formål: Studiens formål er å bidra til ny kunnskap om hvordan kvinner med genitalt descens i rurale deler av Amhara regionen i Etiopia erfarer å leve med tilstanden, hvordan de søker behandling, og opplevelse av bedring og rehabilitering etter gjennomgått (gratis) kirurgisk behandling.

Metode: Studien har et eksplorerende kvalitativt design. Datamaterialet ble samlet inn gjennom feltarbeid fra 2015 til 2016 på sykehus og lokalt i landsbyer og landdistrikt i Amhara regionen i det nordlige Etiopia. Feltarbeidet innbefattet deltakende observasjon, dybde-intervju og fokusgruppe-intervju. Hovedinformantene bestod av totalt 32 kvinner i alderen 24 til 70 år med ulike grader av genitalt descens. Det varierte hvor lenge de hadde lidd av tilstanden. Totalt 18 andre informanter deltok i studien, inkludert helsearbeidere, lokale healere og representanter for lokale helsemyndigheter og fra ulike organisasjoner.

Resultater: *Artikkel I* beskriver hvordan kvinnene opplever tilstanden sin som forårsaket og forverret av fødsler, mangel på nok næringsrik mat og tungt fysisk arbeid. Videre beskrives de daglige utfordringene kvinnene står overfor, og deres forsøk på å håndtere disse for å klare å gjennomføre dagliglivets tunge arbeidsoppgaver. Kvinnene var pinlig berørt og skamfulle over tilstanden og holdt den skjult for andre i frykt for å bli ydmyket og diskriminert.

Artikkel II illustrerer gjennom tre case, hvordan kvinnene strevde med å finne behandling og hjelp for sine økende plager. Sterkt preget av fattigdom, av mangel på kunnskap om tilstanden, av religiøse og spirituelle overbevisninger og av skam, manøvrerte de mellom ulike tilgjengelige behandlingsalternativer, både innenfor og utenfor det offisielle helsesystemet. Artikkelen illustrerer videre hvilke implikasjoner innføringen av gratis helsehjelp for kvinner med genitalt descens kan ha i denne konteksten.

Artikkel III fokuserer på tilhelings-perioden til kvinner som hadde gjennomgått gratis kirurgisk behandling for genitalt descens, og den positive forandringen som mange opplevde i etterkant. Mobilisering av familienettverk styrket den praktiske og emosjonelle støtten i perioden like etter operasjonen, og for enkelte på permanent basis. Alle informantene snakket åpent om sin helsesituasjon etter at de kom hjem fra sykehuset, og flere deltok i forbyggende kvinnehelsearbeid i sitt lokalsamfunn ved å spre informasjon om tilstanden.

Konklusjon: Studien illustrerer hvordan alvorlige symptomer på genitalt descens kan ha en sterk negativ påvirkning på kvinners liv i fattige områder, og hvordan betydelige strukturelle barrierer kan forhindre muligheten til å tilegne seg kunnskap og å få tilgang til helsehjelp. Studien illustrerer også hvordan implementering av gratis behandling av en relativt hyppig kronisk kvinnesykdom i en kontekst preget av fattigdom har et betydelig potensial til å forbedre helsetilstanden til rammede kvinner, og samtidig til å endre sykdomsrelatert atferd og åpenhet rundt sykdommer som oppleves som pinlige og stigmatiserende.

List of papers

- Paper I: Gjerde, J.L., Rortveit G., Muleta M., Adefris M., Blystad A. Living with pelvic organ prolapse: voices of women from Amhara region, Ethiopia. *Int Urogynecol J*, 2017; 28: 361-366.
- Paper II: Gjerde, J.L., Rortveit G., Adefris M., Mekonnen H., Belayneh, T., Blystad A. The lucky ones get cured: Health care seeking among women with pelvic organ prolapse in Amhara Region, Ethiopia. Under review.
- Paper III: Gjerde, J.L., Rortveit G., Adefris M., Belayneh, T., Blystad A. Life after pelvic organ prolapse surgery: A qualitative study in Amhara region, Ethiopia. *BMC Womens Health*, 2018; 18: 74.

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List of abbreviations

ANC	Antenatal Care
CIH	Centre for International Health
DABINCOP	The Dabat Incontinence and Prolapse Study
DHSS	Demographic and Health Survey Site
EDHS	The Ethiopia Demographic and Health Survey
FGD	Focus Group Discussion
HEP	The Health Extension Program
HEW	Health Extension Worker
HIV	The Human Immunodeficiency Virus
HSDP	The Health Sector Development Programme
HSTP	The Health Sector Transformation Plan
ICS	The International Continence Society
IUGA	The International Urogynecological Association
MDGs	Millennium Development Goals
MSF	Medecins Sans Frontieres
NGO	Non-Governmental Organisation
POPQ	The Pelvic Organ Prolapse Quantification System
REK	The Regional Committees for Medical and Health Research Ethics, Norway
RRISK	Reproductive Risks for Incontinence Study at Kaiser

RN	Registered Nurse
SDGs	The Sustainable Development Goals
S-POPQ	The Simplified Pelvic Organ Prolapse Quantification System
UHC	Universal Health Coverage
UNFPA	United Nations Population Fund
UoG	The University of Gondar
UoGH	University of Gondar Hospital
WAHA	Women and Health Alliance International
WHO	World Health Organization

1. Introduction

“I asked myself what the use was of telling other people if there is no solution. All other people seemed to be healthy. I was afraid and wondered what was happening to me. Since I didn’t know what it was, I just kept quiet“

(40-year-old woman with prolapse stage III, Amhara region, Ethiopia)

This dissertation focuses on how women in a resource-constrained setting in Ethiopia experience living with the condition of pelvic organ prolapse. The study explores diverse aspects of living with this condition from the affected women’s point of view; practical and social challenges, health care seeking, recovery and reintegration into the community after surgery.

In affluent settings pelvic organ prolapse, along with other pelvic floor disorders, are known to cause physical health challenges and reduced body image and quality of life, creating heavy burdens on women (Ghetti et al., 2010, Jelovsek and Barber, 2006, Lowder et al., 2011, Roos et al., 2014). Less is known about pelvic organ prolapse in resource-constrained settings, including prevalence rates, risk factors and physical, psychosocial, social and economic implications (Walker and Gunasekera, 2011). Pregnancy and childbirth are known to be important risk factors for pelvic organ prolapse (Rizk, 2009, Rortveit et al., 2007). Due to Ethiopia’s high fertility rate, early pregnancy rate, limited access to obstetric care and health services (Central Statistical Agency/Ethiopia and ICF International, 2017), as well as the condition’s strong association with shame and stigma in the country (Gjerde et al., 2017, Adefris et al., 2017, Blystad et al., 2018, Dheresa et al., 2018), there is reason to believe that pelvic organ prolapse constitutes a major women’s health challenge in Ethiopia.

In the following I will attempt to situate the study’s focus within the broader thematic domain of maternal morbidity, followed by a clinical description of pelvic organ prolapse. I will then situate the topic within the study context of Ethiopia. In order to enhance the understanding of living with a prevalent maternal morbidity in a

resource-constrained setting, socio-cultural- as well as structural characteristics of the study context are emphasized in the discussion of the study findings.

1.1 Maternal morbidities – moving beyond number of deaths

For every woman who dies from pregnancy- or childbirth-related causes, it has been estimated that 20 to 30 women experience maternal morbidity (Firoz et al., 2013, Hardee et al., 2012). The burdens of maternal morbidity, alongside maternal mortality, have been estimated to be highest among the poorest women in low- and middle-income countries (World Health Organization, 2017c), and to have consequences far beyond the obstetric crisis itself (Storeng et al., 2010).

Maternal morbidity covers a broad range of diagnoses which vary in duration and severity. The umbrella term covers everything from severe acute maternal morbidity, which the World Health Organization (WHO) refers to as ‘maternal near-miss’ (Pattinson et al., 2009, World Health Organization, 2011), to non-life-threatening morbidity conditions (Firoz et al., 2013). There have been few standardized and well-documented methods to estimate maternal morbidities, partly due to the lack of common definitions and of standard identification criteria (Firoz et al., 2013, Hardee et al., 2012, Ashford, 2002). In 2009 WHO consequently introduced guidelines for defining and identifying ‘maternal near-miss’ (Say et al., 2009). It was defined as “*a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of the termination of pregnancy*” (Say et al., 2009, p. 289)¹. A maternal near-miss commonly involves diseases such as eclampsia or obstetric haemorrhage that may require hysterectomy, intubation or transfusion (van Roosmalen and Zwart, 2009, Hardee et al., 2012). Definitions of non-severe or non-

¹ Page numbers will throughout the thesis only be referred to when use of direct quotes, books/book chapters and longer reports.

life threatening maternal morbidities however remained unclear. In an effort to fill this gap, a maternal morbidity working group was established by the WHO, with the aim to form a joint definition and framework for measurement and monitoring of maternal morbidity beyond near-miss (Firoz et al., 2013). The group categorized conditions of maternal morbidities and their identification criteria, and defined maternal morbidity as “*any health condition attributed to and/or complicating pregnancy and childbirth that has a negative impact on the woman’s wellbeing and/or functioning*” (Chou et al., 2016, p. 2-3). A list of 121 conditions is included in this broad definition. Diseases of the genitourinary system, such as pelvic organ prolapse, are classified under ‘indirect maternal morbidity conditions’ (Chou et al., 2016, p. 4), as there for i.e. pelvic organ prolapse there are risk-factors that go beyond pregnancy and childbirth (Magowan et al., 2014) (cf chapter 1.2.2).

1.1.1 Chronic maternal morbidities

While 1.4 million women worldwide are estimated to experience acute maternal morbidity, 9.5 million women worldwide suffer from other forms of maternal health complications, and approximately 20 million women suffer from long-term maternal health disabilities (Hardee et al., 2012). Anaemia and underweight, both common chronic conditions among women in resource-constrained settings, may moreover increase the risk of complications during pregnancy or childbirth. Anaemia is commonly caused by malaria, micronutrient deficiency, parasitic infestation and chronic infections including HIV (The Human Immunodeficiency Virus) (Magowan et al., 2014).

Chronic maternal health conditions include various types of pelvic floor disorders (Walker and Gunasekera, 2011). A common manifestation of pelvic floor disorder is urinary incontinence, defined as the complaint of involuntary loss of urine (Haylen et al., 2010). Urinary incontinence affects as many as 25-40% of adult women based on studies in Norway and the US (Hannestad et al., 2000, Townsend et al., 2010). It is a condition known to impact several aspects of a woman’s lives, and potentially has physical, psychosocial, social as well as economic consequences (Lagro-Janssen et

al., 1992, Subak et al., 2006). Faecal incontinence is a less prevalent condition and affects 5-8 % of women, but is thought to have more detrimental consequences for the affected women (Varma et al., 2006, Whitehead et al., 2009). Pelvic organ prolapse is estimated to affect 6-7% of women in the US and Europe (Lukacz et al., 2006, Rortveit et al., 2007), while the numbers from low- and middle-income countries are more uncertain (Walker and Gunasekera, 2011). Obstetric fistula, a severe complication caused by obstructed deliveries, creates an artificial connection between the pelvic organs that leads to continuous leakage of urine and/or faeces through the vagina. Annually, some 50,000 – 100,000 new women are affected, of whom the majority live in remote rural areas with limited access to emergency obstetric care (Muleta, 2010, World Health Organization, 2017a). The condition of obstetric fistula has a low incidence in high-income countries, and is commonly caused by obstetric trauma or surgery rather than prolonged obstructed labour (Egeland et al., 2007, Trovik et al., 2016). Globally, there has been a growing interest and recognition of obstetric fistula as a devastating problem for women's health in resource-constrained settings (Muleta et al., 2007, World Health Organization, 2017a). There has however been less focus on women who suffer from other and less severe, but far more prevalent types of pelvic floor disorders (Adanu et al., 2006, Okonkwo et al., 2001, Walker and Gunasekera, 2011).

Due to an ongoing worldwide reduction in maternal mortality, although far from a rapid reduction, there is currently a shift in global attention towards women who survive and suffer from maternal morbidities (World Health Organization, 2017c, Machiyama et al., 2017). The need for measurement criteria of maternal morbidity has thus been emphasized, and is regarded as a crucial step in order to identify and to reach global health targets concerning women's health (Chou et al., 2016).

1.1.2 Global initiatives to reduce maternal morbidities

To improve maternal health, the global community has fostered a number of initiatives, policies and goals which have mobilized attention and funds over the last decades (Hogan et al., 2010, World Health Organization, 2015a). The Alma-Ata

Declaration of 1978 (World Health Organization, 1978), declared primary health care as the means for providing comprehensive, universal, equitable and affordable healthcare service in all countries. More specifically it aimed to ensure access to trained personnel for attending pregnancy and childbirth for all by the year 2000 (Hall and Taylor, 2003). Many low-income countries were however economically constrained, and struggled to finance the demands for a strengthening of their primary health care system (Hall and Taylor, 2003). Due to the slow progress, in the mid-1980s advocates called out to politicians and policymakers for prioritization of maternal health in low-income countries (Rosenfield and Maine, 1985). Subsequently, in 1987, an advocacy movement working for the reduction of maternal mortality and ill-health in low-income countries launched the ‘Safe Motherhood Initiative’ (Family Care International, 2007). The initiative created broad agreement that maternal health services of good quality required skilled health care, a functional referral system and available emergency obstetric services, and a specific global target of reducing maternal mortality by 50% by the year 2000 was set. Progress was to be reported on a number of indicators, among them the coverage of antenatal care and attendance of skilled health personnel at delivery. In countries reporting the highest levels of maternal mortality, there was however little or no progress documented by the year 2000 (Family Care International, 2007).

When the Millennium Development Goals (MDGs) were launched and adopted by the international community, they included ambitious goals for maternal health. They aimed among other to achieve universal access to reproductive health by 2015 and to reduce the maternal mortality ratio by three quarters, between 1990 and 2015 (World Health Organization, 2015a). Meanwhile, the critical importance of timely access to health care services was emphasized, and in 2005 the member states of WHO endorsed the universal health coverage (UHC). In 2010, they committed to “*develop their health financing systems so that all people have access to health services and do not suffer financial hardship paying for them*” (World Health Organization, 2010, p. 7). Since resource-constraints limit the possibility for making all health care services free-of-charge, the goal was to make the progress towards UHC as fair and equitable

as possible and include key services that align well with other social goals (Ottersen et al., 2014).

WHO reported in 2015 a worldwide 45% decrease in maternal mortality, and an increase from 59 % to 79 % in all births globally assisted by skilled health personnel since 1990 (United Nations, 2015). However, the maternal mortality and morbidity was in 2015 still considered unacceptably high in many countries. All member states of the United Nations supported a new initiative; the Sustainable Development Goals (SDGs). The SDGs targets concerning maternal health aim to “*ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programs*” and to “*reduce the global maternal mortality ratio to less than 70 deaths per 100,000 live births*” by 2030 (World Health Organization, 2015b). Meanwhile, UHC remains high on the global and national policy agenda, aiming to continue the strengthening of health care systems and to improve the level and distribution of health care services (Ottersen et al., 2014).

1.2 Pelvic organ prolapse

1.2.1 Defining pelvic organ prolapse

The International Continence Society (ICS) has provided a standardisation of terminology for pelvic organ prolapse (hereby also referred to as 'prolapse'), and for lower urinary tract dysfunctions in general (Abrams et al., 1988). In 2010, ICS and the International Urogynecological association (IUGA) updated the terminology of female pelvic floor dysfunctions due to its increasing complexity. Pelvic organ prolapse was defined as “*the descent of one or more of the anterior vaginal wall, posterior vaginal wall, the uterus (cervix), or the apex of the vagina (vaginal vault or cuff scar after hysterectomy)*” (Haylen et al., 2010, p.10). The descent of the organs are due to a weakness in the pelvic floor muscle that prevents it from upholding the normal positioning of the organs in the pelvic floor (Magowan et al., 2014, pp. 121) (**Figure 1**). As all the organs that can prolapse are attached directly or indirectly to

the pelvic floor musculature, more than one organ will typically be involved in a genital prolapse condition (ibid). (**Figure 2**)

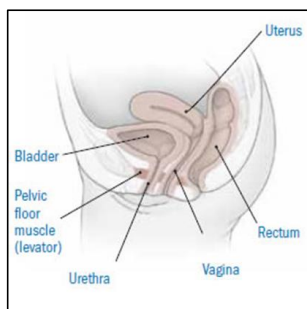


Figure 1: Normal position of pelvic organs (Harvard Women's Health Watch, 2014, [webpage])

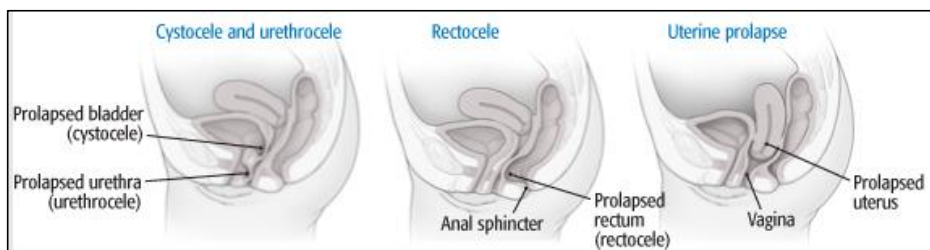


Figure 2: Types of pelvic organ prolapse (Harvard Women's Health Watch, 2014, [webpage])

Urethrocele is the descent of part of the anterior (front) vaginal wall which is fused with the urethra, causing it to protrude into the vagina. The descent of the tissue may alter the urethrovesical angle which often causes the affected woman to also experience stress urinary incontinence (Magowan et al., 2014, pp.121-122). A *cystocele* occurs when the wall between the bladder and the vagina weakens, and the bladder descends into the vagina. This type of prolapse may cause difficulties with emptying the bladder, increased frequency of urination and risk of urinary tract infection. *Uterine prolapse* is the descent of the uterus and the cervix into the vagina, while a *rectocele* is the descent of the rectum into the vagina due to a weakening in

the tissue that separates the two. *Enterocoele* is the protrusion of the peritoneum of the rectovaginal pouch into the vagina which forms a ‘sack’ that may contain small bowel and omentum. Other types of prolapse include *vault prolapse*, which involves the descent of the upper part of the vagina (cervix) into the vagina, either as part of uterine prolapse or after a hysterectomy (removal of the uterus) (Magowan et al., 2014, pp.121-122).

The pelvic organ prolapse quantification system (POPQ) is the standard classification system for reporting pelvic organ support defects and is used in most scientific research on the topic (Treszezamsky et al., 2010). The POPQ system was later criticized for being difficult to understand and to use due to its comprehensiveness (Manonai et al., 2011). The standardization of terminology committee in IUGA thus developed a new version of the POPQ (S-POP) classification system which simplified the terminology and reduced the number of points measured, but retained the stages described in the POPQ (Manonai et al., 2011). According to both systems the prolapse is anatomically staged from 0 to IV (**figure 3**). At stage 0 there is no prolapse demonstrated, while at stage I the prolapse is more than 1 cm above the level of the hymen. At stage II the prolapse is 1 cm or less above or distal to the plane of the hymen, and at stage III the prolapse is more than 1 cm below the hymen, and thus partly visible on the outside of the vagina. Stage IV implies a complete eversion of the prolapse which cannot retract back into the vagina (Haylen et al., 2010).

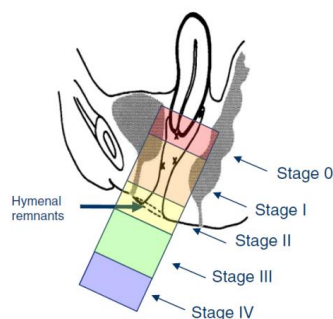


Figure 3: The POPQ staging system (Haylen et al., 2010, p. 10)

It is common to differentiate between reported prolapse symptoms (*symptomatic* prolapse) and prolapse verified by pelvic examination (*anatomical* prolapse) (Megabiaw et al., 2013). Symptoms of prolapse normally include vaginal bulging; pelvic pressure; bleeding, discharge or infection related to ulceration of the prolapse; the need to digitally replace the prolapse (push it inside the vagina) in order to defecate or void as well as complaints of low, sacral backache (Haylen et al., 2010). The symptoms are often worsened by gravity which may make long periods of standing, walking or exercise challenging for the ones affected. Straining in relation to defecation can also make the prolapse more prominent. However, the prolapse-related symptoms are not found to be directly associated with the stage of prolapse; at what point women become symptomatic varies. Stage I is normally experienced as asymptomatic, while women with stage II often report a wide range of symptoms. Women with stage III and IV commonly report severe symptoms (Swift et al., 2003).

1.2.2 Prevalence and risk factors of pelvic organ prolapse

The prevalence of prolapse has been found to vary depending on the population and the definition of prolapse (Rortveit et al., 2007). Population-based studies of middle-aged and older women report that 32-98% have some degree of *anatomical* prolapse upon examination (Nygaard et al., 2004, Handa et al., 2004, Hendrix et al., 2002). This huge variation in reported prevalence of anatomical prolapse may be explained by choice of age group, population and type of measurement tools. However, in studies of *symptomatic* prolapse, the reported prevalence is between 4 to 8% (Bradley and Nygaard, 2005, Tegerstedt et al., 2005, Rortveit et al., 2007). Studies from the US have moreover reported a lower prevalence among African-American women compared to other groups of women (Rortveit et al., 2007, Hendrix et al., 2002).

The few population-based studies on prolapse available from low- and middle-income countries have reported prevalence rates ranging from 3–56%, and commonly include both research on symptomatic and anatomical prolapse (Walker and Gunasekera, 2011). Based on the limited information available, prolapse seems to be a common condition affecting women in low-income settings (ibid). In a study in

rural Gambia of near 1400 women, 46% were found to have some degree of prolapse through examination, while 13% of women with moderate or severe prolapse reported symptoms (Scherf et al., 2002). A study from India among near 3000 women found that 7.6% reported symptoms of prolapse (Kumari et al., 2000).

Prolapse is caused by weakness in the pelvic floor muscle, and factors likely to predispose for the condition are multiple (Magowan et al., 2014). Pregnancy and childbirth are found to be very important risk factors (Rizk, 2009, Rortveit et al., 2007), and the risk has been found to increase with the number of vaginal deliveries (Rortveit and Hannestad, 2014). Other important risk factors include age, as the menopausal state leads to oestrogen deficiency and loss of connective tissue strength (Magowan et al., 2014). A Swedish survey among women aged 20 to 59 years found that age, parity, pelvic floor muscle strength and maximum birth weight (among parous women) were factors associated with symptomatic prolapse (Samuelsson et al., 1999). Studies in the US additionally reported lower education, weight of largest infant delivered vaginally and obesity as associated with prolapse (Nygaard et al., 2004, Hendrix et al., 2002). In a population-based study including middle aged and older women in the US, irritable bowel syndrome, constipation and self-reported fair or poor health status were found associated with symptomatic prolapse (Rortveit et al., 2007).

Several risk factors for prolapse are similar in both resource-constrained and affluent settings, such as age and parity (Walker and Gunasekera, 2011). In a study from the Gambia highly parous women with eight or more deliveries were indeed reported to have 15 times higher chance of developing prolapse compared to nulliparous women, and women aged 45-54 had twice the risk of developing prolapse compared to 15-24 year olds (Scherf et al., 2002). In resource-constrained settings other factors such as early age at marriage and first delivery (Bonetti et al., 2004, Walker and Gunasekera, 2011, Ravindran et al., 1999), heavy manual work, including heavy lifting during pregnancy and shortly after delivery (Bodner-Adler et al., 2007, Ravindran et al., 1999, Bonetti et al., 2004), poor nutrition and anaemia (Scherf et al., 2002, Walker

and Gunasekera, 2011) have also been reported to increase the risk of developing prolapse. Prolapse is moreover often reported to affect younger women with no or only one-two births. It is therefore suggested that the risk of prolapse in resource-constrained settings may be stronger associated with e.g. carrying heavy loads and early-age-deliveries rather than high parity or age (Bonetti et al., 2004, Ravindran et al., 1999).

1.2.3 Management of pelvic organ prolapse

Although a prolapse is defined and staged anatomically, it normally doesn't require treatment unless the affected woman has bothersome symptoms (Magowan et al., 2014, pp. 124). The first-line management of a mild to moderate prolapse is commonly conservative treatment, and includes advise on lifestyle changes, such as weight reduction and smoking cessation, supervised pelvic floor physiotherapy, ring pessary or oestrogen therapy. Pelvic floor muscle training has for example been found to improve prolapse stage and symptoms, including sexual function (Braekken et al., 2015, Bo et al., 2012). However, for such training to be effective it requires proper instruction and close follow-up (Bo, 2012). Ring pessaries have shown to be effective in improving prolapse-related pelvic floor symptoms such as urinary difficulties or incontinence as well as quality of life and perception of body image (Fernando et al., 2006, Patel et al., 2010). Pessaries are however reported to be less effective among women with high parity and previous hysterectomy (Fernando et al., 2006). Conservative treatment is also sometimes chosen as a temporary relief prior to a planned surgical intervention (Magowan et al., 2014, pp. 124). Treatment with low-dose oestrogen gel has been found to significantly improve vaginal health of postmenopausal women before surgical intervention of prolapse, and improved sexual health and quality of life after surgery (Caruso et al., 2017).

There are multiple surgical methods for treating various types of pelvic organ prolapse, and there is a continuous debate among medical experts on the methods with the most desirable long-term outcomes (Maher et al., 2013). Most surgical procedures for pelvic organ prolapse are performed vaginally, as for example anterior

or posterior vaginal wall repair where supporting sutures are placed into the fascia in order to elevate the prolapsed bladder or rectum (Magowan et al., 2014, pp.125). A uterus prolapse may be treated with vaginal hysterectomy or by removal of the cervix. For older women with severe prolapse a surgical alternative is to fully close the vagina. This will prevent sexual intercourse (Maltau, 2011, p. 392).

Among women having undergone surgical correction for prolapse, it has been estimated that up to 30% require a second operation within 5 years (Magowan et al., 2014, pp.126). The risk of prolapse repair has been found to be higher in women whose initial hysterectomy was caused by prolapse and even higher if the initial prolapse was above grade II (Dallenbach et al., 2007). The complete eversion of the vagina is usually caused by a previous hysterectomy, and is known as a 'vault' prolapse. One surgical option to prevent or treat vault prolapse is to fixate the vaginal vault to the sacrospinous ligament through a vaginal procedure (*sacrocolpopexy*). Another method is to suture the vaginal vault to the body of the sacrum by use of a *mesh* (a synthetic or biological material used to reinforce) either through an abdominal incision or through laparoscopy (Magowan et al., 2014, pp. 125-126).

In settings characterised by limited supply and health service availability, conservative treatment for less severe cases of prolapse, such as vaginal pessaries and oestrogen therapy, are commonly not used (Walker and Gunasekera, 2011). Most efforts in resource-constrained setting have concentrated on surgical treatment of severe forms of prolapse (Bodner-Adler et al., 2007, Walker and Gunasekera, 2011). Although surgical treatment for prolapse is commonly available in urban hospitals, only a minority of the women even with the most severe forms of prolapse are likely to receive surgical treatment (Walker and Gunasekera, 2011). Women living in rural areas of various resource-constrained settings experience multiple challenges in reaching health facilities due to distance, unaffordability, social stigma and limited knowledge of the condition and about the existing treatment (Bodner-Adler et al., 2007, Hardee et al., 2012, Adefris et al., 2017, Kumari et al., 2000).

A study from Nepal reports that women with prolapse express great experience of improvement and satisfaction after surgery, but surgical treatment is only scarcely available despite prolapse constituting a significant health problem in the country (Schaaf et al., 2008). Almost half of women suffering from severe prolapse in Nepal were indeed found to not seek help at health facilities at all, mainly due to factors such as the perception of prolapse being a natural ailment for childbearing women, shame, fear of stigma and discrimination as well as male service providers (Shrestha et al., 2014b). In Ghana only one third of women with symptomatic prolapse were found to seek treatment due to the high costs involved (Wusu-Ansah and Opare-Addo, 2008). In Uganda, the majority of affected women were found to have had actively sought help for their prolapse at health facilities, however few had succeeded in receiving proper treatment either due to the unavailability of treatment or receiving inadequate or wrong treatment. Many of these women thus used herbs available in their local communities as a remedy for their ailment (Krause et al., 2014). Innovative approaches, such as surgical camps at rural hospitals (Bodner-Adler et al., 2007) and subsidies assisting people who cannot afford treatment at urban hospitals (Bhatia et al., 2006, Bonetti et al., 2004) have in certain resource-constrained settings given severely affected women the opportunity to receive treatment.

1.2.4 Recovery and reintegration after surgical treatment

Symptomatic pelvic organ prolapse has been reported to negatively affect diverse aspects of life (Jelovsek and Barber, 2006, Lowder et al., 2011, Lowenstein et al., 2009). From studies of advanced stages of pelvic organ prolapse in the US, affected women were found more likely to feel self-conscious and isolated, and less likely to feel physically attractive, sexually attractive and feminine (Jelovsek and Barber, 2006, Lowder et al., 2011). Feelings of embarrassment and discomfort disrupted and changed many of the affected women's daily or work-related tasks as well as sexual intimacy practices (Lowder et al., 2011). A study in Nepal found that prolapse-affected women had difficulties walking, standing, sitting and lifting, and thus experienced an inability to fulfil household chores and their husband's sexual desires,

which for some led to humiliation and severe harassment from their spouse and other family members (Shrestha et al., 2014b).

Research conducted in the United States, Europe and Australia offer strong evidence of quality of life improvements following vaginal surgery for prolapse, including improved sexual function and body image (Larson et al., 2013, Glavind et al., 2015, Lukacz et al., 2016, Ulrich et al., 2015). In a Norwegian study it was reported improvement after prolapse surgery, especially among women who had reached menopause and by women who had gone through an anterior colporrhaphy (Lonnee-Hoffmann et al., 2013). A mixed methods study from the United Kingdom assessing the impact of pelvic floor surgery on female sexual function moreover found significant improvement of physical and partner-related domains. Negative effects on sexual function after surgery were found to be related to dyspareunia (pain during sexual intercourse), fear of causing damage to the surgical result, new symptoms and a disappointing result of the surgery (Roos et al., 2014). Despite the indications of severe negative effects of prolapse, little is known about how women in resource-constrained settings experience the recovery following prolapse surgery. A study from Nepal reported that 74 % of the 646 women who had undergone surgical treatment for prolapse reported an overall improved health status (Chhetry et al., 2012). Another study from Nepal similarly reported a high level (85%) of overall satisfaction with the result of the surgery at 1 to 2 years follow-up (Schaaf et al., 2008).

There is similarly limited knowledge from resource-constrained settings about women's processes of reintegrating after prolapse surgery. Among women suffering from other types of pelvic floor disorders, such as obstetric fistula and severe forms of urinary or fecal incontinence, that may have more detrimental effects on quality of life (Hampel et al., 2004, Hayder and Schnepf, 2010, Lagro-Janssen et al., 1992, Peake et al., 1999, Muleta et al., 2008), it has been reported that a successful surgery only represent a starting point in their process of social reintegration (Khisa et al., 2017, Muleta et al., 2008). Among women successfully repaired for obstetric fistula

in Tanzania, the adaption to a life without urinary leakage proved challenging (Khisa et al., 2017). The majority returned to an environment where they for long had been discriminated and marginalized and lacked support from family members. They had no occupation to return to, which left them in poor living conditions. Many had lost trust in partnerships due to being abandoned and thus remained single, against community norms (ibid).

Although the consequences reported of living with prolapse have less detrimental physical, social and practical consequences compared to obstetric fistula, reintegration after prolapse surgery may for some also prove difficult, due to the consequences reported on the practical, social and intimate aspects of life. As mentioned earlier, a successful outcome of prolapse surgery is not a guarantee, and new symptoms such as urinary incontinence, voiding difficulties, difficulty during defecation and vault prolapse may appear (Pham et al., 2009). However, many positive long-term outcomes after prolapse surgery have been reported. In a study from Poland quality of life was assessed among women treated for advanced pelvic organ prolapse, and significant improvement was reported in various self-perceived quality of life dimensions after 16-18 months such as vitality, mental health, physical and social functioning (Bartuzi et al., 2013). In a US based study, depressive symptoms among women with prolapse were moreover reported reduced after surgical intervention (Ghetti et al., 2010). In a Nepalese study, the large majority of prolapse treated women experienced that the surgery had brought a positive shift in their husband's attitudes towards them (Chhetry et al., 2012). In a rural setting in Nepal, it was moreover reported that nearly 50% of prolapse treated women had been able to change their daily activities to lighter work after the surgery (Schaaf et al., 2008).

1.3 Pelvic organ prolapse in the context of Ethiopia

There are few studies in Ethiopia that address the prevalence of pelvic organ prolapse. In a population-based pilot study by Megabiaw and colleagues (2013) which was related to the present study and conducted in the present research site in the Amhara region, 6.3% of women (aged 16-80) reported symptoms of prolapse, while

severe anatomical prolapse (stage III and IV) was detected in 7.1% of women by pelvic examination and the use of the S-POP staging system (Manonai et al., 2011). This divergence figures can be best explained by under-reporting (Blystad et al., 2018), and will be elaborated further on in chapter 3.2. A recent community-based study among 3432 ever married women in eastern parts of Ethiopia reported a 9.5% prevalence of symptomatic prolapse (Dheresa et al., 2018). A large scale face-to-face survey including 23,000 women of reproductive age (15-49 years) from 113 rural villages located in north and western parts of Ethiopia reported a low prevalence (1%) of symptomatic prolapse (Ballard et al., 2016). This low figure is likely coloured by the exclusion of women above 49 years of age, and may bear similar challenges of severe under-reporting as reported by Megabiaw et al (2013).

In stark contrast to the low reported numbers of prolapse, a hospital-based retrospective descriptive study on prolapse in south-west Ethiopia revealed that prolapse accounts for more than 40% of major gynecological operations at the specialized hospital level (Akmel and Segni, 2012). The study also demonstrated significant association between prolapse and age, parity, residing in rural areas and the occupation of farming (ibid). In a hospital-based case-control study in north-west Ethiopia, the age of women, sphincter damage, parity, non-attendance in formal education, the carrying of heavy objects, body mass index and delivery assisted by non-health professionals were factors found to be significantly associated with prolapse (Asresie et al., 2016). Megabiaw et al (2013) also found *anatomical* prolapse stage II-IV to be associated with the carrying of heavy objects for five or more hours per day, a history of prolonged labour and residing in rural highland.

These findings call for a look at the contextual factors that seem to generate starkly different risk scenarios from the ones found in more affluent settings. In the next section I briefly introduce the historical context and the current health care strategies for improved maternal health in Ethiopia and the health care system in general, before introducing existing knowledge about how women with prolapse in Ethiopia seek solution for their ailment.

1.3.1 The maternal health context in Ethiopia

Ethiopia has generally demonstrated great success in the achievement of the Millennium Development Goals (MDGs) (Assefa et al., 2017). The progress in the proportion of women giving birth in health facility has been reported to have increased from 5% in 2000 to 26% in 2015, and the use of skilled birth attendants has been reported to have increased from 3% in 1990 to 28% in 2015 (Assefa et al., 2017, Central Statistical Agency/Ethiopia and ICF International, 2017, p. 138). Moreover, the maternal mortality ratio has reduced by 70%, i.e. from 1400 deaths per 100,000 live births in 1990 to 412 deaths per 100,000 live births in 2015 (Assefa et al., 2017, Central Statistical Agency/Ethiopia and ICF International, 2017, p. 249). However, maternal mortality figures in most resource constrained areas are highly uncertain. They have become politicized, as they serve as objective comparisons of development across countries, i.e. through global initiatives such as MDGs and the Sustainable Development Goals (SDGs) (Wendland, 2016, Storeng and Béhague, 2017). The total fertility rate has moreover shown a slow reduction from 5.5 children in the year 2000 to 4.6 children in the year 2015 (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 77).

Despite the overall positive progress, huge disparities remain between urban and rural areas, and between the different regions within the country in Ethiopia. The total fertility rate is 2.3 children for urban woman while 5.2 children for rural woman. Similarly, variation stretches from 1.8 children per woman in Addis Ababa to 7.2 children per woman in the Somali region (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 77-78). During pregnancy, 90% of urban women versus 58% of rural women receive any antenatal care from a skilled provider (ibid, p. 134). At birth 80% of urban mothers are assisted by a skilled provider and 79% delivers in a health facility while the corresponding figure for rural women is 21% and 20% respectively (ibid, p.137). In the Ethiopian context '*skilled assistance during delivery*' involves births delivered with the assistance of a doctor, a nurse or midwife, a health officer or a Health Extension Worker (HEW) (ibid, p.138). Postnatal check-up after two days of delivery was moreover received by 45% of urban mothers

compared to 13% of rural mothers (ibid). Beyond the widespread practice of home birth, educational status and household wealth correlate to maternal health indicators including maternal morbidity (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 133). Around 70% of urban women and 30% of rural women in Ethiopia are literate. Among mothers with no education 17% of births were assisted by a skilled provider and 16% were delivered at a health facility, compared to 93% and 92% among mothers with more than secondary education.

Due to the low rate of institutional deliveries in Ethiopia, data on birth outcomes in terms of maternal morbidity is not yet universally or routinely available. Obstetric fistula has in a population-based study been estimated to affect 2 per 1000 women in rural Ethiopia (Muleta et al., 2007) and 161 000 women in Ethiopia are estimated to suffer from different severities of urinary leakage (Ministry of Health Ethiopia, 2015, p. 27), although substantial underreporting is likely due to the extreme shame connected to these conditions (Gjerde et al., 2013, Muleta et al., 2008).

1.3.2 Strategies to improve maternal health in Ethiopia

In the current Health Sector Transformation Plan (HSTP) launched in 2015, the following relevant strategic objective is described under the aim of improving equitable access to quality health services: ‘to eliminate obstetric fistula and clear all backlog cases of fistula and pelvic organ prolapse’ (Ministry of Health Ethiopia, 2015, pp.102). The HSTP constitutes the first phase of a 20-year health sector strategy named ‘Envisioning Ethiopia’s Path to Universal Health Care through strengthening of Primary Health Care’ (Ministry of Health Ethiopia, 2015p. 12-13), and aligns with the health related goals of the Sustainable Development Goals (SDGs) (World Health Organization, 2017b, Ministry of Health Ethiopia, 2015). Other maternal health related goals in the HSTP to be reached by 2020 are ambitious, and include reducing maternal mortality ratio from 420 to 199 per 100,000 live births, reducing total fertility rate from 4.1 to 3 children per woman, reducing unmet need for family planning from 24% to 10%, reducing teenage pregnancy rate from 12% to

3%, increasing antenatal care visits from 68% to 95%, increasing deliveries attended by skilled health personnel from 60% to 90% and increasing post-natal care coverage from 90% to 95% (Ministry of Health Ethiopia, 2015, p. 98-100). These ambitious aims indicate the current focus and political will to implement measures to reduce maternal morbidities in Ethiopia.

Ethiopia's maternal health policies have the last 20 years been formulated through a series of four 5-year investment programs known as the Health Sector Development Programme (HSDP). HSDP I was initiated in 1996, and one of the core elements in the strategy was decentralising the health care system to ensure accessibility of health care for all segments of the population. Priority was placed on maternal and child health care. For the realization of the HSDP, a Health Extension Program (HEP) was introduced in 2003. The aim of the HEP was to ensure universal coverage of primary health care through health promotion, behavioural change communication and basic curative care. In the HEP, Health Extension Workers (HEWs) were trained to provide basic preventive and curative maternal and child health services in the rural communities (Central Statistical Agency/Ethiopia and ICF International, 2012, p. 6).

In the last HSDP (HSDP IV) from 2011-2015, family planning, antenatal care and skilled birth attendant remained high-priority interventions. In an effort to improve key health interventions, including increased institutional delivery, the 'Health Development Army' was established to mobilize families, mainly women, through networks at community levels (Ministry of Health Ethiopia, 2015). Overall, since the implementation of the HSDP and HEP, Ethiopia has strongly engaged in the strategy of massively expanding and strengthening primary health facilities through the construction of 16,440 health posts, 3,547 health centres and 311 hospital (Ministry of Health Ethiopia, 2015, p. 49). There has furthermore been encouraging improvements in the coverage and utilization of basic reproductive health services in Ethiopia, although the huge variations between regions and urban and rural settings continue to remain a challenge (Ministry of Health Ethiopia, 2015).

1.3.3 The Ethiopian health care system

The Ethiopian health care system follows a decentralized model with a growing countrywide network of health care facilities (Workie and Ramana, 2013). Both the Health Extension Program (HEP) and the Health Development Army are at the centre of focus for the provision of primary health care services to the broad masses. The HEP is fully integrated into the broader primary health care system and delivers free preventive, promotive and basic curative services (Workie and Ramana, 2013).

The primary health care level in Ethiopia consists of health posts, health centres and primary hospitals, while the secondary health care level consists of general hospitals and the tertiary health care level consists of specialised hospitals (Central Statistical Agency/Ethiopia and ICF International, 2017). The health posts are community-based and staffed with two Health Extension Workers (HEWs), while the health centres are normally located in semi-urban areas and should be staffed by a health officer, nurses, midwives as well as laboratory- and pharmacy technicians. In addition to the government health facilities there are various health facilities run by private actors for profit, and by non-governmental organisations (NGOs) and mission- or faith-based actors for non-profit (Ethiopian Public Health Institute et al., 2017).

Among the government health facilities 62% charge routine user fees for general health services, while exemption schemes exist for particularly vulnerable groups of patients, including paediatric, obstetric and gynaecological emergencies. Additionally, many health facilities operate with a formal or informal system to waive fees for the very poorest (Ethiopian Public Health Institute et al., 2017). However, rural Ethiopian health facilities are, like many other resource-constrained settings, faced with challenges such as limited resources and stock interruptions, poor referral linkage and shortage of qualified health personnel to carry out adequate emergency obstetric services (Admasu et al., 2011, Ministry of Health Ethiopia, 2015).

1.3.4 Seeking solution for pelvic organ prolapse in Ethiopia

In studies of women with obstetric fistula and pelvic organ prolapse conducted at the University Hospital of Gondar (UoGH) in north western part of Ethiopia, it was reported that near 70% of women with stage III and IV prolapse had symptoms of depression (Zelege et al., 2013). Near 83% of patients with prolapse moreover delayed to seek help for an average of seven years after experiencing prolapse symptoms (Adefris et al., 2017). Among the women, the fear of disclosing the condition was one of the strongest barriers to seek health care (ibid). Other studies reveal that prolapse and other types of pelvic floor disorders are considered extremely sensitive and shameful, which further restrict or delay women from seeking health care (Blystad et al., 2018, Gjerde et al., 2013, Megabiaw et al., 2013, Muleta et al., 2008).

Inability to pay for treatment as well as for the indirect costs involved in seeking treatment at hospital level has also proved to be a strong barrier to seeking health care (Adefris et al., 2017). Women's autonomy and freedom to make decisions are moreover an important limiting factor linked to patriarchy and social norms in the Ethiopian rural context (Woldemicael and Tenkorang, 2010). These factors coupled with high levels of illiteracy among rural Ethiopian women, and the substantial distances to health care facilities make it challenging for affected women to reach the health care system (Admasu et al., 2011).

From our own previous study reporting on urinary incontinence in north-western Ethiopia, women who faced similar barriers in health care seeking, sought alternative solutions to health care such as religious healing as Holy Water (*'tsebel'*), worshipping spirits within the home, by guidance of a local spiritual healer (*'awaki'*) or by use of locally available remedies (Gjerde et al., 2013). From a study exploring health seeking behaviour among women with cervical cancer in Ethiopia, similar findings were reported, and by many study participants various alternative treatment options would be exhausted before seeking help at health facilities (Birhanu et al., 2012).

It has been estimated that up to 80% of the population in Ethiopia on a regular basis seek care and cure outside the public or private health sector (Giday et al., 2007, Kassaye et al., 2006). Following the Alma-Ata Declaration of 1978, the Office for the Coordination of Traditional Medicine was established in Ethiopia with the aim to bring together ‘traditional’ and ‘modern’ medical practice. However, with limited guidance, funds and personnel the initiative had difficulties of fulfilling the aim (Kassaye et al., 2006). In 2013 WHO developed a “Traditional Medicine Strategy 2014–2023” with the aim to support countries’ health care leaders in developing proactive policies to strengthen the role ‘traditional medicine’ plays in keeping populations healthy (World Health Organization, 2013). Although it continues to be a priority within Ethiopian health policy to gradually integrate parts of the ‘traditional medicine’ into the ‘modern medicine’, the ‘traditional’ healers continue to practice outside of the public health sphere as the main providers for many Ethiopians (Kassaye et al., 2006, Birhan et al., 2011).

Healing in Ethiopian ‘traditional’ medicine is as commonly found elsewhere encompassing in its approach and concerned with the protection and promotion of human physical, spiritual, social, mental and material wellbeing (Bishaw, 1991). Common means of healing in the North-Western part of the country, where this study was based, involves the use of local remedies, medical plants or spiritual guidance (Giday et al., 2007). Holy water is also commonly used in the Ethiopian Orthodox Church, which is believed to facilitate spiritual and physical cure (Berhanu, 2010, Hannig, 2012). The Holy Water is found in or around most Orthodox churches, and usually originates from a natural spring said to have been discovered by a saint or water blessed by a priest. The blessed water is commonly consumed in large amounts for days or weeks on end and splashed on ailing body parts or showered in (Berhanu, 2010, Hannig, 2012).

1.4 Theoretical perspectives

During the fieldwork and the continuous analysis process it very early emerged how nearly every dimension of the women’s lives were coloured by the severe conditions

of poverty they were living in. The large majority of our participants lacked any kind of schooling and were thus illiterate. They had limited medical health knowledge; they had married at a very early age and faced very tough physical tasks in a context where electricity and tap water were non-existent. They all lived in rural or semi-urban communities where it was little acceptance for not being a strong and hard-working woman. Disorders concerning the reproductive organs were moreover regarded as sensitive, disgusting and shameful. These factors combined made it extremely challenging for women suffering from prolapse to seek knowledge regarding the condition when the prolapse appeared, to disclose the problem to anyone, to seek help for the challenges and thus to receive the necessary treatment. For some the harsh living conditions also affected the healing process after treatment, and subsequently affected their reintegration into the community. Due to such a complex web of barriers, theoretical perspectives located at the heart of critical medical anthropology emerged as useful in the interpretation of the study findings. This theoretical perspective established a frame for an interpretation that heightened the understanding of the diverse layers of economic and gendered power structures that constrained women's lives and opportunities. At the same time the women's perceptions of the condition and actions taken in relation to it were strongly influenced by socio-culturally constructed meanings and perceptions. Thus it proved useful to simultaneously draw upon thinking within social constructionism, a theoretical perspective located at the heart of anthropology, in making sense of and in the discussion of the findings.

The role of culture in creating and maintaining meanings of illness and suffering has been extensively documented within medical anthropology (Helman, 2007, Kleinman, 1980). Social constructionism is a theory of knowledge that examines the development of jointly constructed understandings in a social context. Experience is perceived as contextual and relative, and understanding, significance and meaning are developed in coordination with other human beings. An important aim is to uncover the ways in which individuals and groups participate within their own perceived social reality, for example through looking at how a particular social phenomenon is

created or established and maintained or transformed by humans in a particular context (Helman, 2007, p. 7-8).

The anthropologist and physician Arthur Kleinman (1980) emphasized in his classical works the importance of illness narratives. He opened up a discourse where alternative explanations of etiology, course and treatment of disease were explored from within a hermeneutic tradition (Loewe, 2004, p.44). With the term *explanatory model* Kleinman (1980) offered an approach to disease as a product of the complex interactions between culture and nature (Loewe, 2004, p.44). Kleinman revealed how both patients and practitioners hold explanatory models that involve explanations of aspects such as the causation of the condition, the natural history and severity of the illness and the appropriate treatments for it. The models are influenced by personal, educational and cultural factors (Helman, 2007, p. 128-130). Kleinman (1988, p. 31-32) further reveals how members of a community are socialized into a cultural setting constituted by complex webs of guides that tell them how to behave, how to respond towards other people and supernatural forces, as well as how to see the world, including how to make sense of and act upon illness and suffering. Such '*shared understandings*' influence the experience and action taken in relation to an illness in a particular setting and within a particular social group (Kleinman, 1988, p. 48-49).

Despite its valuable provision of insight into health-related beliefs and behaviours at local levels, a common critique against social constructionism is a potentially too narrow focus on the micro level of cultural dynamics, not taking sufficiently into consideration the wider causes and determinations that influence human decision-making and action (Singer, 2004, p. 24). According to a critical perspective within medical anthropology, it is essential to pay attention to the connections between the social group in question as located within larger regional, national and global connections in order to enhance the understanding of the patterns of human perception, belief and conduct related to health and illness (ibid).

The development of a distinct critical orientation within medical anthropology had a particular boost during the early 1970s through the symposium and volume “Topias and Utopias in Health” (Ingman and Thomas, 1975). From the early 1980s, medical anthropologists such as Baer, Singer and Johnsen (1986), Farmer (1999), Morsy (1993), Scheper-Hughes (1990) and others developed a body of literature increasingly coloured and informed by a critical medical anthropological theoretical perspective. This constituted a shift from a prime focus on the culture of health, illness and healing towards a focus on the political-economic dimension combined with the micro-level understandings of thought and practice in local settings. Making sense of socio-cultural dynamics and meaning-making continued to be located at the core, but was coupled with a focus on structural constraints (Singer, 2004, p. 25). According to Morsy, the aim of critical anthropology is to “*extend the realization of the relevance of culture to issues of power, control, resistance, and defiance associated with health, illness and healing*” (Singer, 2004, p. 26). Baer and Singer describe how intricate social factors such as poverty and economic insecurity, malnutrition, poor housing and political powerlessness affect people’s lives, their movements, their self-perceptions, their decisions making processes and their day to day practices in ways that lead to greater susceptibility to- or consequences of disease and illness (Baer et al., 1986, Singer, 2004).

Farmer has for several decades drawn upon critical theory in the interpretation of the inequalities in health, and continues to be an influential figure within critical medical anthropology. In his early book “*AIDS and Accusation: Haiti and the Geography of Blame*” (Farmer, 1992), which was based on a long-term ethnographic work, he described the intricate dynamics inherent in social inequalities and its relationship to the likelihood of becoming infected with HIV/AIDS in Haiti. Farmer introduced the term ‘*structural violence*’, referring to how social structures or social institutions harm people by preventing them from meeting their basic needs, consequently increasing their risk behaviour and thus the likelihood of becoming sick, causing premature death and disability (Farmer, 1996).

Scheper-Hughes in a similar manner draws upon critical theory in her classical book *“Death without Weeping: The Violence of Everyday life in Brazil”* (1993). She describes how the collapse of the local sugar plantation industry in shantytowns in Brasil, instigated dynamics that generated life-contexts where mothers in quite desperate situations had to ration their love and food to the children who had the best chances of survival, leaving the youngest and weakest to die. Her work illustrates through detailed descriptions how women’s perception and conduct towards their children ultimately was connected to transformations in the global economic system (Scheper-Hughes, 1993). Although a critical medical perspective typically argues and demonstrates how large and unseen social forces impact human suffering, it simultaneously attempts to reveal how individuals have a stake in their own bodies and to various degree have agency that shapes their lives (Medanth, 2018).

Critical medical anthropology commonly implies research among categories of people who in diverse ways are disprivileged. The perspective informs the exploration of how both macro- and micro-level structural dynamics impact a particular group’s health challenges, and thus attempts to provide a broad understanding of the dynamics behind particular scenarios of suffering (Medanth, 2018). Research within critical medical anthropology as such attempts to bring a critical theoretical perspective to global health related problems, such as disease-maldistribution, health care inequalities and challenges within health care management (Pfeiffer et al., 2008). Pfeiffer and colleagues (2008) moreover argue that critical medical anthropology provides valuable contributions within health diplomacy, advocacy and problem-solving, by illustrating the *“social processes, power relations, development culture and discourses that drive the global health enterprise”* (Pfeiffer et al., 2008, p. 413). Critical medical anthropology has been criticized for in some works to be too materialistic in its scope, and too concerned with the distribution of wealth and how this impacts access to care, to some degree leaving out the socio-cultural aspects and dynamics (Medanth, 2018).

2. Aims of the study

2.1 General objective

To explore experiences of living with pelvic organ prolapse among women in rural Amhara region, Ethiopia.

2.2 Specific objectives

Explore how women explain, experience, and handle the practical and social implications of living with severe conditions of untreated pelvic organ prolapse in northern Ethiopia.

Explore health care seeking practices and the dynamics between choices of local healing options versus public health services among women with pelvic organ prolapse in northern Ethiopia.

Explore women's experiences related to recovery and reintegration following the provision of surgical treatment for pelvic organ prolapse in northern Ethiopia.

3. Methods

3.1 The study context

Ethiopia, a landlocked country located at the horn of Africa, has a population of more than 100 million (Central Intelligence Agency, 2017) and has an average life expectancy of 64.6 years (The World Bank, 2017). Since 1991, Ethiopia has been a federal republic, with the Ethiopian Peoples' Revolutionary Democratic Front (EPRDF), composed of four regional parties, in control of the government (Global Security, 2018). Currently, Ethiopia is going through a large political transformation; the prime minister resigned in 2018 due to years of instability and unrest in the country leading to several periods of state of emergency (Global Security, 2018). The present prime minister, Abiy Ahmed, signalled major policy shifts in the country and has in short time managed to assert his authority, yet the implications of his approach remains to be seen (BBC News Africa, 2018).

There are more than 80 ethnic groups in Ethiopia, the largest being the Oromo (35%) and the Amhara (30%) (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 34). Consequently there are more than 80 different languages in the country, the main being Amharigna (Amharic), Oromigna and Tigrigna. The main religions in Ethiopia are Orthodox Christianity and Islam (World Health Organization, 2002).

Since 1991, Ethiopia has been divided into nine regions plus the two administrative cities of Addis Ababa and Dire Dawa (**Figure 1**). Each region is further divided into zones, districts ('*woredas* ') and communities ('*kebeles* '), the smallest administrative unit in Ethiopia (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 331).

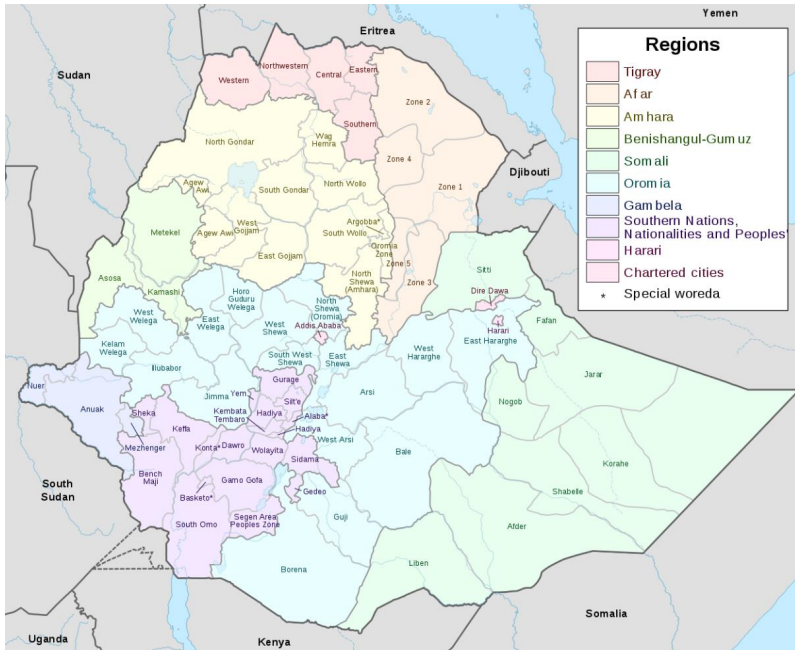


Figure 1: Map of regions and administrative zones within Ethiopia (Wikipedia, 2018)

Ethiopia is currently experiencing rapid economic growth mainly due to government investment in infrastructure as well as sustained progress in the agricultural and service sectors (World bank group, 2017). Higher economic growth has led to a reduction of Ethiopians living in extreme poverty, from 55.3% in 2000 to 33.5% in 2011 (The World Bank, 2018). There has also been great progress in primary school enrolment, child mortality and the number of people with access to clean water (ibid). The introduction of the Health Extension Program (HEP) in 2003 also substantially increased rural peoples access to primary health care services (Central Statistical Agency/Ethiopia and ICF International, 2012) (cf section 1.3.2).

Ethiopia is however still classified as a ‘low-income economy’ and as a ‘non-resource-rich country’ (World Bank, 2017). According to the World Bank, key challenges for development has been related to limited competitiveness, an underdeveloped private sector and political disruption (The World Bank, 2018). Although access to education has increased, learning outcome and quality of

education have not kept pace, and there remains huge regional and gender disparities (ibid). Of the total population, 80% depend on agriculture producing cereals, coffee, oilseed, cotton, vegetables and khat, as well as on the keeping of livestock, primarily cattle, sheep and goats (Central Intelligence Agency, 2017). An enormous population growth, debt levels that exceed 50 % of the GDP and recurrent droughts have increased food insecurity and inflationary pressure in the country. These factors add to the huge barriers in the progress towards elimination of extreme poverty (The World Bank, 2018).

Study setting

The present study was carried out in the Amhara region (**Figure 1**), and all study sites are located within the North-Gondar zone (**Figure 2**). Amhara region is the second most populous region in Ethiopia with over 20 mill inhabitants (Central Statistical Agency/Ethiopia, 2018). The large majority of the people in the region belong to the Amhara ethnic group; speak Amharic as their first language and practice Ethiopian Orthodox Christianity (Central Statistical Agency, 2008). Approximately 77 percent of men and 62 percent of women are engaged in agricultural activities in the region, which mainly consists of production of grains and livestock rearing (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 37-38).



Figure 2: Map of Amhara region and its administrative zones (Opride, 2018). The study areas within the North-Gondar zone highlighted.

Of women, 55% are estimated to be illiterate and have never attended school in the Amhara region. In comparison, 34% of the men are illiterate (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 45-46). The Amhara region moreover has the lowest median age at first marriage among women aged 20-49 of 16.2 years as well as among women aged 25-49 of 15.7 years (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 73). Among the 19% of women aged 15-49 who attended school prior to marriage, the majority (64%) dropped out of school after getting married. The main reasons reported for discontinuing school

being the burden of work at home and refusion by their husband (Central Statistical Agency/Ethiopia and ICF International, 2017, p. 279).

According to the 2016 Ethiopia Demographic and Health Survey (EDHS) (2017, p. 78), the total fertility rate of the region is 3.7 children per woman, which is among the lowest in the country. Indeed, the use of modern contraception among currently married women in Amhara region is reported to be the highest (47%) in the country after Addis Ababa (50%). The most common methods of contraceptions in the region are injectables (29%) and implants (12%) (ibid, p. 114). In Amhara region, 67% of women received antenatal care by a skilled provider during their last pregnancy, most commonly from a nurse/midwife or from a Health Extension Worker (HEW). Yet, only 27% delivered at a health facility, compared to 57% in the neighbouring region Tigray (ibid, p. 142). The person assisting during delivery at home was most commonly a traditional birth attendant or a relative, friend or neighbour (ibid, p. 150). While 21% of women delivered by caesarian section in Addis Ababa, only 2.3% did so in the Amhara region (ibid, p.151). Problems in accessing health care for themselves when they are sick has been reported by 56% of the women in the region, and the challenges are most commonly reported to be caused by lack of money, distance, not wanting to go alone or not getting permission to go from the husband (ibid, p. 160).

The hospital-based study site

One part of the study took place at the Fistula Centre of the University of Gondar Hospital (UoGH) (**Picture 1**) which is located in the city of Gondar (**Figure 2**). UoGH is a referral teaching hospital with around 500 beds. It is estimated to serve more than five million people, and has an annual in-patient admission of more than 20 000 patients and more than 5 000 attended deliveries (University of Gondar, 2017). In 2011, a Fistula Centre with 70 beds capacity and two operating theatres was opened in close collaboration with the Women and Health Alliance International (WAHA), United Nations Population Fund (UNFPA) and other partners. Due to the high capacity at the Fistula Centre, it is also serving patients with other

gynaecological disorders, including patients with pelvic organ prolapse and cervical cancer (University of Gondar, May 2014, Adefris et al., 2017).



Picture 1: The University of Gondar International Fistula Training Centre (top floor) (University of Gondar, May 2014).

The community-based study sites

The community-based part of the study took place in two *woredas* (districts) within the North-Gondar zone, namely Dabat and Debark. The *woreda* of Dabat is located 76 km north of Gondar town, and held a population of about 146 000 according to the 2007 Population and Housing Census of Ethiopia (Central Statistical Agency, 2007), but the population is likely to have increased since this census. The large majority of the population lives in the rural areas of the district. There are 27 rural *kebeles* (communities) situated in mountainous low- or highland areas, and three urban *kebeles* in Dabat town (Central Statistical Agency, 2007). Dabat *woreda* holds six health centres (**Picture 2**) and 30 health posts, one for each *kebele* in the district. There is a Demographic and Health Survey Site (DHSS) run by the Dabat Research Centre at the University of Gondar (UoG) in Dabat, which biannually since 1996 collects has collected demographic data from a population of about 50,000 inhabitants in ten *kebeles* within Dabat district (University of Gondar, 2017).



Picture 2: Health Centre in Dabat town (private photo)

The *woreda* of Debark is situated north of Dabat *woreda*, 103 km from Gondar town. It had a population of nearly 160 000 in the 2007 census, including 21 000 living in the urban town of Debark (Central Statistical Agency, 2007). The district holds the Simian Mountains National Park which contains *Ras Dashen*, the highest mountain in Ethiopia some 4,543 meters above sea level (Simien Mountains National Park, 2017). The district consists of 28 rural *kebeles* and five urban *kebeles*. The *woreda* has one hospital, 10 health centres and 30 health posts in the rural *kebeles* (**Picture 3**) (Health authorities Debark *woreda*, 2015).



Picture 3: A health post in a rural kebele in Debark district (private photo)

Common for both districts (**Picture 4 and 5**) are climate conditions that vary from high-land and relatively cold temperatures (*dega*), to mid-land and a temperate climate (*woina dega*) to low-land areas with hot temperatures (*kolla*). Altitudes of household settlements vary from 1000 meters to around 3000 meters above sea level (Simien Mountains National Park, 2017).



Picture 4 and 5: Rural parts of Dabat and Debark (private photos)

3.2 Situating the study

The present study started out as a sub-study under the Dabat Incontinence and Prolapse (DABINCOP) Study, initiated in 2010 by collaborative partners at the University of Gondar (UoG) in Ethiopia and the University of Bergen in Norway. By the use of the infrastructure established by the Dabat Research Center at the UoG, a pilot study constituting an epidemiological and an anthropological part was carried out in 2011. The pilot study aimed to examine prevalence and risk factors of pelvic floor disorders, and experiences of living with pelvic floor disorders in an Ethiopian community.

The epidemiological part of the study aimed at assessing the prevalence and risk factors of urinary and faecal incontinence and pelvic organ prolapse among women in the Dabat district, as well as assessing the validity of a prolapse questionnaire (Megabiaw et al., 2013). Three *kebeles* (communities) in three different climatic and

sociocultural settings (one semi-urban, one highland rural and one low-land rural) of Dabat *woreda* (district) were randomly selected, and 395 women were included in the study. Symptomatic pelvic organ prolapse was assessed by questions previously used in the American RRISK Study (Reproductive Risks for Incontinence Study at Kaiser) (Rortveit et al., 2007). After completion of the quantitative interview, the women were asked to volunteer for a pelvic examination set up at the nearest health facility by the research team. Of the 395 study participants, 294 women participated in the pelvic examination. The examination was performed by two trained Medical Doctors, and the simplified Pelvic Organ Prolapse Quantification (S-POPQ) staging system was applied to assess whether the women had an anatomical pelvic organ prolapse (Manonai et al., 2011). The results of study revealed that near half of the women reported having moderate urinary incontinence, while 12.9% had severe urinary incontinence. Less than 1% reported faecal incontinence. Symptomatic prolapse was reported by 6.3% of the women, of whom only one said she had previously sought professional help for the condition. The results from the pelvic examination detected that 48.1% had stage II prolapse, while 7.2% of the women had prolapse stage III or IV. The main factors associated with anatomical prolapse were found to be carrying heavy objects for five or more hours a day and a history of prolonged labour (Megabiaw et al., 2013).

The anthropological part of the study aimed to explore experiences among women living with urinary incontinence (Gjerde et al., 2013) and pelvic organ prolapse (Gjerde et al., 2017). Informants were recruited partly at the University of Gondar Hospital (UoGH) and partly from within DABINCOPs three selected *kebeles* in Dabat *woreda*. Identified cases of urinary incontinence or prolapse by the epidemiological team were approached and asked for an in-depth interview. Health personnel were additionally included for qualitative interviews. The results of the study revealed that the women suffering from urinary incontinence knew little about the condition that they were suffering from and that hardly anyone took any action to seek help. The women were living under harsh conditions with limited access to water, soap, pads and spare clothes, which made the management of the condition

extremely challenging. Shame and fear of being discriminated led many of the women to hide their condition. The ones who were not able to hide their leakage experienced being humiliated and discriminated, which often led to divorce and self-isolation (Gjerde et al., 2013). The results of the study involving the women suffering from prolapse is described in the result chapter as well as in paper I (Gjerde et al., 2017).

Within a year after the pilot study had been conducted a formative qualitative follow-up study was carried out (Blystad et al., 2018). The questionnaire used and validated by the pelvic examination in the pilot study had detected severe underreporting of clinically relevant prolapse (Megabiaw et al., 2013). The aim of the follow-up study was to explore the reasons behind the underreporting, and to gather information to strengthen the sensitivity and local relevance of the questionnaire for the planned main quantitative study of DABINCOP. Women who had not self-reported prolapse in the questionnaire, but were diagnosed with severe prolapse after the pelvic examination, and health care workers in the DABINCOP research team were recruited for in-depth interviews in the follow-up study. The results revealed that shame and fear of social exclusion, lack of trust in the study and in the data collectors, as well as lack of hope for a cure were the main reasons that had prevented the women from disclosing their condition to the data collectors. The health care workers who had operated as data collectors during the pilot study moreover reported weaknesses in the questionnaire and the research approach - such as time pressure and competition among the data collectors - aspects that may have prevented the women from disclosing their condition (Blystad et al., 2018).

The main study was planned to expand in both the epidemiological and anthropological part of the study, and aimed to 1) estimate prevalence and risk factors for urinary incontinence, faecal incontinence and symptomatic pelvic organ prolapse in the Ethiopian female population, and 2) to explore factors related to living with these pelvic floor disorders. However, funding for research on maternal chronic conditions proved difficult, and only the anthropological part initially proceeded. The

main qualitative study constitutes the current PhD project. From 2015, part of the research team, including one of my co-supervisors and my main collaborative partner at the University of Gondar (UoG), and a local PhD candidate at the UoG took on the task of conducting a revised version of the planned epidemiological part of the DABINCOP study, based on local funding. The present qualitative study has continuously informed the quantitative study since 2015 through meetings in Gondar, e-mail correspondence and mutual authorship.

3.3 Situating the researcher

I am a Registered Nurse (RN) with a background in Development Studies / Social Anthropology at Bachelor Degree level and I hold a Master of Philosophy in International Health. During my nursing studies I spent two months at a hospital in Yirgalem town in South-Ethiopia. Through this experience I gained an interest in work in resource-constrained settings and found continued studies in Ethiopia meaningful. In 2010, when I embarked on my Master studies, I was invited to join the DABINCOP study through my supervisors who were part of the research team. Together with a female local RN as my research assistant, I carried out the anthropological sub-study during the DABINCOP pilot study. My master thesis was empirically focused on exploring how women suffering from different severities of urinary leakage experienced and handled their condition.

Upon completion of my Master degree, I got employed as a RN at the department of General Gynaecology at the Haukeland University Hospital in Bergen, Norway. This provided me with hands-on clinical experience of caring for women with pelvic floor disorders in a Norwegian setting, and broadened my understanding of pelvic floor disorders from a clinical point of view.

During the preparation phase of the current PhD project in 2014 I attended a three months long formal Amharic Language training in Addis Ababa, Ethiopia, with the aim of building up a basic level of Amharic skills for the fieldwork period.

During the PhD period I was granted seven months leave and went for three short missions as a RN for the international NGO Doctors Without Borders (MSF). In March to May 2014 I took part in a Flying team in South Sudan, providing health care support and medical supplies through temporary mobile clinics and established projects sites in the rural parts of Jonglei region. In November to December 2014 I took part in MSFs work against the large outbreak of Ebola claiming more than 11 000 lives in six affected countries in West Africa. My role was to support local health care staff in the care and supportive treatment of Ebola affected patients at MSFs Ebola management centre, located in Monrovia, Liberia. In June to September 2016 I took part in MSFs activities in Ethiopia related to a drought that particularly hit the Eastern part of the country. I participated in several projects in Afar and Somali region during this mission.

3.4 The choice of study design

A qualitative design was chosen to best answer the research objectives in the present study. Qualitative research aims to interpret meaning-making processes, and thus to make sense of the phenomenon that is being studied (Patton, 2015). By focusing on people's meaning of illness and illness related behaviour, the understanding of how people handle illness and suffering is enhanced (Malterud, 2011, p.27). In studies of sensitive topics it is particularly useful to include components of a more explorative kind, as the flexibility of explorative qualitative designs allows for the dwelling and probing in a manner that enhance the understanding of what is at stake for the study participants (Francis and Heggenhougen, 1999, p. 100). As the focus chosen for the study was complex and sensitive in nature it required time to establish trust from the study informants, which called for periods of longer follow-up of the informants. A broad qualitative methodological approach was thus opted for, grounded in an ethnographic tradition based on extended hospital and community fieldwork.

The dimension of time is particularly emphasized in the literature on ethnography, and the immense importance of the researcher to remain in the field over longer periods of time (Hammersley and Atkinson, 2007, p. 3). Hammersley and Atkinson

(2007) describe analysis of ethnographic studies as an “interpretation of the meanings, functions and consequences of human actions and institutional practices, and how these are implicated in local, and perhaps also wider, contexts” (Hammersley and Atkinson, 2007, p. 3). They also provide an explanation, on a very practical level, of what ethnographic work involves. Firstly, as ethnographic research takes place ‘in the field’, the ethnographer studies people’s actions and accounts within their everyday context. Secondly, data may be collected from a range of sources, most commonly through participant observation, documentary evidence and reflexive interviewing. An ethnographer normally does not ask each interviewee the exact same questions or in a fixed sequence. Rather, they allow the conversation to flow in a natural manner while ensuring that the relevant research topics are covered. Third, the data collection is characterized by being relatively ‘unstructured’ as it doesn’t follow a prepared fixed plan or pre-set categories. Fourth, to facilitate an in-depth study, the study may be small-scale, and the focus is often on a single setting or a specific group of people (Hammersley and Atkinson, 2007, p. 3).

3.5 Data collection

Apart from paper I which includes some data from the DABINCOP sub-study conducted in the research area in 2011, the data for all the three papers that make up this dissertation were collected from February 2015 to March 2016. Part of the preparation phase of the study from June to August 2014 was spent participating in Amharic-language lessons in Addis Ababa. A visit to the University of Gondar (UoG) to establish collaborative partnerships and to apply for ethical approval was conducted in September 2014 (cf chapter 3.7). The total time spent in Ethiopia during the PhD study was approximately one year.

3.5.1 Three phases of data collection

During the course of the fieldwork the time spent in the field was divided into three phases, as ‘stepping back’ from the field gave room for reflection and analysis. In the following I will briefly describe the main activity taking place during the three different phases.

The first phase - February to April 2015

During my pre-visit to the field in 2014, my local research collaborator situated at the UoG suggested that a good place to start my fieldwork was at the Fistula Centre at the University of Gondar Hospital (UoGH). That would give me close access to women suffering from various pelvic floor disorders, and through participant observation on the ward I could engage with the women as well as with the health care workers in order to gain a better understanding of which aspect I should emphasize and explore further in my study. This first phase of the fieldwork lasted for three months, of which eight weeks were spent on the ward as a participatory observer. My accommodation was located next to the hospital compound during this stay.

When I arrived at the hospital, I quickly learnt that up until recently, all women admitted to the ward for prolapse treatment, in contrary to those with obstetric fistula, had to cover all costs in relation to their hospital stay themselves. There were a few exceptions, such as if the women arrived with an exemption letter from their district due to severe poverty. However, during the previous year, in 2014, a new initiative involving women with prolapse, had started up at the UoGH. Several actors, including WAHA, UNFPA, Save the Children International and the government hospital itself supported the start-up of a 'prolapse-campaign', and foreign senior surgeons from partner Universities were involved in training of surgical staff. The campaign involved providing HEWs in selected districts with knowledge about the condition of prolapse to be included in their continuous community mobilization activities in their respective *kebeles*. Following the community mobilization, several women came forward with their problem and got registered by the HEWs. A medical team from the UoGH set up a screening site in the selected districts and examined the registered women. A certain number of the women with the most severe cases of symptomatic prolapse were selected, and sent in groups by organized transport to the Fistula Centre at UoGH for free surgical treatment. All costs during the hospital stay were covered for the selected women. The first round of the campaign took place during autumn 2014, approximately half a year before I arrived in the field.

When I entered the Fistula Centre they had started another round of the campaign, involving free treatment of approximately 50 women from three different districts, including Dabat and Debark. When I looked into the patients' medical charts, the majority had reported severe complaints of their prolapse and many had an ulcerated prolapse that needed to heal prior to the surgical treatment. The majority of the women had lived with their prolapse for more than 10 years. These were all women who, for various reasons that are described in paper II, had not been able to reach the hospital for treatment.

As the ethnographic research design is exploratory and flexible in nature, the research themes are often modified during the course of the fieldwork to pursue emerging lines of inquiry (Hammersley and Atkinson, 2007). In conversations with senior gynaecologists, among them my local research collaborator, it was expressed a gap of knowledge in the reasoning behind the severe delays in health care seeking. Beside one follow-up appointment one to three months following the surgery, the hospital staffs knew very little about how these women recovered and eventually were reintegrated into their communities after leaving the hospital. I was thus encouraged to carry out a study with the aim of exploring the women's experience of having lived with the prolapse, as well as their health care seeking experience with emphasis on factors delaying them in reaching the health facilities and the recovery process after surgery. As we wanted to follow up as many of the women in the study in their respective homes after the surgery, we aimed to limit our group of informants at the hospital to women coming from two districts only, for logistic reasons.

In order to facilitate and plan ahead for the second phase of the research project, we visited the two selected districts towards the end of this first fieldwork phase. Firstly, we visited both the district authority offices to present ourselves and the research project. In Dabat town we interviewed a health officer at the health centre and a Health Extension Worker (HEW) working in a nearby rural *kebele*. In Debark we interviewed a maternal and child health officer from the district health office; a

representative from a funding organization of the campaign as well as a HEW. These interviews were informative and gave us important insights into the context of our informants. Furthermore, it provided us with an overview of the activities carried out on the district- and community level in relation to the ongoing prolapse-campaign.

The second phase - August to December 2015

The aim of the second visit to the field, which lasted for four months, was to follow up the women included in the study at the hospital during the first phase of the fieldwork after they had returned to their communities. By the help from local coordinators of the campaign in both Dabat and Debark we were able to map out how many of the previously interviewed women we would be able to reach. By guidance of the HEWs in the respective *kebeles* we successfully reached the homes of eight women, often by the help of a three-wheel motor driven 'bajaj', followed by up to half an hour walk. All the women welcomed us and expressed appreciation for our visit and follow-up conversation. In two *kebeles*, the HEWs made us aware of other women who also had been treated for prolapse through the ongoing campaign, and we decided to also include four of these women for interviews. Additionally, we were made aware of and included one woman with prolapse who was not yet treated, but who had been signed up for the next round of the campaign. We moreover talked to and interviewed health care workers from both community and district levels; representatives of a funding organisation and from the health authorities.

Through our previous talks with the women and the health care workers, we had understood that the use of religious and spiritual healing options were important aspects of the women's health care seeking experiences. Several observation visits to Holy Water sites within the two districts were thus conducted, as well as visits to known local healers within the communities. This added valuable observational and informative knowledge that strengthened our understanding of the women's health care seeking experiences.

During this phase my main accommodation was still in Gondar city, while frequent visits lasting up to five days at a time were conducted in Dabat- or Debark town. In between the visits to the field I kept close contact with the Fistula Centre at the University of Gondar Hospital (UoGH).

The third phase – February to March 2016

The third phase of the fieldwork lasted for one month. The main aim of this last visit was to review the remaining data material together with my research assistant to review the full material and clarify potential misunderstandings; to add cultural specific clarifications and to discuss aspects that we needed to explore further. At this time, another round of the prolapse-campaign was taking place at the Fistula Centre, including women from both Dabat and Debark districts. A bulk of the material was already in the final process of analysis at this point, but we decided to conduct two focus group discussions (FGDs) with the women from Dabat and Debark currently present on the ward. This gave us the opportunity to discuss the research findings, to confirm main patterns in the material and to elaborate on some of the central aspects emerging in our material.

3.5.2 Data collection methods

Participant observation

As ethnographic research takes place ‘in the field’ it is common to negotiate access to a role in the field being studied, which enables one to involve in daily activities over an extended period of time; to watch what happens in the setting; to listen to what is being said; to ask questions through formal or informal interviews and so forth (Hammersley and Atkinson, 2007). A central method of accessing information in the current study was through participant observations or from mere observations.

During the participant observation on the ward I participated as a nurse assistant. Daily activities included taking part in the nursing rounds; assist in pre- and post-operative care of patients; communicate with health staff on the ward and small-talk

with patients to the extent possible due to the language barrier. The time spent on the ward gave me insight and understanding of a number of aspects related to the care and treatment the women with prolapse received; the organisation of the ongoing campaigns and a glimpse into how the women themselves experienced the time spent at the hospital. Detailed field notes were written at the end of each day and included reflection and perceptions of the day's happenings and interactions on the ward. The communication with the patients during participant observation was managed by my very basic Amharic language or by the translation by the nurses that I was working alongside with. The stay at the ward furthermore facilitated the opportunity to seek additional knowledge about the women from their medical charts, as well as to carry out interviews and focus group discussions (FGDs).

During the interviews, the majority of the women revealed that they had sought solution for their prolapse condition at Holy Water sites. Several short participant observation visits were thus made to Holy Water sites in the women's communities. This involved sitting among people during preaching and prayers; observing the area and the baptism taking place following the prayers and talking to people who approached us. A longer period of participant observation was carried out at a Holy Water site in Gondar and implied daily visits to the site for a total of five days. It was mainly conducted by the local research assistant. The aim was to interact with women on the site while participating in the activities taking place, such as the Morning Prayer and baptism in Holy Water. This resulted in rich field notes describing in a detailed manner the interaction with people and observations and perceptions of the site.

Other observations took place at several occasions throughout the fieldwork period. The interviews taking place in the women's homes, were often conducted in the main room of the house around the fireplace used for cooking, where animals such as chicken, calves and goats were moving in and out during our visits. As our visits were unannounced, many of the women were in the middle of their work when we arrived, and we encouraged them to continue their activities during our talk. Prior to

or after the talk we also often met their husband, children or other relatives who happened to be around at the time of our visit. This gave us the opportunity to observe the women in their own physical environment as well as in the social context involved. Detailed field notes were written either shortly after the tape-recorded interviews or at the end of each day in the field.

During our visits to local healers we were invited into their consultation room, and at one occasion a healer attended a client during our visit. This gave us the opportunity to see the type of interaction taking place between the healer and the client, to observe the objects used by the healer, and to get a sense of the atmosphere of the healing session.

Interviews

While a phenomenological interview aims to elicit personal descriptions of a 'lived experience' in as concrete and live-through terms as possible, the ethnographic interview is perceived as a support or supplement to the direct observations made in the field (Patton, 2015, p. 98-101). The interviews carried out in the current study, drew upon both of these interview approaches.

The interviews carried out with the women at the hospital normally lasted for one to two hours, and took place in a private room at the ward. A semi-structured interview guide with open-ended questions that had been prepared during the planning phase of the project was adjusted prior to the first interview and modified several times during the course of the fieldwork. However, the interview guide mostly served as a tool to remember what topics that I wished to cover. The women were encouraged to reflect and speak at length with minimum guidance and interruption, but with probes and follow-up questions asking for clarification in attempts to get as much in-depth information as possible. The interview guides consisted of open-ended questions concerning experiences of the potential practical or social consequences of living with prolapse and their health care seeking in relation to the condition (**Appendix IVa**).

As the topic was sensitive, the conversation started with small talk, followed by questions on factual background information, before moving into the women's experiences related to the prolapse. The majority of the women appeared shy and spoke with a quiet voice at the beginning of the conversation, but most of the women slowly opened up and during the course of the interview willingly shared their stories in what emerged as an open manner. An important reason for the experienced openness among the women with prolapse may have been that they, prior to the interview, had been surrounded by women with prolapse on the ward. For days at end they had been lying in their beds talking among themselves about multiple aspects concerning their condition. Many had previously not been aware that others were suffering from a similar condition. Our interview was thus a continuation of an openness-process that had been initiated among the women during the recruitment phase in the villages and not the least during the days spent with women suffering from similar conditions at the ward. Some women interviewed may have avoided talking openly about spiritual healing practices, due to its strong connection to secrecy in their communities. However, such experiences were sometimes revealed during the follow-up interviews, when the interview took place in their homes and increased trust had been created between us and the informant.

The follow-up interviews in the communities had a similar form, but required less unrelated small talk as a certain level of trust and knowledge of the other already had been established at the hospital. The visit often lasted from one to two hours, depending on the women's availability and our schedule. The women spoke openly and with little concern about family members potentially listening to the conversation. An interview guide focusing on diverse aspects of recovering of prolapse and reintegrating into the community was employed (**Appendix IVb**). The interviews with four women in the community who were not interviewed previously required substantially longer time, as it was our first meeting and required time to cover topics from both above-mentioned interview guides (**Appendix IVa-b**).

However, these women all appeared very willing to talk about their experiences both before and after their prolapse treatment.

Semi-structured interview guides were also used during interviews with the health care workers; local healers; representatives from district health authorities and the funding organisations. These interviews mainly took place at the participants working places, and the interviews were to a larger extent characterized by the given structure of the guides (**Appendix IVc-g**).

The majority of the interviews were carried out in Amharic with continuous translation from Amharic to English and from English to Amharic between the informant and myself by the help of a research assistant, as I will return to in more detail in section 3.5.4. Five of the interviews with health care workers and representatives from funding organizations were carried out in English by the PhD candidate, while two of the interviews with the health authorities and health care workers were carried out in Amharic by the research assistant alone.

Focus group discussions

The purpose of group interviews are driven by the research inquiry and the method is often used to get a variety of perspectives and to increase confidence in whatever patterns emerge during the group interview. What characterizes a research focus group is a small and relatively homogeneous group being interviewed on a specific topic of research interest (Patton, 2015, p. 475).

The two focus group discussions (FGDs) conducted in the current study took place in a private room at the Fistula Centre, and each FGD included six women. A topic guide was used to guide the conversation (**Appendix IVh**), although the women were encouraged to speak freely and to each other rather than to the moderator on the overarching topics presented. A research assistant moderated the FGDs while another research assistant took notes. The main purposes of the FGDs were to allow the participants to discuss the emerging study findings, especially related to health care

seeking, in order to confirm seeming patterns as well as ambiguities and thus add substance and nuances to the data material. I was present during both FGDs, however we decided to limit the English translation in order to ease the flow of the discussion.

The women in both groups appeared open and willing to share their opinions and experiences, even if their opinions contradicted with others in the group. Those who were more quiet than others in the group were carefully probed for their opinions, and slowly increased their participation during the discussions. The majority of questions focused on how people in their communities commonly perceive and handle illness and go about seeking health related solutions. However, some women shared their own perceptions and experiences with the group.

Informal conversations

Many oral accounts in an ethnographic study are unsolicited, but yet represent a useful source of information, for example about the setting or about perspectives and concerns of the people who produce them (Hammersley and Atkinson, 2007). Many informal conversations took place during the course of the fieldwork, both at the hospital; around Gondar city; in the district towns and in the communities we visited. It involved people I was introduced to through my role as a researcher, but also friends I made during the course of the fieldwork and a variety of people that my research assistant and I randomly met in the communities. These informal talks added substantial information and enhanced the knowledge about the socio-cultural context within which the study was conducted. At times it also provided us access to new informants, as was the case with two of the local healers. The HEWs in every *kebele* we visited also provided us with descriptive and detailed information about their job responsibilities and the maternal health situation in their communities while they were walking us to our informant's homes, which enhanced the understanding of the work of the HEWs.

3.5.3 Study participants

The study included a total of 50 participants (**Table 1**). Purposeful sampling was used in the recruitment process with the aim to recruit women at different ages and with different lengths of suffering from prolapse. Diversity among study informants leads to varied information, and gives an opportunity to grasp additional nuances around the topic in question (Malterud, 2011). We recruited informants based on their home districts in the hope of being able to follow them up in their home after surgery. The majority of the women with prolapse were recruited at the hospital during the time of the campaign (19 women in total), while the remaining women were recruited in the community by the assistance of Health Extension Workers (HEWs). The local healers were recruited based on their known 'title' and were recruited by the help of local acquaintances and by a HEW while in the field. Two HEWs were recruited based on their availability at the time, while the remaining two were recruited based on the respective *kebeles* they worked in. The health care workers at the hospital and at the health centre in the district were recruited based on their potential experience with women seeking health care for prolapse. Finally, the representatives from the health authorities and from the NGOs were recruited based on their role and potential knowledge about the ongoing campaign. The recruitment of informants followed the general qualitative principle of 'theoretical saturation' (Patton, 2015, p. 271), and the recruitment was thus gradually discontinued when no major new topics emerged within the three topic areas in focus. A total of 32 women with prolapse were included in the study, and are featured and presented in either paper I, II and/or III.

Among the 32 women with prolapse at least 25 had stage 3 or 4 prolapse, and 19 of the women had lived with the prolapse for ten years or longer. The majority of the women with severe stages of prolapse suffered from difficulties of urinating, and some from urinary incontinence. 23 of the women were married, while the remaining were either divorced (5) or widowed (4). The mean age was 43.7 years [range 24-70 years]. The mean age at first marriage was 14 years and at first delivery 18.1 years. They had given birth to an average of 5.9 children. Of 32 informants, 20 women had delivered all their children at home. The remaining 12 had primarily received skilled

attendance for one particularly complicated birth at the health centre or at the hospital. Among the women only two were formally employed. The others had responsibility for all household activities in their home including the fetching of water and firewood, cooking, cleaning, child care etc. Some moreover participated in the family's agricultural activities. Of the 32 women, 27 had never gone to school and were thus illiterate.

Table 1: Categories of interviews per research topic

Category of informants	Number	Location	Paper I	Paper II	Paper III
Women recruited for free treatment through campaign	18	Hospital	X*	X	X**
Women admitted for treatment outside of campaign	1	Hospital		X	
Women not yet treated	1	Community		X	
Women treated through previous round of campaign	4	Community		X	X
Women recruited through the DABINCOP study (2011)	8	Community and hospital	X		
Local healers	4	Community		X	
Health extension workers (HEWs)	4	Community		X	X
Health care workers – health centre	2	District town		X	X
Health care workers - hospital	3	Hospital		X	X***
Informant from health authorities	2	District town		X	X
Informant from organization (NGO)	3	District town and hospital		X	X

* 16 out of 18 included in first phase of the fieldwork

** 8 out of the 18 were included at the hospital and again for follow-up interview

*** 2 out of 3 included

3.5.4 Research assistance and language

The fieldwork was highly dependent on assistance from local research collaborators. Firstly, in order to gain ethical approval by the University of Gondar (UoG), an established and documented collaboration with a partner at the university had to be in place. A senior gynaecologist who had been responsible for training and follow-up of the physical examination team during the DABINCOP pilot study was willing to take on the role as my official research collaborator at the UoG. As he had substantial experience in both research and treatment of prolapse at the University of Gondar Hospital (UoGH), he became a very valuable discussion partner and collaborator throughout the fieldwork. We regularly met at the Fistula Centre during working hours, but also had scheduled meeting where I updated him on the progress of the data collection and received his important inputs. Together with my Ethiopian co-supervisor who at the time was affiliated with the UoG and regularly visited the Fistula Centre during my fieldwork, he moreover facilitated and eased my access to several parts of the field. The collaboration facilitated the possibility for my stay at the Fistula Centre and opened possibilities to communicate freely with staff and key informants involved in the ‘prolapse campaign’. Our first visit to the field moreover took place together with a small team from UoGH in relation to the campaign, which facilitated our first introduction to important stakeholders in the communities.

The main research assistant who worked with me throughout the three phases of the fieldwork was from the area and spoke Amharic as her first language. As the study involved a sensitive topic it was of importance that the research assistant was a woman with excellent communication skills as well as fundamental knowledge of local codes and customs. The research assistant had educational background in sociology and had previous relevant work experience as a research assistant in a long-term anthropological research project in and around Gondar. She was thus experienced in the use of qualitative methods, but unfamiliar with my specific research topic. We thus initially spent considerable time discussing the present research topic, as well as the ethical guidelines and consent form to be used in the study.

During the focus group discussions (FGDs) in the third phase of the fieldwork a research assistant with background in anthropology assisted in developing the topic guide and moderated both the FGDs. She held a Master in Anthropology from UoG and was my official research collaborator during the DABINCOP sub-study, and was thus familiar with the study topic. A research assistant studying social work on Master level, took notes during the FGDs. She was also assisting in transcription towards the end of the fieldwork.

Translation and transcription process

After carrying out the two first interviews with women at the hospital, the main research assistant and I spent considerable time evaluating our oral communication and non-verbal interactions in the interview setting. We quickly found a good rhythm in our work, where I asked all the questions and follow-up questions, while she purely translated between the informants and myself. Slowly, as she became familiar with the topic, the questions and the common probes and follow-up questions that I asked, she slowly took over the probing and the follow-up questions, and thus translated longer sequences to me once the question had been answered fully. This proved successful, as the flow of the conversation with the informant improved and less information was lost in the longer translation sequences. During the course of the fieldwork I was moreover able to pick up words or meanings during the interviews, so that I to a certain degree could grasp what follow-up question my research assistant was asking, or pick up terms of interest from the informants that I asked the research assistant to elaborate on during or after the interview. During the last phase of the fieldwork, the research assistant carried out two interviews alone.

All interviews were audio-recorded, transcribed verbatim to Amharic and subsequently translated to English. From our very first interviews we proofread the transcriptions that were produced by a trained translator situated in Addis Ababa. Due to the initial evaluation of the transcriptions we were able to pick up limitations that were improved in the remaining work. We however continued to check the

transcriptions to ensure that the content was correctly captured and culturally specific expressions were retained during the translation to English. As my main research assistant gained more experience during first phase of the fieldwork, she later took over the job of transcription and translation of the material. She translated the text, as far as possible literally, and with both Amharic and English within the same document, to ease the tracking of the Amharic wording if necessary. Upon completion of a translated interview we reviewed the interview together to ensure that I understood the meaning of the text, and to clarify Amharic words that do not have an equivalent word in English or that had a central cultural meaning. This time-consuming but central process of transcription and translation followed by the review of each interview took place continuously during the fieldwork, and was for practical reasons and time constraints not always completed before the next interview took place. However, our small discussions after each interview still made it possible to do the necessary evaluation and potential readjustment of the method during the data collection. Towards the end of the data collection, due to time constraints, another local research assistant transcribed the remaining data material, while the main research assistant continued to translate the transcribed material.

3.6 Data analysis

Qualitative analysis intertwines the data collection phase with the interpretation of the material, a process that involves finding substantively meaningful patterns and themes in the interviews, observations or documents gathered that can answer the research questions (Patton, 2015, p. 521). The qualitative research process involves transforming what is said during conversation or seen from observations into written text. However, according to Malterud (2011) it is important to be aware that the text may lose non-verbal cues and surely can never represent reality itself. It can only present attempts at representing a 'reality' as communicated by informants and groups. The text thus becomes an indirect representation of certain aspects of the reality, collected from a certain perspective (Malterud, 2011, p. 188).

The analysis took place throughout the data-collection process by continuous evaluation after each interview, with special emphasis on emerging topics and necessary clarifications or cultural-specific elaborations. After the first phase of the fieldwork, the data for paper I was analysed and the write-up of the paper initiated. After the second phase all data concerning health care seeking and aspects related to recovery and reintegration was read through with the aim to discover aspects that needed further clarification or more in-depth exploration during the third phase of the fieldwork. After the third and final phase of the fieldwork all the material had been transcribed. The full data set was imported into NVivo 11, a qualitative data-analysis software tool that was employed to organise the material and to ease the analysis process.

The analysis process of paper I followed the principles of systematic text condensation (Malterud, 2012). The framework was found useful for the development of descriptions and perceptions related to the diverse aspect of living with and handling the prolapse. Four essential steps of the method were followed. The first step of the method involved reading through all the material to get an overall impression of the content and obtain a '*sense in the whole*'. Recurrent themes, as well as nuances were noted down. During this first step a table of the informants and their demographic background as well as some of the major patterns of conduct related to prolapse was developed. The second step of the method involved identifying '*meaning units*', which is important in order to separate relevant information in the text from more irrelevant information. A time consuming and systematic review, sentence-by-sentence, paragraph-by-paragraph, of each interview was conducted. The content was then 'coded' based on the themes that emerged from the first step of the method. The themes were coded as 'nodes' in the NVivo program, while the more detailed nuances of the empirical material, the sub-themes, were coded as a 'sub-node' under the given 'node'. The third step of the method involved a *condensation* or summarization of the meaning and content of the coded groups into broader meaning units. Each coded groups' main content were summarized in own words, and relevant quotes were used to highlight the recurring topics and patterns as well as

nuances. The fourth and final step involved to ‘*synthesize*’ the material. The insights from the condensed meaning units were now described, reflecting strong patterns in the material. In the process of writing, new headings for the categories were developed and other categories emerged from the sub-groups, aiming at getting as close to the content of the material as possible.

The data for paper II constituted a substantially larger amount of data material, and the data analysis process was guided and inspired by the writings of Miles and Huberman (1994). They define analysis as consisting of three concurrent flows of activity: *data reduction*, *data display* and *conclusion drawing and verification* (Miles and Huberman, 1994, p. 10-12). *Data reduction* is similar to the term “data condensation”, and refers to a form of analysis that sharpens and organizes data so that ‘final’ conclusions can be drawn and verified. According to Miles and Huberman (1994) this process starts before data has been collected when the researcher decides which cases, which research questions and what data collection methods to use. Data reduction then continues through the process of selecting, focusing and simplifying the data that appear in field notes or transcriptions. *Data display* refers to the development of various types of matrices, graphs, charts etc, with the aim of organizing a large amount of data material into a compact form that makes it easier to see what is happening and ease the process of drawing justified conclusions. The *conclusion drawing and verification* process starts, according to Miles and Huberman (1994), from the very start of the data collection, through noting of patterns, causal flows, explanations and so on. It is however important to hold these ‘conclusions’ lightly throughout the data collection, meanwhile keeping an open and sceptical mind. ‘Final’ conclusions may not be drawn before the end of the data collection, depending on the amount of data material. As the analyst proceeds, conclusions have to be verified. This can be done in various ways, e.g. by going back to the field notes or through review among colleagues (Miles and Huberman, 1994).

Before entering the field I had developed a research protocol deciding on data collection methods and had developed preliminary interview guides. Although

adjustments were done after entering the field, the process of *data reduction* had already started, and surely continued during the data collection through the selection of informants and by focusing the questions asked. When all the material was collected, the complete material was read through to get an overall impression of the contents of the material, and a table was made to organize a demographic overview of the women with prolapse and their associated prolapse related data (*data display*). The material was then coded line-by-line into overarching ‘nodes’ or themes in NVivo. Each ‘node’ was then re-read and scrutinized for central patterns and was organized into ‘sub-nodes’ or sub-themes if necessary. Potential nuances, ambivalence and contradictions within the node or sub-node became important parts of the coded material. A large amount of coded text remained, and I saw the need for organizing each node and its sub-nodes in a more visual form to continue the analysis, following Miles and Huberman’s (1994) argument about the usefulness of *data display*. By the use of the program *bubbl.us* I created computerized ‘maps’ over each of the four remaining nodes and their sub-nodes (**Figure 3**). This process facilitated an important reorganization within each of the nodes before the new organized mind-map was transferred back into a written document. This helped in the process of developing the final cases and themes to present in paper II.

The analysis of the data material for paper III followed the same principles of paper II, except that it did not make use of bubbl.us as the amount of data material was smaller and easier to administer.

3.7 Ethical considerations

Ethical approval for the DABINCOP sub-study in 2011 and for the fieldwork carried out in 2015-16 was first obtained from the Regional Committees for Medical and Health Research Ethics (REK) in Norway (**Appendix Va**) followed by the Institutional Ethical Review Board of the University of Gondar in Ethiopia (**Appendix Vb**). The purpose of the research project and the ethical approval were presented to the Chief Executive Officer of the hospital, and approval was given to conduct participant observation and data collection at the relevant hospital ward.

All patients on the ward were informed about the study, the ongoing participant observation and their rights not to participate or to be observed or read about in their medical charts. They were told explicitly that talking to me had no influence on their treatment, and that accepting or rejecting to talk to me or to be observed had no consequence for them at all. No patients declined to be observed, however, three women declined to be interviewed. This to some extent confirmed to us that the message of voluntary participation had been understood. No refreshments, items or money were given to the women who participated in interviews at the Fistula Centre in order to avoid potential disruptions or negative feelings among the patients.

In the two districts, the head of the district health administration was informed about the purpose of the research project and was provided the ethical approval letter before any research activity was initiated. During the DABINCOP sub-study, the data collection in the field took place alongside the quantitative pilot study in Dabat district, which was run through the Dabat Research Centre.

Prior to each interview and FGD, the information sheet about the study which had been translated from English to Amharic was read aloud to the informants who could

not read (**Appendix VI**). This included information about the aim and purpose of the study; assurance of anonymity, and the right to withdraw their consent at any time without having to provide an explanation. Written or oral consent to participate was obtained depending on literacy status (**Appendix VI**). All informants consented to the use of an audio recorder during the interview. Due to the sensitive nature of the research topic, utmost care was taken to secure privacy and confidentiality during the interviews with the women both at the hospital and in their homes.

Ethical principles based on the 'Declaration of Helsinki' (World Medical Association, 2008) were followed by both the research assistants and myself throughout the fieldwork. All the data material, both oral and written material, was kept secured in locked data files, and the transcribed interviews were additionally coded to secure anonymity. Files with information about informants' identity were kept in separated locked files. Data material from the DABINCOP sub-study was deleted in 2014 following the permission given by REK, and the remaining data material will be deleted by 31 Oct 2018 unless our application for extension is approved.

In order to obtain temporary residence permit in Ethiopia during the time of the fieldwork, I got associated with the Institute of Ethiopian Studies at the University of Addis Ababa (**Appendix VII**). Both temporary residence permit and a research status identification card were obtained for the duration of the research stay in Ethiopia (**Appendix VIII**).

4. Results

Due to limitations of space this section merely contains a brief summary of the main findings of the study's three papers. The findings across the three papers are based on the same data, and thus a similar group of informants express their views and experiences on three different but highly interrelated themes: I) the challenges of living with prolapse; II) health care seeking in relation to prolapse, and; III) life after surgical intervention of prolapse.

4.1 Synopsis of paper I

Living with Pelvic Organ Prolapse: A qualitative study from Amhara region, Ethiopia

This paper focuses on how women living with severe conditions of pelvic organ prolapse explained and handled practical and social implications of their condition. The study included 24 women with prolapse ranging from 24 to 65 years, of whom half had suffered from their condition for more than 10 years. The key study findings are presented under the following five headings: "Conceptualizing the condition", "Challenges of daily life", "Sexual implications", "Managing the condition" and "Difficulties of disclosure".

The majority of the women related their condition to previous bodily strain such as childbirth, including lack of rest during and after pregnancy, their young age when giving birth as well as multiple childbirths. General food scarcity and hard physical work was also emphasized, while others explained their condition as God's will or as caused by spirits or a person with 'evil eyes'.

The greatest challenge in women's daily lives was the pain or discomfort experienced during chores involving heavy lifting or long distance walking. Some found strategies for avoiding certain chores or making them more bearable, such as delegating chores to their children, sitting down to rest during long walks, applying oil on the prolapse,

etc. The majority of the married women continued to be sexually active as long as they managed, despite pain during sexual intercourse. Some however had not had ‘understanding husbands’, and as a result got divorced due to their condition.

Prolapse, as well as other reproductive disorders such as incontinence and obstetric fistula, were regarded as extremely shameful in the study area, and very few therefore spoke openly about their condition and continuously lived in fear of embarrassment, discrimination or divorce. The ones who did disclose their condition to a person close to them, including a husband, did by and large experience substantial support.

4.2 Synopsis of paper II

The lucky ones get cured: Health care seeking among women with pelvic organ prolapse in Amhara Region, Ethiopia

The findings of the second paper give insights into the experiences of health care seeking among the women suffering of prolapse, and particularly what influenced their choices of health care and the dynamics taking place between their choices of public health services and other available healing options in the area. The study included 24 women with prolapse who were offered free treatment at a governmental hospital, as well as a total of 18 additional informants including health care providers (9), local healers (4) and actors from the health authorities (2) and non-governmental organisations (3). The key findings are highlighted through three case stories that each emphasizes one particular avenue of help seeking that was recurrent in the material. The headings are presented as follows: “Seeking help at health facilities” (Hanna’s story), “Seeking cure through local healing options” (Aberash’s story), “Seeking healing through holy water” (Rahel’s story), “Navigation between available health care options” and “Changing scenarios?”

The findings revealed three main arenas for seeking health care for prolapse, namely the public health system, religious healing through ‘holy water’ and various local healing methods. Many women moreover navigated between these options and combined the various healing options, often being referred across the diverse health

care arenas by the ‘practitioners’ themselves. Their choices and preferences of place and type of healing were influenced by factors such as poverty, lack of knowledge about the condition they suffered from, religious and spiritual aetiology and beliefs, limited decision-making power on part of women and the feelings of shame and sensitivity that surrounded the condition of prolapse. Although the majority of the affected women at some point had sought help or advice for their condition, none had received any treatment that had given them long-term relief of the suffering. This led many to lose faith in a potential solution for their health problem. The study context was however characterized by transforming conditions. The use of local healers appeared to be increasingly surrounded by secrecy. A newly introduced community mobilisation program spreading awareness about the condition of prolapse was dramatically increasing women’s knowledge and awareness about available surgical treatment in the study area, creating more openness and new hopes of cure among affected women.

4.3 Synopsis of paper III

Life after pelvic organ prolapse surgery: A qualitative study in Amhara region, Ethiopia

The findings of the third paper present a continuation of the second paper, and describe in greater detail women’s experiences of recovery after surgical treatment of prolapse, and the following reintegration process into their communities during and after their recovery. The study’s main participants include the follow-up of 12 women, five to nine months after their surgical treatment at the hospital. The follow-up took place in their respective homes, which provided excellent opportunities for observations of the women’s living conditions and community context. The findings are presented under the following four headings: “Recovery”, “Disclosure”, “Reintegration” and “Engagement”.

Only half of the women experienced full recovery at the time of the research, while the other half still experienced challenges such as urinary leakage or a re-emerging

prolapse. However, nearly all expressed a certain degree of relief compared to the past. What was more, all had received substantial support with the household chores from close family members, neighbours and distant relatives during their recovery period. After the initial recovery period the informants depended on their children or other close family members to take over the heaviest household chores on a more permanent basis. This left the divorced, widowed or single women in a more vulnerable position than the ones married and with children at home.

Encounters between women who suffered from prolapse during the recruitment process in the communities and during the hospital stay proved vital in terms of their choices to disclose during the recovery period in the communities. In stark contrast to earlier, the majority of the women now decided to speak out openly about the condition they had suffered from. They received positive feedback on their openness, which was said to slowly initiate a process of reducing the extreme sense of embarrassment and shame surrounding the condition among their female friends and ultimately in their communities. Moreover, due to the increased openness, a number of women suffering from prolapse now came forward asking for help. As a part of the prolapse initiative taking place in the communities, selected women who had been treated were trained as ‘maternal-health advocates’ after their recovery, and joined the community health workers in spreading information about maternal-health matters and in seeking and registering women who suffered from prolapse.

5. Discussion

5.1 Discussion of main findings

As mentioned in section 1.4 it proved necessary to shed light on *both* socio-cultural dynamics and the prominent structural factors at work in our study context, and hence the discussion will mainly concentrate on how these socio-cultural and structural dimensions relates to our study findings and beyond. It is furthermore important to discuss how initiatives such as the health campaign that was initiated in the present study setting at the time of the study is relevant within the current health aims and priorities in Ethiopia, and to discuss how such initiatives may develop into a sustainable and free health care service for all Ethiopian women suffering from the condition of prolapse.

5.1.1 Socio-cultural and structural dimensions of suffering related to prolapse

Spiritual and religious explanations of ill health underpinned the data material. These understandings had vast impact on the way women perceived their condition and how they went about finding a solution as described in paper II. These perceptions may be represented as culturally constituted '*shared understandings*' (Kleinman, 1988) of reproductive disorders among people in this particular context. It appeared common in the area to link understanding of disease to forces such as evil spirits or to God's will, and many perceived their prolapse as either a punishment or attack from a spirit or as God's will. In line with this reasoning it made sense to seek solution for their prolapse through conducting spiritual ceremonies in their home, seeking advice from an *awaki* or *tenquay* (local spiritual healers) or visiting religious Holy Water sites in their area, rather than going to the health centre or hospital. These practices were clearly a part of many of our informants culturally constituted *shared understandings* of their condition, which in turn influenced their *explanatory models* and hence the health seeking conduct for their prolapse conditions in this particular cultural setting.

The patriarchal structure and the gender-related social norms moreover limited the women's possibility to make important decisions concerning their health. Such gendered norms and structures have deep historical roots in rural parts of the Ethiopian society (Woldemicael and Tenkorang, 2010). The typical role of women as dependent on a husband and/or extended family members to seek health care has been reported from various rural areas of Ethiopia (Berhane et al., 2001, Woldemicael and Tenkorang, 2010). The majority of our study informants got married as young girls and throughout their lives worked with household related chores. They were highly dependent upon their husbands in most matters, including in connection to the seeking of health care. Similar findings have been reported from a number of contexts, for example from Nepal, where gender bias regarding education and choice of occupation influences and retains women's social and economic position, consequently increasing their dependence on spouses or other family members and likely contributes to the delayed health care seeking among women suffering from prolapse (Shrestha et al., 2014b).

The shame and embarrassment connected with the condition was moreover an important part of the women's culturally constituted *shared understandings*. To not be able to speak openly about- and share experiences with others likely made prolapse an unfamiliar and lonely condition to live with, which may in turn have strengthened their experience of shame. Although the condition of prolapse is reported as shameful also in affluent settings (Jelovsek and Barber, 2006, Lowder et al., 2011), the condition seems to gain particular severity for the affected women in our study context. This has similarly been documented for other sensitive gynaecological disorders both within and outside of our study context in Ethiopia (Birhanu et al., 2012, Gjerde et al., 2013, Muleta et al., 2008). In addition to having reduced possibilities to share their symptoms with others, they also had limited means of seeking information about the condition, although the majority of our informants shared medically relevant perceptions about causation of their condition. Some, despite their fear and embarrassment, disclosed their condition and sought help at the local health centre, although it often did not lead to actual help due to a range of

obstacles, including a fear of going to the hospital. Many others had sought help at the health centre for other health issues, but never dared to disclose their prolapse symptoms due to the embarrassment of suffering from what they perceived to be a rare and disgusting condition. Seeking help at Holy Water sites and/or with spiritual healers proved to be far easier, as it did not necessarily require a full disclosure of their symptoms. Among women suffering of cervical cancer in south-western part of Ethiopia, fear of stigma and discrimination were also important factors hindering the affected women from disclosing their condition and seeking early treatment due to the common perception that the condition was caused by unacceptable social behaviours. Many of the affected women thus relied on home based ‘traditional’ treatment or Holy water (Birhanu et al., 2012)

As described in section 1.4, medical anthropologists drawing upon a critical theoretical perspective argue that the susceptibility to disease is linked to a complex series of social or ‘structural’ factors, affecting disproportionately the ones living in impoverished conditions (Baer et al., 1986, Singer, 2004). This general observation is strongly reflected in the findings of women suffering from prolapse in the current study setting. The large majority of the 32 women who were followed in the present study got married as young girls, many as young as 10 years of age, as has been a cultural norm the area. Due to substantial political pressure, this custom is slowly changing in Ethiopia. The fight against early-marriage (before the age of 18 years) is presently located at the core of the global health agenda, and is defined as a human right violation (UNICEF, 2018). Over the last decade, Ethiopia has launched a National strategy against “harmful traditional practices”, including child marriage, and has documented a steep decline in early marriage (Girls Not Brides, 2018). Yet, 40% of Ethiopian girls are still estimated to be married before the age of 18, and 14% before they are 15 years old (Central Statistical Agency/Ethiopia and ICF International, 2017). The official law is however not readily enforced, and it may often be difficult for authorities to prove that a girl is underage due to the lack of a national or regional birth registry system (Girls Not Brides, 2018). As mentioned in section 3.1, Amhara region has the lowest median age of first marriage in the country,

and nearly 45% of girls in the region are estimated to be married before they turn 18 (Girls Not Brides, 2018).

There is little doubt that the opportunity for the women in our study to attend or continue school was severely compromised as a result of marriage at a very young age. Education is to equip women (and men) with the skills needed to make important decisions related to their health, and being prevented from attending school will imply illiteracy and thus exclude them from any form of written health care information (Woldemicael and Tenkorang, 2010). In the present study context, lack of schooling and limited circulating health information about sensitive pelvic floor disorders left the women with little or no knowledge of prolapse. It furthermore lead to a limited possibility of knowing what the symptoms they experienced were a result of and little knowledge about how to search for information and help. It is likely that the lack of knowledge also enforced the already strong feelings of helplessness, shame and embarrassment connected to the condition encountered in the study area. In a study assessing knowledge of prolapse among women in Nepal, 53% of the women reported to never have heard of prolapse, and educational level was found to be one of the strongest associated factors. Among those who had heard about prolapse, the information had been accessed from various sources including from the radio, television, female community health workers, friends/relatives, health workers and newspapers (Shrestha et al., 2014a). This illustrates that there may be many important alternative sources of spreading information of prolapse beyond education or written pamphlets in rural settlements where few girls and young women attend school.

Naturally, a serious and potentially harmful implication of early marriage is early pregnancy, and it has been documented that girls who are married before the age of 18 have an earlier median age of first birth, give birth to more children, but also lose more children due to neonatal deaths or childhood diseases (Walker, 2012).

Pregnancy constitutes the leading cause of maternal mortality and morbidity worldwide for women aged 15 to 19 (ibid). Studies on obstetric fistula in Ethiopia

found that most of the ones who were affected were young rural women who delivered for the first time and got married early through family arrangement or abduction (Muleta et al., 2007). Studies on prolapse from resource rich contexts have primarily found that multiple vaginal deliveries increase the risk of developing prolapse over time (Rortveit and Hannestad, 2014, Walker and Gunasekera, 2011). The women in our study had given birth to an average of nearly six children, and were thus in a high risk group for developing prolapse. While women in high-income settings normally develop symptoms of prolapse later in life and after reaching menopause, the majority of the women we interviewed told us that they experienced their first symptoms of prolapse already in their twenties, possibly related to the early onset of childbearing. Consequently the prolapse appeared at a time when the women were busy bringing up their children, taking care of heavy household chores, meanwhile striving to live up to the expectations of a good wife for husbands and the extended family.

Living in impoverished conditions in rural communities implied enormous physical strain as described by the women in our study. Nearly all of the women in the study were responsible for all household activities, many of which were very heavy and were performed manually as described in some detail in section 3.5.3 and in Paper I. The fact that many of the women did not get time for rest during pregnancy or after giving birth coupled with early age delivery, may moreover potentially have increased the risk of developing prolapse. These factors have not been extensively documented as risk factors for prolapse, but are factors suggested to have particular relevance in resource-constrained settings (Bonetti et al., 2004, Megabiaw et al., 2013, Walker and Gunasekera, 2011, Ravindran et al., 1999).

The women in our study living in rural '*kebeles*' (communities) furthermore had long distances to reach the health centre, which commonly was located in the semi-urban area of the districts. Some had gravel roads leading into their communities, but we observed very few making use of any motorized vehicle or other transport means to reach town. People were most commonly seen walking, some with donkeys who

carried goods to and from town, e.g. to sell or buy things at town markets. Others, particularly the ones living in the low-land areas, had no roads leading to their villages and had to climb up and down often steep mountain sides to reach town, a walk that could take a full day for people in good health. Even if women suffering from prolapse reached the health centre, this was far from a guarantee that they would be referred and proceed to the hospital for the required treatment, not the least because of the high costs involved, combined with the difficulties of leaving behind duties at home for an extended period of time.

The above mentioned factors constitute central structurally grounded aspects that locate the women who participated in our study in a severely disprivileged and vulnerable position, and thus more likely to be at a higher risk of developing prolapse compared to women living in more affluent settings. We will argue in line with Farmer (1992) that the condition of prolapse does not solely exist within the bodies of the ones affected, but is influenced by intricate structural webs of gender inequality and poverty related scenarios. The concept '*structural violence*' (Farmer, 1996) is highly relevant for the discussion of our findings. Lack of educational opportunities combined with impoverization and the gender norms of very early marriage jointly leave women in starkly structurally inferior positions. The implication is that it leaves rural Ethiopian women with little or no grounds for attaining the means necessary to prevent and to deal with highly problematic conditions of reproductive morbidity.

We will also point out Scheper-Hughes (1993) argument about suffering being far from a local phenomenon. The young girls in our study context have little influence or power to change or overcome the many barriers that constrain their lives, be it social structures or cultural norms. However, the ongoing initiatives to stop early marriage, the national emphasis on increasing the number of children who attend school, the roll out of community health programs and the general economic development and political transformation in the country do provide reasons for a carefully optimistic view regarding the likelihood of improvement of life conditions for rural Ethiopian women.

5.1.2 From policy initiatives to sustainable health care services: Making prolapse treatment available and accessible

Global policy agendas such as the Universal Health Coverage (UHC) and the Sustainable Development Goals (SDGs) introduced in section 1.3.2, aiming to strengthen national health systems and to improve overall health globally, have left many resource-constrained countries in a pressured position (Travis et al., 2004). In Ethiopia, where 80% of the population live in rural and often remote areas, it is an immense challenge to secure that all people gain timely access to health care services (Central Intelligence Agency, 2017). The country shows promising economic development, has rolled out an impressive Health Extension Program (HEP) in communities throughout the country, has prioritised health facility construction at community level and has indicated great political will and ability to implement important measures to reduce both maternal mortality and morbidity (Ministry of Health Ethiopia, 2015). Yet, huge variations in the coverage of health care services remain between regions and urban and rural settings (Ministry of Health Ethiopia, 2015, Central Statistical Agency/Ethiopia and ICF International, 2017), and the provision of free health care for all remains a utopic aim in the foreseeable future.

Foreign governments, multilateral agencies, NGOs and private agencies provide funds or conduct activities with the aim of improving health in low- and middle-income countries (Khan et al., 2018, Ravishankar et al., 2009). Such actors may play vital roles in reaching development goals. Their influence has however been increasingly scrutinized as it influences or even directs the decisions of national health policymakers, for example through the use of conditionality in policy-based lending and through the funding of ‘vertical’ programs (Khan et al., 2018). Some of the known disadvantages of such donor driven initiatives include the risk of overshadowing existing national programs and priorities, and the lack of sustainability of programs once the donor funding ends or decides to change priorities (Travis et al., 2004, Khan et al., 2018). In ‘vertical’ programs particular types of diseases that gain broad public attention and support, such as HIV/AIDS, tuberculosis and malaria, are often prioritised. Within the women’s health sphere, maternal

mortality has gained a substantial focus the last decades (cf. section 1.1), slowly opening up for more attention also on maternal morbidities. Within pelvic floor disorders in Ethiopia, obstetric fistula has for decades gained attention, and consequently community mobilization, treatment centres and reintegration programs have importantly been established in many parts of the country (Hannig, 2012, Hamlin Fistula Ethiopia, 2018). Meanwhile, other more prevalent, yet less detrimental pelvic floor disorders such as urinary incontinence and pelvic organ prolapse, have gained less attention, and thus received less prioritization and funding.

The ‘prolapse-campaign’ in the current study setting was funded by organisations such as the Women and Health Alliance International (WAHA), the United Nations Population Fund (UNFPA) and Save the Children International, and may thus be regarded as a ‘vertical’ program. However, the collaborating funding partners worked closely together with the governmental hospital, with the intention to integrate prolapse treatment in the already existing obstetric fistula program and to achieve a sustainable service for prolapse patients. According to our sources in Gondar, Ministry of Health (MoH) recently decided that prolapse should be treated for free at tertiary hospital level across the country, although this is still in the process of being realized due to the costs involved. In the meanwhile, UNFPA continue their activities at the University of Gondar Hospital (UoGH), offering women with prolapse free treatment through campaigns two to three times per year. Initiatives such as the one launched in Gondar thus contributes to the continuous increased attention and prioritization of the condition of prolapse in Ethiopia.

Similar ‘prolapse-campaigns’ have moreover taken place in other settings within and beyond Amhara region. WAHA and Worldwide Fistula Fund, organisations engaged in women’s health work in Ethiopia with a particular focus on obstetric fistula, have expanded their focus beyond obstetric fistula and included attention and activities towards pelvic organ prolapse (WAHA International, 2018, Worldwide Fistula Fund, 2018). Also UNFPA has supported training and logistics of prolapse treatment in other parts of the country (United Nations Population Fund, 2015). There is moreover

increasing interest in gaining more knowledge about prevalence, risk factors and the implications of prolapse in Ethiopia (Megabiaw et al., 2013, Ballard et al., 2016, Adefris et al., 2017, Dheresa et al., 2018).

All abovementioned initiatives moreover illustrate important steps towards achieving the strategic objective described in the current Health Sector Transformation Plan (HSTP) (cf. section 1.3.2), aimed at clearing all ‘backlog cases of pelvic organ prolapse’ (Ministry of Health Ethiopia, 2015, pp.102). Obstetric emergencies are already among the key services that are provided free of charge by the government in Ethiopia (Ottersen et al., 2014, Ministry of Health Ethiopia, 2015), and although the coverage and utilization of e.g. facility-based births or births attended by skilled personnel is still relatively low in the rural population, encouraging improvements have been documented over the last decades, as mentioned in section 1.3.1 (Central Statistical Agency/Ethiopia and ICF International, 2017). These are examples of developments that allow for hope for both improved prevention strategies and early treatment of prolapse if seen in a longer term perspective.

There is little doubt that the ‘prolapse-campaign’ had a substantial impact on the women and communities involved in the present study. Through spreading awareness about prolapse, initially by the Health Extension Workers (HEWs), and later by the treated women themselves, a profound increase in people’s awareness about prolapse and the existence of potentially curable and affordable treatment at the hospital took place in the study area (as described in paper III). The implication was increased interest in seeking help at the hospital. Although many connected the prolapse condition to spiritual or religious causations, informants in the present study were willing to embrace the opportunity that they were provided after years of suffering. Many moreover found ways of combining the medical treatment with the religious healing (as described in paper II), scenarios that have been documented from plural medical contexts from other parts of the world as well, including in a study of Ethiopian women suffering from cervical cancer (Birhanu et al., 2012).

The current study thus indicates that the introduction of a ‘prolapse-campaign’ implying community mobilization with the aims to spread awareness about the condition and to offer free surgical treatment, does open women’s minds to new treatment alternatives, alternatives that may contrast with or challenge their existing *explanatory models*. This aligns well with Good et al. (2010) and their discussion on how people are pragmatic and may be able and willing to change or modify their perceptions and preferences in health care when they see the change as a realistic and positive opportunity and they experience the treatment offered to be effective.

5.2 Discussion of methods

As qualitative methods strongly depend on the insights, conceptual capability and the integrity of the researcher, criticism towards qualitative inquiries in the medical community is often related to doubts about the credibility of the findings and accusations of predispositions and biases of the researcher (Patton, 2015, p. 653). Several analytical processes for enhancing quality and credibility of qualitative research have been proposed, many corresponding with the validation criteria’s used in quantitative research methods (Guba, 1981). It is clearly not possible to judge qualitative research by use of conventional quantitative and mechanical criteria. Some prefer to use broad concepts such as ‘validity’ and ‘relevance’, but to operationalize them differently in order to make sure distinctive goals of qualitative research are maintained (Hammersley and Atkinson, 2007, Mays and Pope, 2000). Although ‘reflexivity’ is part and parcel of validity, Malterud (2001) argues that a reflexive research practice deserves even more attention in the process of enhancing the quality and credibility of qualitative research methods, and should be an essential part like that of validity and relevance (Malterud, 2001). In the following I will discuss the methods used in the present study through an attempt at critical reflection surrounding my own role in the study, the language barriers and the use of research assistance as well as the overall validity and relevance of the study.

5.2.1 Reflections on researcher's position

A researcher's background and position in a qualitative research project will affect every step of a research project, from choosing what to investigate, to the approaches and questions chosen, to the research encounter and to the communication of the conclusions of the study (Malterud, 2011, p. 38). Hence, researchers may access different but equally valid representations of a phenomenon depending on their position and perspectives (Malterud, 2011, p. 39-40). Reflexivity involves identifying and making explicit the researchers' preconceptions, pre-study beliefs and motivation brought into the study. It also includes the presentation of previous personal and professional experiences deemed to be of particular relevance for the study. The researcher has to be especially careful of mixing or blurring knowledge embedded in preconceptions with knowledge emerging from systematically obtained data (Malterud, 2011, p. 40-42). In ethnography, as well as in other qualitative research approaches, the researcher through the role of active participation, functions as the research instrument. The researchers' influence on the context, including shifting behaviour and conduct, thus becomes central to the analysis (Hammersley and Atkinson, 2007, p. 17).

Being a European looking foreigner and a student at PhD level gave certain advantages during the fieldwork. It for example generated a certain level of perceived 'seniority' that gave me 'natural' access to talk to those above me in the hierarchical medical system while being on the ward, such as residents, gynaecologists as well as surgeons visiting from abroad. Also in the communities it may have given me an advantage, as it was fairly easy to access actors from the relevant NGOs and from the health authorities.

Throughout the study, and especially during the participant observation at the hospital, my background as a Registered Nurse (RN) from a gynaecology ward in Norway influenced how I understood pelvic floor disorders, and the ways in which I perceived the care and treatment given to the patients at the hospital. It also played an important role in the interaction with the health care staff at the Fistula Centre. The

nurses may at times have perceived me as ‘one of them’ as we shared similar educational background.

As the Fistula Centre is a training centre, and often accommodates foreign clinician’s whose purpose is to teach, as well as to learn about obstetric fistula treatment, my participant observational role was initially perceived as unfamiliar among the nurses. It was in fact an expectation that I would teach and share from my knowledge and experience. However, after another round of explanation of the purpose of the method and the research, my role did not seem to be any problem, and the nurses continued to include me in their daily work-activities. During one incidence when the majority of the nurses were taken out of the ward for a workshop, the head-nurse told me to stay behind at the ward together with one other nurse. I perceived this as a sign of trust, and that my presence on the ward was both accepted and in some instances perceived as helpful. During another incidence when an important donor was visiting the ward, I observed how the ward was made even cleaner and nicer than on ‘normal’ days. This also confirmed that my presence on the ward did not substantially influence the ‘natural setting’ of daily routines and activities at the ward. I assume that social desirability bias to some extent may have influenced the nurses to perform best practice in my presence. However, it may have been somewhat reduced by the fact that the nurses were informed about the focus of my study. The fact I stayed on the ward over an extended period of time possibly also limited such potential bias.

The interactions with the women on the ward were to a larger degree influenced by my ‘otherness’. On one side they may have regarded me as part of the formal health system, as I was wearing a nursing uniform and was performing nursing activities alongside the other nurses. On the other side, I assume that they perceived me as a ‘ferrenji’ (a light-skinned foreigner), which comes with common preconceptions of being an ‘expert’/‘specialist’ and/or wealthy. Although I was clearly regarded as an outsider, it is likely that speaking with the local language, although at a very basic level, created a closer contact between me and the patients. At the ward as well as during the interviews with the women, being female was assumed an advantage for

my main research assistant and myself, since the topic in question was highly gender specific and sensitive. Our somewhat young age (both in the beginning of our 30ties) compared to the majority of the informants, and the fact that none of us had yet given birth, might have limited the women's sense of connecting with us, especially the older informants.

Although the research assistants' and my own background surely influenced the encounters with the women and the way in which they shared their experiences with us, the research assistant and I perceived the large majority of the women to be surprisingly open. This perception was based on my previous experience of interviewing women with various degrees of urinary incontinence in the same area during the DABINCOP fieldwork in 2011. The women with urinary incontinence were extremely shy in the interview situation, and many spoke with such a low voice that it was difficult to hear what they said. An important difference between the two groups is that the condition of prolapse was reported as easier to hide compared to urinary incontinence. Another important difference is that the women with prolapse, at the time of the interview, had already started to open up about their condition with their fellow sufferers through their role as participants in the 'prolapse-campaign'.

During the follow-up visits, although removed from the hospital setting, the women most likely associated us with the hospital. However, the appreciation that they expressed in relation to our visit and their willingness to continue to share their experiences with us, indicated that a certain level of trust had been established during the hospital stay and the previous interview. During our visits to the communities, the research assistant and I moreover strove to be sensitive towards local social and cultural norms, e.g. by following the socially acceptable dress code for women in the area and to greet people in a socially acceptable and respectful manner.

During our visits to the Holy Water sites, both in the communities and in Gondar, my 'outsider' appearance gained some attention and people approached us with

questions. Often these were men asking for health advice, assuming that I as a ‘ferrenji’ was a physician or another kind of specialist.

5.2.2 Reflections on language and research assistance

Conducting cross-cultural research with the use of translation may have several implications for the findings that researchers must be aware of, not the least if the aim of the research is to improve knowledge and understanding of experiences from a non-English speaking setting (Twinn, 1997). The lack of language competence implies substantial barriers in a research context. A lot of the details and the exact ways in which a message is phrased will simply not be grasped. For example when no equivalent word or expression exists in the target language and slightly different words are chosen in the presentation of the questions or in the translation of what the informant answered that may alter the meaning of the content. Also different cultural background may influence the way people communicate, for example by answering direct questions in a circumvent manner or use certain indirect or (to outsiders) unrelated words to explain a particular phenomenon. Intra-cultural disparities in language use, gestures and cultural norms when interviewing across gender, age, social class and religion, can be difficult to detect (Kvale, 2007, p. 68). Kvale (2007, p. 68) thus states that it is vital that the researcher spends enough time in the research field area in order to establish familiarization with the culture and learn verbal and non-verbal meanings of communication and acceptable conduct in an interview setting. When sufficient language competence is lacking an interpreter should be selected based on culturally acceptance and proficiency in the language. Using a non-professional as an interpreter may obviously have implications for the quality of the translation, especially if the interpreter has a particular agenda (Kvale, 2007, p. 68). The use of different translators who interpret differently may reduce the reliability of the study (Twinn, 1997).

In the current study, substantial effort was invested into learning at least basic level Amharic, the language practiced in the study area. During a three months long language course, I learned how to read fairly simple texts in Amharic and to speak at a

very basic level. The health care providers at the hospital were all trained in English, and all patient information in the medical charts was written in English. The level of spoken English was good among residents and senior physicians, while it was at a very basic level among the majority of the nurses. As I was far from mastering the medical terminology in Amharic, I mainly communicated in English with the health care workers. In conversations of more social character among the nurses I attempted to communicate in Amharic. I moreover decided not to bring the research assistant with me on the ward when interacting with the nurses and the patients, as I believed this could disturb the interaction and distance myself from the nurses on the ward. This clearly meant that I lost some of the content in the patient / health care provider interaction, as I had to rely on my own observations, my basic understanding of Amharic and the non-verbal communication taking place. Sometimes the health care personnel would explain the content of a particular conversation afterwards. My own conversation with the patients often developed into a deeper conversation from the women's side, which I was not able to follow, and which meant that I lost potentially valuable information. However, some of these conversations were continued during interviews at a later stage.

During the interviews with the women at the hospital and in the communities, as well as with HEWs and local healers in the communities, I relied more heavily on my main research assistant. The main research assistant and I spent considerable time together revising the questions in the interview guides to decide on the suitable and equivalent Amharic wording and phrasing, so that she became familiar with the medical concepts and knew what terms would be appropriate to use in the conversation with the women. However, during the course of the interviews, her choice of wording changed according to how she perceived that the women best understood our questions.

During the course of the fieldwork, as my main research assistant allowed the informant to speak for longer periods of time and asked relevant follow-up questions herself, the women may have felt more relaxed in the conversation and shared more

details. Because of the main research assistant's ability to remember long sequences of a story when the women spoke for long, I rarely felt there were large gaps or important issues that missed during the interview settings. However, the later revisions of the transcribed interviews certainly revealed that I missed certain details in the conversations.

The first transcriber and translator of the written material, who was situated in Addis Ababa, preferred to translate the Amharic into 'proper sounding' English sentences. This appeared nice when reading the text, but after comparing the transcripts to the translated version, my main research assistant and I found that important cultural terms, loaded concepts and their meanings sometimes disappeared in the translation. We experienced that there was a substantial distance between what was communicated as the sentences were not literally translated. We thus revised these translated interviews to add the necessary clarifications.

Due to my language limitations, I am aware that the findings I present is to some extent the research assistant's interpretations of the women's words. There are always multiple layers of interpretation between how an informant has in fact experienced a phenomenon and how the readers of a produced text understand the phenomenon. One cannot expect that we necessarily got the infinite and experienced "truth" from any of our informants, as what and how the informants chose to communicate to us may have been influenced by multiple factors, such as feelings of shame or the interest of presenting her situation in a better or worse manner than it actually was experienced. The translation taking place was furthermore influenced by how the translator herself interpreted what was told by the informant and how she communicated that interpretation to me. My understanding of what was translated to me might also have been influenced by my own preconceptions or limited contextual and cultural understanding. How I perceived the interviews and the written data material clearly influenced the manner in which the data was coded and categorized, and later how I chose to construct the text and present the findings. There are however a number of factors that in the research process are likely to have reduced

substantial misinterpretations of the women's stories, such as the long periods of time spent in the study field, conducting follow-up interviews and the use of triangulation.

5.2.3 Validity and relevance of the study

Qualitative research, like other research, employs strategies for assessing and questioning the validity of their studies (Malterud, 2001). While the internal validity relates to whether the study investigates what it is meant to, the external validity relates to what other contexts the study findings may apply to. Mays and Pope (2000) suggest several ways of improving validity in qualitative research, however, they, as well as Malterud (2001), emphasize that assessment using concrete criteria is not a straightforward matter, but requires continuous process of judgements and assessment.

Triangulation involves the comparison of results from different data collection methods or data sources, with the aim of finding corresponding and diverging patterns to sustain an overall interpretation (Mays and Pope, 2000). The assumption is that weaknesses in one method to some extent may be compensated for by strengths in another, which may improve the comprehensiveness and reflexive analysis of the data (Mays and Pope, 2000). Ethnographic studies imply an "inherent triangulation", as one by definition observes, participates and speaks to different people, commonly from the full spectre from informal talk to formal qualitative interviews. Hence a substantial degree of methods and source triangulation normally takes place over an extended period of time (Hammersley and Atkinson, 2007).

The four months spent in the research area during 2011 had made me somewhat familiar with the culture, conduct and the physical environment in the study context. Having spent a total of one year in Ethiopia during the present PhD project, increased my cultural and language competence in the research area which obviously has had an important impact on my ability to make sense of the data collected.

Inclusion of different categories of informants broadened the knowledge of the phenomenon in question and gave insights from differently positioned actors, such as

women with different backgrounds and various categories of health workers, which added important contextual information and nuances to the material. The inclusion of local health workers proved extremely useful for my understanding. Continuous informal talks with a variety of people throughout the time spent in the field added to the understanding of both the topic in question and the socio-cultural context in which the study took place.

Conduction of the focus group discussions (FGDs) towards the end of the fieldwork provided a very good opportunity to scrutinize my study findings with a similar group of informants. We did not encounter substantial contradictory findings through the FGDs, compared to the already gathered material. Rather, the discussions seemed to confirm the preliminary conclusions, but provided additional information about common patterns of health care behaviour in the research area, and thus strengthened the previous material. For example, relatively few informants elaborated on or admitted that they had sought help at local healers or carried out spiritual ceremonies for their health problem during the individual in-depth interviews, although we suspected that it was a common practice in the area, and thus probed the women on the topic. The women in the FDG to a large degree confirmed that it was common to seek spiritual help when facing illness, and not to speak openly to others about it as it was religiously not accepted by the Orthodox Church and hence shrouded by secrecy. This explained the seeming reservation among our previous informants to share the full extent of their health care seeking strategies and experience.

Another way to improve validity of a qualitative study, according to Mays and Pope (2000), is through *respondent validation*. This involves comparing the researchers' interpretation to that of the study participants', and to incorporate the study participants' reactions into the study findings (Mays and Pope, 2000). A respondent validation with the informants themselves did not take place, however the FGDs with women from the same area and condition validated to a large degree the findings for paper II, as mentioned above. The follow-up interviews constituting the findings for paper III implied an important opportunity to clarify earlier mentioned issues, for

example related to health care seeking. Prolonged engagement, persistent observation and follow-up of many of the informants over a longer period of time moreover allowed for a certain level of trust to be built up between the informants and myself, as well as with the health care workers at the hospital. Working closely together with the main research assistant during the translation-process of the complete material was also vital in the process of continuous questioning and validation and clearly enhanced my understanding of the women's stories.

Mays and Pope (2000) furthermore emphasize the importance of presenting a clear account of the process of data collection method and the analysis in qualitative research. The different phases of the present fieldwork allowed me to 'step back' from the field to carry out preliminary analysis of the material, and to discuss emergent findings with my supervisors, the main research assistant and the research collaborator at the hospital before starting the next phase of the fieldwork. During the more rigorous analysis process of the material after leaving the field, I had close communication with the main research assistant which allowed for clarification of particular parts of the material. During the write up of the articles, several of my Ethiopian research collaborators were involved in the process as co-authors, which further limited the possibility of serious cultural or contextual misunderstandings in the interpretation and presentation of the findings.

Another important way to enhance the validation process in qualitative research is through a 'deviant case analysis'. This involves, according to Mays and Pope (2000), to search for and discuss elements in the data that contradict the emerging explanation of the phenomenon under study. Through the process of analysis, I tried to keep an open mind, and made efforts throughout the coding and categorization of the material to include and display any kinds of experiences related to the topic, to secure that the findings from the study were as close to the stories that had been communicated to me as possible. It was however not difficult to encounter variations in the present study material, e.g. experiences described by single women revealed hardships of a very different and more severe kind compared to married women due

to the lack of possibilities to get assistance in connection with the physical demanding daily chores. I also made strong efforts to avoid emphasizing the stories or experiences that appeared more ‘exotic’ based on my own curiosity or interest. Due to strict word constraints in the medical journals for paper I and III, the presentation of the findings, as well as the description of the research methods employed, were however restrained.

Although an important aim of research is to produce information that can be shared and applied beyond the study setting, the relevance of the findings from a qualitative study beyond the research setting should not be exaggerated, as it most and foremost produces descriptions, notions or theories applicable within a specified setting (Malterud, 2001). A thorough presentation of the contextual background of the study is however vital to clarify for which situations or settings beyond the study setting the findings may provide valid information (Malterud, 2001, Mays and Pope, 2000).

As prolapse is a topic yet limited researched in resource-constrained settings, there is scarce knowledge to compare the findings of the present study with. This however reinforces the initial aim of adding to existing knowledge within the topic-area. Choosing women from two different districts of rural or semi-urban locations, and who varied in age and length of experienced symptoms, we attempted to ensure that the findings included different factors that might affect variability in experience among women living with prolapse in the study area. Through detailed descriptions of the context in which the women live, the reader should to some extent moreover be able to judge the relevance of the findings for other similar contexts. As the majority of the women included in the study lacked formal education and lived in rural areas, and thus represent the large majority of women in Ethiopia, it is moreover likely that the findings from the present study has relevance and transfer value to similar settings within Ethiopia, but also to some extent to other resource-constrained settings that experience substantial constraints in terms of education, poorly developed or equipped health services, early marriage practices etc.

6. Conclusions and future perspectives

Living in a severely resource-constrained setting has various negative effects on women's health. This study illustrates the case of living with pelvic organ prolapse in severely impoverished settings of the Amhara region in Ethiopia. The study results reveal that the affected women, who had suffered for years or even decades from their prolapse condition, were severely affected by pain and discomfort. Yet, due to the shame and sensitivity connected to the condition and the fear of being discriminated against, they used a variety of strategies to manage their daily chores while avoiding disclosure of the condition. Meanwhile they strove to find remedies and solution for their aggravating ailment both within and beyond the public health sector. Their choices of health care solutions were strongly influenced by culturally constituted aspects such as spiritual and religious perceptions, gender specific norms and not the least by the shame and embarrassment related to the condition. More than anything their strategies were coloured by their extremely marginal life conditions, by utter poverty, by gender-based restrictive social norms, by the weaknesses in the health care system and by their lack of knowledge about the condition. Hence there were multiple culturally constituted and not the least structurally grounded factors that limited the women's chances of reaching adequate health care services.

The provision of free quality services dramatically altered the women's health- and illness-related opportunities, and at the same time their perceptions about healing options and thus their health seeking conduct. In the process, many of the women who participated in the study went from a life dominated by physical suffering and a fear of disclosure, discrimination and divorce, to a life of gradually regained physical health and of reintegration into the community's social life. The positive impact of the surgery furthermore extended to the communities in which the women lived through increased openness and awareness about prolapse as a common and treatable condition. It is likely that the findings from the present study may have relevance for women suffering from prolapse living in similar rural settings within Ethiopia, but

also to some extent to other resource-constrained settings that face related socio-cultural or structural barriers.

The current study calls for an increased focus on highly prevalent chronic maternal morbidities, morbidities that severely impact the lives of huge numbers of women living in resource-constrained settings. There is particular need for further research on the prevalence and risk-factors of prolapse from resource-constrained settings. The information will inform policy health makers and health care personnel who are currently engaged in a process of creating increased awareness about prolapse and other pelvic floor disorders, efficient prevention strategies and more accessible treatment for the affected women. Counselling for prevention and early treatment of prolapse in rural areas could relatively easily be included in the already established Health Extension Program (HEP) in Ethiopia and become an integral part of family planning and antenatal care services. Increased knowledge about chronic maternal illness in the general population is in turn likely to increase the number of women seeking help at hospital level. Facilitating available and affordable treatment at public hospitals in this context emerges of utmost importance in a joint effort to alleviate unnecessary suffering for a prevalent and highly life constraining chronic maternal disorder.

7. List of appendices

- I** Paper I
- II** Paper II
- III** Paper III
- IV** Interview guides:
 - a) Interview guide for women undergoing treatment for pelvic organ prolapse at the hospital
 - b) Interview guide for women recently treated for pelvic organ prolapse
 - c) Interview guide for health workers at hospital
 - d) Interview guide for health workers at the health centre level
 - e) Interview guide for rural community health workers (health extension workers)
 - f) Interview guide for local healers
 - g) Interview guide for various stakeholders in the districts
 - h) Topic guide for focus group discussions
- V** Ethical approvals
 - a) Ethical approval from the Regional Committees for Medical and Health Research Ethics (REK) in Norway
 - b) Ethical approval from the Institutional Ethical Review Board at the University of Gondar in Ethiopia
- VI** Information about the study and informed consent, English and Amharic
- VII** Letter of affiliation from the Institute of Ethiopian Studies
- VIII** Researcher identification card and temporary residence card, Ethiopia

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Appendix I

Living with pelvic organ prolapse: voices of women from Amhara region, Ethiopia

Janne Lillelid Gjerde^{1,2}  · Guri Rortveit^{3,4} · Mulu Muleta⁵ · Mulat Adefris⁶ · Astrid Blystad⁷

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Abstract

Introduction The objective of the study was to explore how women with symptomatic pelvic organ prolapse in a low-income setting explain, experience, and handle the potential practical and social consequences of the condition.

Methods An explorative qualitative design was employed using in-depth interviews in the data collection. A total of 24 women with different degrees of symptomatic pelvic organ prolapse were included; 18 were recruited at the hospital and 6 from the community. Fieldwork was carried out in the Amhara region of northwest Ethiopia in 2011 and 2015.

Results The informants held that the pelvic organ prolapse was caused by physical strain on their body, such as childbirth, food scarcity or hard physical work, particularly during pregnancy and shortly after delivery. Severe difficulties and pain while carrying out daily chores were common among the

women. The informants used a variety of strategies to manage their work while striving to avoid disclosure of their condition. Disclosure was related to embarrassment and fear of discrimination from people living close to them, including the fear of being expelled from the household. Most of the informants, however, experienced substantial support from relatives, friends, and at times also from their husband, after disclosing their condition.

Conclusions The study highlights how symptomatic pelvic organ prolapse may severely affect women's lives in a low-income setting. The condition is perceived to be both caused by and aggravated by the heavy physical burdens of daily work.

Keywords Ethiopia · Experience · Low-income setting · Pelvic organ prolapse

✉ Janne Lillelid Gjerde
Janne.Gjerde@uib.no

¹ Department of Global Public Health and Primary Care, University of Bergen, P.O. Box 7804, 5020 Bergen, Norway

² Department of Obstetrics and Gynecology, Haukeland University Hospital, Bergen, Norway

³ Research Group for General Practice, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

⁴ Research Unit for General Practice, Uni Research Health, Bergen, Norway

⁵ Women and Health Alliance (WAHA) International/Gondar Fistula Center, Gondar University Hospital, Gondar, Ethiopia

⁶ Department of Obstetrics and Gynecology, School of Medicine, University of Gondar, Gondar, Ethiopia

⁷ Centre for International Health, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

Introduction

Existing knowledge on the prevalence, risk factors, and consequences of living with prolapse in low-income settings is scanty. The fertility rate is higher, and the access to obstetric care is far more restricted than in more affluent settings, factors that may have implications for the risk of pelvic floor disorders [1]. It has been argued that prolapse may be more common in resource-constrained settings owing to risks related to these established factors and to heavy physical burdens, and that the condition may affect daily life more severely than in high-income settings [2]. The few available publications on prolapse in low-income settings illustrate how the suffering related to conditions of prolapse severely affects the women's emotional well-being and the relationship with their husbands, not the least because of the inability to perform chores

expected of them [3–6]. Depressive symptoms among women with prolapse have also been reported from northwest Ethiopia [7].

The current study was conducted in the Amhara region of northwest Ethiopia, where the median female age at first marriage is 15.1 years [8]. The major ethnic group in the area is the Amhara, who practice Ethiopian Orthodox Christianity and speak Amharic as their first language [9]. Skilled personnel attend only 10 % of all births in rural areas; the fertility rate is 4.1 children per woman [10], and the maternal mortality ratio is 497 deaths per 100,000 live births in Ethiopia [11]. Health facilities in the rural areas are poorly equipped, with inadequate emergency obstetric services [12]. Additionally, only 40 % of the women in the region are literate [10].

With these indicators, Ethiopia is a low-income setting that may be well suited to the study of women's experiences and the management of prolapse. The present study aimed to explore how women living with prolapse in northwest Ethiopia explain, experience, and handle the potential practical and social implications of prolapse.

Materials and methods

The first part of the study, carried out in 2011, included 8 women with prolapse, 6 of whom were recruited from the sample of women identified with prolapse through the Dabat Incontinence and Prolapse (DABINCOP) pilot study [13, 14]. The second part of recruitment took place in 2015 at Gondar University Hospital, where all 16 informants were admitted and underwent surgical treatment for their condition. The informants were invited to participate in the study based on their home district, age, and length of time suffering from the prolapse, aiming to obtain a wide variety of experiences and the possibility of following them up at a later stage.

Both sessions of fieldwork were carried out by the first author. The design during both study periods employed a qualitative explorative approach with in-depth interview as the main data collection approach. Semi-structured interview guides with open-ended questions mainly concerning experiences of the potential practical or social consequences of living with prolapse were employed during the data collection. Both research assistants were from the area and were familiar with language, culture, and respectful conduct in the area. All the interviews were conducted in Amharic with continuous translation to English. The interviews lasted 1–2 h and were aimed at letting the informant speak freely and without interruptions. The six interviews carried out in the community took place in the informants' homes and outside the health centre or health post located in their village. The remaining informants were all interviewed in a private room at the hospital ward where they were admitted. A

digital recorder was used to record the interviews, and all interviews were transcribed verbatim, with continuous checks by the research assistants to ensure that the content was correctly captured and culturally specific expressions retained. The interviews were transcribed in Amharic, followed by translation into English.

The analysis process was based on the principles of systematic text condensation [15]. The analysis took place throughout the data collection phase and during a rigorous analysis phase after completion of the fieldwork. The data material from 2011 was organized and coded manually, whereas the data material from 2015 was organized and coded by the use of NVIVO, a qualitative data analysis computer software package.

Ethical approval for both study periods was obtained from the Regional Ethics Review Board in Western Norway and from the Institutional Ethical Review Board at the University of Gondar, Ethiopia. The aim and purpose of the study, and the contents of the consent form, were read aloud to all informants before the interview. Written or oral consent to participate was obtained depending on literacy status. Three women who were asked to participate declined shortly after being approached. None of the participants withdrew their consent.

Results

A total of 24 women with symptomatic prolapse, ranging from stage II to IV, were included in the study. All of the informants were from the Amhara region and nearly all were Orthodox Christians. The median age of the informants was 40.25 years (range 24–65). 18 informants were married, whereas the remaining 6 included two widows and four divorcées. The mean age at first marriage and first delivery was 13 years (range 7–30) and 19.2 years (range 13–32) respectively. The majority (22) of the informants were multiparous, with the mean number of deliveries being 4.4. Furthermore, 20 of the informants had delivered all of their children at home. Twenty of the 24 informants had never gone to school and were illiterate, and 21 were unemployed and mainly carrying out housework and helping out with farming activities. The 24 women with prolapse had stage II (2 informants), III (20 informants) or IV (2 informants) according to the simplified pelvic organ prolapse quantification staging system (S-POP) [14, 16]. Approximately half of the women had had prolapse for the last 10 years or more, including 7 who had lived with the condition for more than 20 years. Eleven of the women reported difficulties urinating because of the prolapse, whereas five suffered from urinary incontinence, ranging from mild to severe leakage.

Conceptualizing the condition

Most of the informants argued that physical strain on their body, such as childbirth, labor or food scarcity, had caused the prolapse. One informant stated: “Most of the time it happens due to delivery, because most of us didn’t go to a health facility for delivery. We deliver at home where we go through labor for two to three days. When we finally give birth it’s so hard that the uterus will ‘go out’” (39 years, prolapse stage II). Also, early age and multiple pregnancies were mentioned as causes. Others related the prolapse to their heavy workloads: “I am busy working and carrying heavy goods. Due to this my uterus comes out” (47 years, prolapse stage IV). “Our area is mountainous, and I used to help him [husband] dig while he was holding the ox ploughing. I realize that I have been exposed to this heavy workload, and I keep thinking that if I had refrained from working that much, I could have been fine” (40 years, prolapse stage III). Some, moreover, mentioned the lack of appropriate nutrition as putting the body under continuous strain, causing the prolapse: “It is because of scarcity of food. Like many other mothers I don’t get proper food” (39 years, prolapse stage III). A few informants blamed their condition on God’s will or linked it to the agency of the spirits. One informant said: “I considered it as God’s anger. What else shall I think?” (50 years, prolapse stage III). Another explained her experiences of “bad eyes”: “People’s eyes can make you disabled or can make you die. My sister-in-law...Her eyes are bad...It is because of her that I’m sick” (33 years, prolapse stage III).

Challenges of daily life

In particular, the married women in the study were responsible for all household chores, including childcare and cooking, and the fetching of water and firewood. Fetching water often involves walking several hours a day holding 20–30 L of water on one’s back. This is considered women’s work, and is an integral part of everyday life for women and girls in this area. Married women typically also help their husband in farming activities until the children are old enough to help out. Almost all of the informants emphasized the constant burden of work and the challenges this caused owing to their condition. “I do weeding, grinding, harvesting, the fetching of water and collection of firewood. A woman doesn’t get rest” (45 years, prolapse stage III). Another woman explained: “My uterus comes out while I am working or when I am walking. We don’t even get rest during pregnancy or right after delivery” (39 years, prolapse stage III). While working, the prolapse was often experienced as very uncomfortable, and sometimes painful, as expressed by a large number of informants: “It is especially severe when I walk for long. I do manage to control the problem, although with pain” (40 years, prolapse stage III). “When I walk, it [the prolapse] rubs against my thighs

and the skin peels off” (65 years, prolapse stage III). For a few of the women the challenge was experienced as worst in relation to urination: “Whenever the uterus comes out and I go to urinate, it [the urination] is blocked. This year was terrible; it [the prolapse] blocked me; pressed me from inside. It was like giving birth” (33 years, prolapse stage III). Some of the women talked about how they no longer were able to fulfill the social role expected of a wife: “I used to invite people to come to our home on St. Mary’s day, but then I stopped because I was unable to grind, to serve food and to host guests” (42 years, prolapse stage III).

Sexual implications

Many of the married informants continued being sexually active as long as they managed, although commonly with pain: “I used to push my uterus inside and do the intercourse. Even though I feel sick, what can I do? It is marriage” (33 years, prolapse stage III). At times however, the prolapse prevented women from having sexual intercourse: “When my uterus is out, I usually sleep alone. When I’m in that situation I tell him that I’m ‘on period’ or that I’m sick” (35 years, prolapse stage III). Other women had not been able to have sex for years: “When it [the prolapse] started to become sore I refused him. It has been five or six years since I started to forbid him to have sex with me. He didn’t say anything; he started looking for another woman” (45 years, prolapse stage III). Another informant got support from her husband: “When I told him I have been suffering a lot because of it [the prolapse] he didn’t push me to have sex with him anymore. He understood the problem, and we stayed one year without intercourse” (33 years, prolapse stage III). All four divorcées explained that they got divorced due to their prolapsed condition. One of them explained: “Sometimes when we were about to have sex he saw that my uterus was out and we had to stop. When that happened repeatedly he started to feel discomfort. He then gathered my family and relatives and gave me money. We got separated without having any conflict or discussion” (39 years, prolapse stage II).

Managing the condition

Despite the challenges, all the women interviewed strove to continue with their lives and not the least with their daily chores: “Since I have a husband and children I have to work, so I grind and I prepare the meals even if I feel the pain” (42 years, prolapse stage III). “Even though I don’t work as I used to, I still work as much as I can” (50 years, prolapse grade III). Several practical strategies for managing their condition were employed. One woman explained: “When I walk I feel like something is pushing me down and I get a cramp at my waist. When that happens I sit down and take a rest until the prolapse goes back inside. Then I can continue walking.

This is how I live” (45 years, prolapse stage III). Another woman explained: “Whenever I can, I try to work while sitting down” (40 years, prolapse stage III). However, this was not the best solution for all: “It is difficult to sit so I usually sit on folded clothes” (42 years, prolapse stage III). Yet another woman explained how she handled difficulties urinating: “Since it [the prolapse] blocks my urine, I push it in with my hand in order to urinate” (33 years, prolapse stage III). For some, however, pushing the prolapse back didn’t help for long, and at times, not at all. A woman with the most severe stage of prolapse explained: “I moisten it with oil. When I use the oil, it becomes soft and I can sit, and it will draw back a little. After that I can walk again, but it is still difficult to make long walks” (47 years, prolapse stage IV). Other practical strategies included delegating work-related chores to children, or at times finding excuses for not doing particular chores.

Difficulties of disclosure

Disclosing the condition was experienced as challenging for nearly all of the women. Suffering from prolapse was regarded as extremely shameful, and disclosing the condition was believed to potentially have severe implications. One informant at the hospital, after having discussed the issue among other women with prolapse explained: “In my home town everyone is equal and healthy. Talking about our problems will make people ignore us. So we are scared to be open about our health problems” (45 years, prolapse stage III). Most had kept it to themselves for years before deciding to disclose: “I used to think that it was disgusting to talk about and that no one else in my hometown had a similar problem” (65 years, prolapse stage III). A few informants had in fact never disclosed their condition to anyone close to them: “I asked myself what the use was of telling other people if there is no solution. I was scared and wondered what was happening to me. Since I didn’t know what it was I just kept quiet” (40 years, prolapse stage III). Most feared the social consequences: “If they hear about it they would discriminate me and talk about me behind my back” (40 years, prolapse stage III). Despite this fear of discrimination or rejection from people close to them, more than half had chosen to disclose to trusted family members, such as sisters, mothers or a child: “I have told only my mother and sister. They sympathized with me when I told them” (40 years, prolapse stage III). “My daughter insisted that I tell her about my problem. I told her that it was no use telling her because there is nothing we can do anyway. She told me that at least she could share my worry and pain” (47 years, prolapse stage IV). Some informants had told a friend or a neighbor: “My neighbor told me a year ago that she has prolapse, so then I decided to tell her that I have the same condition. Both of us were thinking that we were the only ones having this problem. Then we openly talked about our secret which we had kept for

so long. We felt so sorry for one another” (40 years, prolapse stage III).

Of the 18 married women, more than half had disclosed to their husbands. Most of those chose to do so at a point when the condition had become serious and very difficult to hide: “I told him recently when it got worse. I told him that I was caught by a disease that people don’t know about. He got angry and asked me why I had hidden it for such a long time and didn’t tell him before” (35 years, prolapse stage III). However, there were women who regarded it as unthinkable to disclose to their husbands. One explained: “My husband is not concerned about my health. I know of many women who were victims of gossip, and I know some who were chased away from their home due to this kind of problem. I am very concerned that one day he might know or suspect that I have this problem” (39 years, prolapse stage III). One of the divorcees explained her previous husband’s reaction when disclosing to him: “He insulted me. He said I was less than a person” (40 years, prolapse stage III).

Discussion

Most of the women explained that their prolapse was linked to delivery. Additionally, the informants indicated that demanding chores were carried out during pregnancy and shortly after delivery, causing undue strain on their bodies. In a study from rural Nepal, women similarly reported that they believed that childbirth, lack of rest during the postnatal period, and heavy lifting when carrying out daily house chores were the main reasons for their prolapse [4]. Findings from research in India similarly revealed that hard work soon after delivery was common, and was an important factor associated with uterine prolapse among the informants [5]. While childbirth is a well-known risk factor for prolapse [17, 18], little is documented regarding hard physical labor as a risk factor from studies in high-income settings, most likely because physically demanding labor simply is less common in these settings. In the DABINCOP pilot study carried out in the current research area it was found that carrying heavy objects for 5 h or more daily was associated with anatomical prolapse [14]. The highly demanding physical labor that women perform in many resource-constrained settings suggests work load as a factor of particular relevance to be explored in population-based studies in similar contexts.

Despite the severe difficulties and pain experienced when carrying out expected chores, the women in the study strove to manage the tasks while simultaneously working hard to hide their condition. Although all the study participants feared the consequences of a general disclosure of their condition, and some had very negative experiences following disclosure, most of the women who had disclosed encountered great support, commonly from a mother or sister, but at times also from

the husband. Study findings from research in Uganda report that half of the women with prolapse did not receive any support from their husbands, and several got divorced as a result of the disclosure [3]. Similarly, in a study from Nepal, some women with prolapse experienced humiliation and harassment both from their husbands and from other family members [4]. In rural Ethiopia, women's power to make decisions is known to be hampered by illiteracy and early marriage [8]. The immense shame and perceived stigma connected with prolapse and with other pelvic floor disorders in this area [7, 13, 14] is likely to be at least partly related to the lack of health education available to women in rural and suburban areas. This makes the symptoms of prolapse unfamiliar, and in turn nourishes the dynamics of secrecy. The DABINCOP pilot study suspected underreporting by the informants owing to substantial discrepancy between the reported and the clinically observed prolapse [14]. This is likely to be at least partly related to the perceived shame and stigma leading to secrecy among women with prolapse.

Kleinman [19] reveals how pain and suffering are rarely limited to individual sufferers, and commonly extend to one's family and to the broader social network. In the case of prolapse, the present study suggests that the entire family might be affected if a woman is unable to provide the household with water, firewood or food; children may miss school if they have to take on their mothers' work; and it would affect the children severely if their mothers were expelled from the household. This scenario indicates that a potential health information program for prolapse may need to involve not only the women themselves. Husbands, as the prime decision-makers, commonly have substantial influence over how women in practice can handle the condition. Such concerns, however, need to be carefully balanced against the potential implications of disclosure for the particular woman.

Living in a setting with high illiteracy rates—where women have little knowledge about common maternal morbidities and have limited decision-making power, where household chores include heavy manual labor, and where health system resources to meet even minor health challenge are severely limited—living with a prolapse has very severe implications. In addition to the need for further research on the prevalence and risk factors of prolapse in resource-constrained settings, there is also need for increased knowledge on what would enable women to reach the public health care system for treatment of the prolapse. Such knowledge may importantly inform the development of effective future interventions for this prevalent and readily treatable maternal health challenge in Ethiopia and in other severely resource-constrained settings.

An important limitation of the present study is the extreme taboo this topic represents in this study setting. Owing to the shyness of many of the informants, we may have lost some of the depth of the illness narration. Despite several longer research-based stays in Ethiopia, the first author has

limitations in terms of socio-cultural and language competence. As commonly pointed out, there is, however, also a possibility that the informants may have been more open about their condition than they would have been in encounters with local researchers, as a stranger is presumably not familiar with the culturally embedded taboos and stigma surrounding such conditions.

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Compliance with ethical standards

Conflicts of interest None.

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Appendix III

III

RESEARCH ARTICLE

Open Access



Life after pelvic organ prolapse surgery: a qualitative study in Amhara region, Ethiopia

Janne L. Gjerde^{1,2,7*} , Guri Rortveit^{3,4}, Mulat Adefris⁵, Tadesse Belayneh⁶ and Astrid Blystad¹

Abstract

Background: Women living in resource constrained settings often have limited knowledge of and access to surgical treatment for pelvic organ prolapse. Additionally, little is known about experiences during recovery periods or about the reintegration process for women who do gain access to medical services, including surgery. This study aimed to explore women's experiences related to recovery and reintegration after free surgical treatment for pelvic organ prolapse in a resource-constrained setting.

Methods: The study had a qualitative design and used in-depth interviews in the data collection with a purposive sample of 25 participants, including 12 women with pelvic organ prolapse. Recruitment took place at the University of Gondar Hospital, Ethiopia, where women with pelvic organ prolapse had been admitted for free surgical treatment. In-depth interviews were carried out with women at the hospital prior to surgery and in their homes 5–9 months following surgery. Interviews were also conducted with health-care providers (8), representatives from relevant organizations (3), and health authorities (2). The fieldwork was carried out in close collaboration with a local female interpreter.

Results: The majority of the women experienced a transformation after prolapse surgery. They went from a life dominated by fear of disclosure, discrimination, and divorce due to what was perceived as a shameful and strongly prohibitive condition both physically and socially, to a life of gradually regained physical health and reintegration into a social life. The strong mobilization of family-networks for most of the women facilitated work-related help and social support during the immediate post-surgery period as well as on a long-term basis. The women with less extensive social networks expressed greater challenges, and some struggled to meet their basic needs. All the women openly disclosed their health condition after surgery, and several actively engaged in creating awareness about the condition.

Conclusions: Free surgical treatment substantially improved the health and social life for most of the study participants. The impact of the surgery extended to the communities in which the women lived through increased openness and awareness and thus had the potential to ensure increased disclosure among other women who suffer from this treatable condition.

Keywords: Ethiopia, Experience, Pelvic organ prolapse, Recovery, Reintegration, Surgery

* Correspondence: Janne.Gjerde@uib.no

¹Research group for Global Health Anthropology, Centre for International Health, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

²Department of Obstetrics and Gynecology, Haukeland University Hospital, Bergen, Norway

Full list of author information is available at the end of the article



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Background

Symptomatic pelvic organ prolapse (hereafter 'prolapse') occurs in 6–7% of women in the United States, [1, 2] with a 12% lifetime risk of undergoing surgical treatment [3]. Pregnancy and childbirth are important risk factors for prolapse, [2, 4] and the risk increases with the number of vaginal deliveries [5]. Prolapse may be more common and may more severely affect daily living in resource-constrained settings due to high fertility rates, early-age deliveries, limited access to obstetric care, and the rigors of manual work [6, 7]; however, information from such settings on prevalence and risk factors remains limited. The few studies on prolapse available from low- and middle-income countries have reported prevalence rates ranging from 3 to 56% and include research on prolapse symptoms and prolapse verified by pelvic examination [7–9]. In Ethiopia, a population-based pilot study conducted in the same research area as this study reported a 55% prevalence of stages II–IV prolapse among participants who had undergone pelvic examinations using the simplified Pelvic Organ Prolapse Quantification (POPQ) staging system [6, 10]. Other studies from Ethiopia have suggested an association between prolapse stage and age, and parity and occupation [11] as well as between prolapse and underweight conditions, lack of formal education, and childbirth without health professionals [12].

Independent of place of residence, prolapse has been reported to negatively affect the quality of life including sexual function and body image [13–15]. Findings from rural parts of Ethiopia and other resource-constrained settings suggest the severity of the social consequences of prolapse, including the possibility of divorce and discrimination [16–20]. Like urinary incontinence and obstetric fistula, prolapse is commonly considered by rural Ethiopian women as a sensitive topic as well as a shameful and repulsive condition [16, 21, 22]. Recent publications from the United States and Australia offer strong evidence of quality of life improvements following vaginal surgery for prolapse, including improved sexual function and body image [23–26]. However, there is an ongoing and comprehensive debate among medical experts worldwide as to which type of surgical method gives the most desirable long-term outcome [26, 27].

Little is known about how women in resource-constrained settings experience the recovery period following prolapse surgery. Moreover, there is limited knowledge about women's processes of reintegration into their communities after the surgery. Studies on obstetric fistula in Ethiopia and Kenya suggest that surgical repair only represents the starting point for affected women who wish to seek social reintegration [22, 28]. The current study aimed to explore women's experiences related to recovery and reintegration following the provision of free surgical treatment for prolapse in a rural Ethiopian setting.

Methods

Study setting

The current study took place in the Amhara region of north-western Ethiopia. Roughly 20% of births among rural women in Ethiopia are attended by skilled personnel or occur at health facilities. The nation's fertility rate is 4.6 children per woman, and the maternal-mortality ratio is 412 deaths per 100,000 live births [29]. Rural Ethiopian health facilities are in general poorly equipped and lack adequate emergency obstetric services [30]. The Amhara people, who primarily practice Orthodox Christianity and speak Amharic as their first language, are the majority ethnic group in the region [31]. The median female age upon first marriage in the Amhara region is 16.2 years, and around 55% of the women are illiterate [29].

The present study, which was conducted in 2015–16, featured repeated visits to the field. The three-months-long first part of the fieldwork was conducted at the University of Gondar Hospital (henceforth 'the hospital'), a referral teaching hospital located in the city of Gondar. The second part of the study, which lasted 4 months, took place in semi-urban and rural parts of the districts of Dabat and Debark, located 78 and 106 km north of Gondar, respectively. Free surgical treatment was introduced at the hospital at the time of the fieldwork and was offered to women with prolapse. It was initiated and funded by the hospital and UNFPA in collaboration with two non-governmental organizations (NGOs). The women were informed about prolapse and the possibility of free treatment from health-extension workers (HEWs) in the communities. Those who were found eligible for surgical treatment were selected at the district level and sent to the hospital in small groups.

Participant recruitment and data collection

The study had a qualitative, explorative approach and included 25 participants (Table 1). The first part of the fieldwork was conducted at the hospital where women with prolapse were admitted for surgery. Women who had undergone prolapse surgery were interviewed and recruited for follow-up visits in their homes after expected recovery. The criteria for follow-up included prolapse surgery and the accessibility of the women's homes. The first author carried out participant observations at the hospital, which were primarily conducted in connection with another sub-study focusing on health-seeking behaviours in the same patient group. The author's presence at the ward also facilitated the recruitment of informants for the present sub-study and secured access to the informants' medical histories. Health-care providers and a representative from one of the organizations involved in the newly introduced free prolapse-treatment initiative were also interviewed at the hospital.

Table 1 Study participants according to recruitment place

Hospital	Number	Community	Number
Women admitted for surgical treatment of prolapse ^a	8	Follow-up of women having undergone surgical treatment at hospital	8
Health care providers	2	Women who had undergone surgical treatment at the same facility and time period	4
Representative from organization affiliated with the hospital	1	Health extension workers working at community level	4
		Health care providers working at health centre level	2
		Representatives from international NGO	2
		Representatives from the health authorities at district level	2
Total interviews	11		22

^aThese women were primarily taking part in a sub-study that focused on the experience of living with prolapse [16], and were recruited for a follow-up visit in their homes

The second part of the study took place in the women's communities and included home visits 5–9 months after their surgeries. HEWs who were involved in community mobilization activities in connection with prolapse surgery were interviewed. They were engaged in the identification of potential prolapse cases and referred women with suspected prolapse to the district level. Health-care workers at the health-centre level, as well as representatives from an international NGO and representatives from the health authorities at the district level, all of whom were involved in the newly introduced free prolapse-treatment initiative, were also interviewed to provide contextual information for the study.

All interviews were performed in close collaboration with a local female interpreter who was familiar with the language, culture, and respectful conduct in the area. The interviews were conducted in Amharic with continuous translation from English to Amharic and vice versa between the researcher and the informants. Semi-structured interview guides with open-ended questions were used (see Additional file 1). The interviews, which were held either inside or outside the women's homes, lasted from 1 to 2 h with the aim of allowing the informants to speak freely and with few interruptions. All the interviews at the hospital were held in a private room on the ward while the interviews with the health-care providers and stakeholders in the communities were held in a private room at their work facilities.

Analysis

The analysis took place throughout the data-collection process and during a rigorous analytical phase that followed the completion of the fieldwork. All interviews were audio-recorded, transcribed verbatim to Amharic and translated into English. The completed material was carefully reviewed to identify core themes [32]. The subsequent post-fieldwork analysis concretized the initially identified themes into categories of meaningful units followed by coding of the material line-by-line [33]. Each

sub-category identified during the first phase was scrutinized for central patterns and 'case-stories' as well as for potential nuances, and ambivalence and contradictions. The full data set was then imported into NVivo 11, a qualitative data-analysis software tool that was employed to organize the material.

Ethical considerations

Ethical approvals were obtained from the Regional Ethics Review Board in Norway and the University of Gondar in Ethiopia. With the assistance of the interpreter, all patients on the ward were provided with information about the study, the role of the first author's participant observation, and their rights not to participate or be observed. The aim and purpose of the study, as well as the contents of the consent form, were explained to the research participants prior to all interviews. Written or oral consent to participate was obtained, depending on literacy status, and the utmost care was taken to secure privacy and confidentiality during the research process. Two patients at the hospital declined to participate, and two women were lost to follow-up with the research team due to distance or lack of accessible roads to their homes.

Results

The main category of informants consisted of 12 women (Table 2), all of whom had undergone surgical treatment for prolapse. Upon admission, 11 of the 12 women were diagnosed with stage III prolapse of the uterus, bladder and/or rectum according to the simplified POPQ staging system [10]. The majority had undergone a vaginal hysterectomy and sacrospinous fixation and/or an anterior or posterior colporrhaphy under spinal anaesthesia. None received oestrogen therapy prior to or after the surgery. All women, except for one, returned to the hospital for their follow-up appointments scheduled by the hospital staff to take place 1–3 months after surgery. Two women got confirmed vault prolapse during their

Table 2 Characteristics of main participants

Mean age	43.3 years [range 32–60]
Marital status	
Married	8
Divorced	3
Widowed	1
Mean age at first marriage	13 years [range 7–19]
Education	
No school / illiterate	10
Literate	2
Occupation	
Housework	6
Housework and farming activities	5
Daily laborer	1
Mean number of children	3.6 children [range 0–8]
Mean age at first delivery	18.5 [range 13–24]
Place of delivery	
All deliveries at home	10
One or two deliveries at health facility	2

hospital appointment. During our follow-up interviews 5–9 months after the surgery, half of the women explained that they had a highly improved health condition with few or no complaints, whereas the other half still had some challenges. Some again felt that something was emerging from their vagina and others could not control their urination.

Recovery

Although only half the women had fully recovered 5–9 months after the surgery, nearly all expressed appreciation for their present situation:

I used to have to walk by holding the prolapse; I couldn't walk like I wanted to. I had a lot of problems. But I'm thankful after the surgery; it was a big change. I had suffered for six years. (32-year-old married woman)

Following surgery, the women were told to avoid heavy strains and lifting for their lifetime and to avoid sexual intercourse for up to 3 months. The women in this region of Ethiopia normally have full responsibility for household chores, including the procuring of water and firewood and occasionally taking part in farming activities. Collecting water for many of the women involved daily multi-hour walks carrying 20–30 l on their backs. The avoidance of chores after the surgery, hence, depended on receiving substantial support from their neighbours, family members, and more distant relatives. The customary support systems related to illness and births were mobilized in these cases; indeed, all the

informants explained that they had received substantial support when they returned from the hospital:

Until my [hospital follow-up] appointment was approaching, I lay on my bed while my neighbours fed my family and me and took turns doing my chores. (52-year-old married woman).

After a month or more of rest, the external support system slowly decreased as relatives and neighbours returned to their own homes. The condition nonetheless required continuous support to avoid having the woman return to heavy chores. The assistance was commonly provided by immediate family members:

I don't work at home much anymore. My daughter is cleaning the house, inside and outside. I used to help with the farming, but now I've stopped doing that too. My husband manages by himself. (40-year-old married woman).

Many of the women expressed fear of returning to their previous heavy chores:

I feel I am cured now. But I don't doubt that if I start doing heavy work again I would feel sick. Now I fear to do heavy work. (32-year-old married woman).

Divorced and widowed women largely lived by themselves and depended on their children or on extended family members to decrease their work burdens after the initial healing period. These women who were socially vulnerable found it more challenging to cope, not the least in cases of delayed healing:

I used to work as a labourer preparing food for people. I don't feel good enough yet to start work. I can't even walk long distances or lift anything, and I don't have anyone to help me. I ask neighbourhood children to fetch water for me. I no longer have any money saved, and I feel that darkness has surrounded me. I had to send my two young children to work in other people's houses. If I sit like this, how can I feed myself? I'm still waiting to recover, and then I'll start working again. (39-year-old divorced woman).

Although many of the women interviewed referred to stories of other women who had been unable to abstain from sex upon their return home to their husbands, the women interviewed in the present study seemed to have husbands who accepted their conditions:

We haven't had sex for five months now, and he hasn't forced me. He hasn't asked me during this time—he

can see the pain I've been in. (35-year-old married woman).

The HEW's overall impression was that the women made strong attempts to follow the advice they were given by the hospital after the surgery, but they also mentioned cases where the woman had no choice but to work due to lack of available support.

Disclosure

Most of the women had disclosed their conditions to very few confidantes prior to their surgery. Typically, they shared with their mother, sister or close friend in addition to the HEW. All the married women disclosed their conditions to their husbands, but the majority did so at a late date and only after the condition had worsened. Before disclosing, some had considered divorce to escape the shame they experienced. Although many of the husbands were said to be supportive, they commonly had a limited ability to assist their wives. The divorced women had chosen to leave their husbands because of the prolapse, either due to being ignored and disrespected or because they were unable to fulfil their expected roles as wives due to their condition.

The period when the informants were brought together with their fellow prolapse sufferers in connection with the hospitalization process proved to be vital for disclosure. During the time they spent together, they established close ties:

Once we travelled together to the hospital, we didn't talk about anything but our conditions for five days. We didn't know each other, but we still talked a lot. We laughed and discussed like mothers and daughters do. We all shared our experiences with the prolapse. (35-year-old married woman).

Once the women had returned from the hospital, many faced questions about the treatment they had received, and the majority decided to be open about what they had experienced:

After the treatment, people asked me where I'd been and what had happened to me. I told them all about my condition and the treatment I'd received. (39-year-old divorced woman).

The response from their neighbours and relatives was mainly positive; many expressed sympathy and wondered why they had kept the prolapse a secret for so long. All the women expressed great relief related to their newly gained experience of openness:

Why should I feel shame now? I've seen the light. I hid the condition for 20 years. But now that I've had the

treatment, I've escaped the pain. I feel relaxed now. (40-year-old married woman).

The HEW's also reported noticing a change in openness among women in the communities:

Women have become more open to talk to us about their problems. We usually speak about prolapse when we get a chance in the Church or at community meetings. Then women come directly to us and say: "I have this problem. I kept it to myself." (HEW 2).

Reintegration

Many of the women told of the extreme social restrictions caused by the prolapses, and explained how they had been unable to fulfil the social roles expected of them. When living with the prolapse condition, the crucial inviting and hosting of people for holidays had become increasingly challenging for many since food preparation often involved heavy lifting, including the procurement of extra water for the occasion. Walking longer distances to attend social gatherings, such as funerals or events with far-off relatives, had also become problematic. One woman, who had found it difficult to sit among people because of the pain and itching of her ulcerated prolapse, and from her frequent need to urinate, explained the transformation she had experienced:

It used to be embarrassing to sit with people outside or inside others' homes. It was shameful for me to eat, drink and [suddenly] go outside to urinate. I stopped attending social gatherings because of that. That situation cannot be compared to the present. I urinate less frequently, and I can sit how I want to sit and talk with relatives without a problem. (35-year-old married woman).

Not all the women felt ready to fully engage in every social gathering at the time of the study.

I haven't started visiting relatives yet because the doctor told me not to go anywhere far for six months. I might start having long journeys and visit relatives soon, God willing. (45-year-old married woman).

Most, however, lived relatively close to other women they had been hospitalized with, and many of them stayed in touch:

One of these women is my neighbour. Now we drink coffee and fetch water together. Both of us trust each other. (40-year-old married woman) We all have a

wish to meet after the surgery, and we have planned to meet at every holiday. (39-year-old divorced woman).

Engagement

The increased openness among the women after their return home from the hospital had implications in their local communities. One woman explained that prolapse was now a common and unproblematic topic to discuss with friends. Indeed, this was reflected by the health-care workers:

If the new initiative goes on, women won't be hiding this condition anymore. It is a way to avoid women's discrimination. (Health-care provider, Health Clinic).

After returning from the hospital, several of the study participants were approached in secrecy by women in the community who asked for details about the condition and about the treatment they had received:

A lot of women out there haven't yet received treatment [for prolapse]; they hide their condition and pain. One woman from my village came to my home—she had been too ashamed to tell anybody about her condition. I asked her why she felt ashamed. We don't have to hide this condition these days. After our conversation, she talked to the health-extension worker and was sent to the hospital for surgery. She later became a very dear friend. (32-year-old married woman).

As a part of the new prolapse initiative, the selected women who had been treated were now trained as maternal-health advocates. In addition to spreading information about maternal-health matters in their communities, the advocates were trained to seek out and register women who suffered from prolapse:

When mothers return home after being treated, we train them, and the health bureau also gives them a checklist. They mainly work alongside the community health workers (HEWs), and we encourage them to participate in different activities of the project. We also have a radio channel which facilitates the mobilization process. (NGO representative).

The women who had yet to receive training were also eager to spread information about prolapse and to encourage others to get treated:

When I go to fetch water, I inform women [about prolapse]. I also tell their husbands to take their wives to the hospital if they are sick. I explain how I got

better. I advise them to seek medical care because the government supports us now. Many women hide their problems, and that's bad for their well-being. I suffered a lot because I concealed my problem. (40-year-old divorced woman).

Discussion

Main findings

The opportunity for treatment proved to have substantial implications for the rural Amhara women who were followed up in the present study. The majority received substantial practical support during the recovery period and experienced understanding after disclosing their condition. For many of the women, the disclosure and awareness related to prolapse became an important activity to ensure that other women who were suffering alone would learn about prolapse and the available free treatment. The increased disclosure led to a surprising degree of openness and awareness about the condition in the communities in which the study took place. Not all the women, however, experienced improvements in their lives, especially the ones who lived alone and had a problematic healing process. For these women, life continued to be a struggle.

Interpretation of results

The key issues raised by the women in the study were that the surgery alleviated them of the most pressing concerns of discrimination, rejection, and divorce [16]. The sharing of experiences and the relationships that developed among the women who were recruited for treatment proved to be important for the women's increasing sense of knowledge about the condition and sense of empowerment as well as the subsequent openness and disclosure of the condition. The current study thus indicates the immense transformation that can be facilitated when groups of women are recruited jointly for surgery and go through a joint learning process. These factors speak to the importance of the surgery beyond the physical repair itself; the regaining of a social life lies at the core of the stories these women tell. The emphasis of the social dimensions has similarities with experiences from other health initiatives, for example within the field of HIV/AIDS, where beyond the antiretroviral therapy, the training, employment, and empowerment of local mothers who live with HIV have led to reduced HIV-related stigma and discrimination [34].

In a study of women who were treated for obstetric fistula in Kenya [28], finding a sense of belonging after their treatment and reintegration into the community following surgery depended on their available support mechanisms. Although many of the prolapse sufferers in the present study experienced extensive support after

surgery, the available help still proved insufficient for some due to limited social networks. Among tuberculosis patients being treated in Ethiopia [35], the support from family and community members similarly proved crucial although many patients found that the level of support dropped during the course of treatment. Thus, it proved difficult for them to cope, especially the ones with limited human or material resources.

In line with scholars within critical medical anthropology [36–38], we argue that poverty and marginalization increase the likelihood of illness and suffering, such as when life conditions seen as insignificant hamper the potential for receiving adequate care for serious conditions of prolapse. Taking into account the high fertility rates, early-age pregnancies, and strenuous physical work demanded of women in the study area, our study findings strongly support the argument that prolapse may affect daily life more severely in resource-constrained settings than in more affluent settings [6, 7]. Dynamics of poverty and marginalization in diverse ways reduces the opportunity to receive treatment. The dynamics linked to early marriage and limited schooling among rural Ethiopian women also limits the exchange of knowledge, thus laying the grounds for stigma and discrimination [16, 39]. The majority of the women in this study would not have reached the hospital without being exposed to the mobilization initiative that took place in their communities, providing them with free transport and treatment. Such initiatives are rare in Ethiopia, and they require a long-term sustainable commitment and funding to succeed.

Strengths and limitations

The topic of prolapse is perceived as extremely sensitive in the current study area, which may have affected the women's readiness to speak openly. Also, the first author's sociocultural and language limitations, despite several lengthy research stays in Ethiopia and increasing language competence, are likely to have affected the study's results. In this context, we would also like to mention that being an outsider can at times be advantageous as one is perceived to be located beyond the locally embedded normative discourse. Moreover, these challenges were partially ameliorated through the follow-up visits to the women at home and the newly gained openness about the condition in the study area. The women also expressed appreciation for the follow-up interviews in their homes after the surgery.

Conclusions

The present study indicates that the provision of free prolapse treatment in rural Ethiopia has substantial potential in improving the health and social life among affected women. Recruiting women in groups facilitate awareness and empowerment processes that the present

study findings suggest may benefit entire communities. Still, supportive systems—not the least economic—may be required to counteract problematic consequences of the surgery, particularly for vulnerable women.

Further research should be conducted on the prevalence and risk factors for prolapse as well as on women's health-seeking behaviour related to prolapse in resource-constrained settings. Such knowledge is required to inform the development of sustainable interventions for prolapse and other prevalent, treatable, and chronic maternal-health challenges in Ethiopia and similar resource-constrained settings.

Additional file

Additional file 1: The interview guide used for follow-up interviews with women treated for pelvic organ prolapse. (DOCX 15 kb)

Abbreviations

HEW: Health-extension worker; NGO: Non-Governmental Organisation; POPQ: Pelvic organ prolapse quantification (staging system); UNFPA: United Nations Population Fund

Acknowledgements

We would like to express our heartfelt thanks to all the study informants, especially to the women with prolapse who, despite the sensitivity of the topic, decided to share their stories with us. We are sincerely appreciative of the staff at the Fistula Treatment and Training Centre at the University of Gondar Hospital for their hospitality and support throughout the fieldwork. We also owe our warmest thanks and gratitude to the research assistants in the field.

Funding

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Availability of data and materials

The data used and/or analysed during the current study may be requested from the corresponding author. However, only excerpts of particular interest may be shared as the complete data may identify informants.

Authors' contributions

JLG, GR, MA and AB developed the research protocol. JLG carried out the data collection, with support from all co-authors. Data analysis and interpretation of the data was conducted by JLG, with substantial contributions from all co-authors. Manuscript drafting was mainly carried out by JLG and AB, with substantial contributions from GR, MA and TB. All authors read approved the final version of the manuscript.

Ethics approval and consent to participate

Written or oral consent to participate was obtained by all participants in the study. When a participant was not able to write, oral consent was obtained as approved by the ethical committees both in Norway and Ethiopia.

Reference numbers for ethical approvals:

Regional Committees for Medical and Health Research Ethics in Norway, 25 August 2014: 2014/589. University of Gondar Institutional Review Board, 2 February 2015: R/C/S/N/P/05/315/2015.

Competing interests

The authors declare that they have no competing interests.

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Author details

¹Research group for Global Health Anthropology, Centre for International Health, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway. ²Department of Obstetrics and Gynecology, Haukeland University Hospital, Bergen, Norway. ³Research Group for General Practice, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway. ⁴Research Group for General Practice, Uni Research Health, Bergen, Norway. ⁵Department of Obstetrics and Gynecology, College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia. ⁶Department of Anaesthesiology, College of Medicine and Health Sciences, University of Gondar, Gondar, Ethiopia. ⁷Department of Global Public Health and Primary Care, University of Bergen, PO Box 7804, 5020 Bergen, Norway.

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Appendix IV

IV

Interview guides for women undergoing treatment for pelvic organ prolapse at the hospital

Demographic data:

Inform the informant that we would like to start with a few general short questions about her background:

- Age
- Ethnic group
- Religion
- Educational status (can she read and write?)
- Occupational status
- Marital status (at what age did she get married if so? first marriage?)
- If not married, does she live alone or with someone?
- Number of pregnancies (if any)
- Number of children (if any)
- Were any of the deliveries complicated?
- Age at delivery of first and last child
- Where did she deliver? (at home, hospital, while travelling to hospital etc.)
- Duration of prolapse

- 1) About the prolapse – can you tell us about your life-situation from when it started until you got here to the hospital?
 - How long you lived with the condition
 - How it affected your daily activities ; social relations etc
 - Most challenging situations (when working, at social gatherings, on long walks, in intimate situations, etc.)
 - Practical handling
 - Disclosure
- 2) What do you think caused your condition of prolapse?
- 3) Have you told anyone about your condition?
 - Potential probes:
 - o Who
 - o When (how long after problem started)
 - o Reactions (support or discrimination)
- 4) How does your condition affect the relationship with people around you?
 - Potential probes:
 - o Negative implications (embarrassment, comments, discrimination)
 - o Positive implications (support)
 - o Implications for intimacy with husband (protrusion, pain, etc.)
- 5) Have you sought help or advice for your condition anywhere before coming here?
 - Potential careful probes:
 - o Health post, health clinic, hospital, Holy water, Awaki bet, jebahel medianet awaki, other type of traditional healer, etc.
 - o Where? How far from home? Transport method?
 - o Did anyone join you there?
 - o When was it?

- Why there? (Advice from others, religious or spiritual belief, etc)
- 6) What kind of help or advice did you receive there?
- Potential careful probes:
 - Type of treatment (herbal remedies, holy water, prayer, advice on necessary sacrifice, medication, etc.)
- 7) How did you experience the help or advice that you got?
- Potential careful probes:
 - Did it improve your condition?
 - Did it worsen your condition?
 - Respect or harsh handling
 - Did you talk to anyone about the advice/treatment that you received?
 - Cost for advice/medication/treatment
- 8) Is there anything else you would like to share with us regarding your condition?

Interview guides for women recently treated for pelvic organ prolapse

- 1) Can you tell us about how your life-situation has been after the surgery?
 - Complications after surgery / physical complaints (urinary incontinence? Vault prolapse?)
 - Social implications (disclosure/openness, acceptance from others, husband, intimacy, etc.)
 - Possibility to relax after surgery + abstain from sexual relation?

- 2) Have you been back to hospital for your follow-up appointment?
 - If no: Potential challenges she had to overcome (support from husband, leaving the household and children behind, etc)
 - If yes: How did you manage to overcome potential challenges?

- 3) Can you tell us about your experience at the hospital?
 - How she experienced the surgery and treatment in general
 - Interacting with the staff
 - Interaction with other patients

- 4) Clarification or follow-up questions based on the informants first interview at the hospital

- 5) Is there anything else you would like to share with us regarding your condition?

Interview guide for hospital health staff concerning pelvic organ prolapse

Demographic data:

Inform the participant that we would like to start with a few general short questions about his/her background:

- Age
 - Profession
 - Length of stay in the particular ward
- 1) Can you please tell us about your experience with women being admitted for pelvic organ prolapse in this ward?
 - 2) How often do you experience that this group of patients get admitted?
 - 3) What do you typically offer as treatment or support for this patient group?
 - 4) How long do they typically stay at the hospital?
 - 5) Can you please tell us, based on your experience, what concerns this group of patients usually express related to their condition of prolapse?
 - 6) Do the women typically express what they think has caused their condition of prolapse?
 - 7) Do the women talk about or tell you that they have been elsewhere for treatment before reaching here? If so, where did they seek help?
 - 8) Is there anything else that you would like to share with us regarding prolapse patients?

Interview guide for health personnel in rural health centre

Demographic data:

Inform the informant that we would like to start with a few general short questions about her background:

- Age
- Gender
- Ethnic group
- Religion
- Occupation / work description
- Number of months/years in this position

- 1) Can you please tell us about your experience with women seeking help / advice for prolapse (and incontinence) at this health facility?

Potential probes:

- Frequency, magnitude, typical age groups, length of problem, severity of prolapse, etc.

- 2) What kind of care do you offer women with prolapse (and incontinence) at your health facility?

Potential probes:

- What advice or medical treatment is available here?
- Who gets referred to hospital?
- Costs for treatment, support given in certain cases?

- 3) What kind of collaboration / communication do you have with the health extension workers in the communities?

Potential probes:

- Referral of patients from health posts to health centre?
- Any ongoing preventive health work

- 4) Can you explain in which way are you involved in the ongoing campaigns that recently also includes women with prolapse for free treatment in Gondar?

Potential probes:

- How do the women reach the health clinic?
- How do you trace the women for their appointment if they don't come?
- How long do the women normally stay in Debarq waiting for their turn to go to Gondar? Where do they stay? Do some leave due to long wait?

- 5) Can you tell us about your experience and opinion about the campaigns?

Potential probes:

- Well organization?
- In your opinion, does it focus on an important health issue?

- Any feedback from people?
- 6) Have you experienced women coming here after having being treated in Gondar?
Potential probes:
- What kind of complaints did they have?
 - Did they say anything about hospital experience?
- 7) Where do you think women with prolapse normally seek help?
Potential probes:
- What type of treatment received?
 - Distance from home and transport method?
 - When? (in relation to when the problem started)
 - Why? (free choice, advice from others, pressure from others)
 - Disclosure? (do they tell anyone, do they have company)
- 8) What terms do women typically use to describe their condition of prolapse (and incontinence)?
Potential probes:
- Words for prolapse, urinary incontinence/leakage, protrusion, abdomen, uterus, vagina, etc.
- 9) Is there anything else you would like to share with us regarding prolapse (and incontinence) at your health facility or in Ethiopia in general?

Interview guide for health extension worker (HEW) in rural area

Demographic data:

Inform the informant that we would like to start with a few general short questions about her background:

- Age
- Gender
- Ethnic group
- Religion
- Work description
- Number of months/years in this position

1) Can you please tell us about your work related to women's health in general?

Potential probes:

- Focus of the work
- Preventive // curative work
- Collaboration with other actors?
- Reports to who?

2) Can you please tell us about your experience of women suffering of conditions of prolapse and incontinence in your village area?

- A common problem?
- Disclosure - do they typically share it with you?
- Shame // discrimination
- Have many women approached you?
- Do they most often approach you themselves, or through others?
- How do they explain their condition to you?

3) Can you please explain in which way you are involved in the ongoing campaigns that recently also started to include women with prolapse for free treatment in Gondar?

Potential probes:

- Description of role in this relation
- What information is given about prolapse?
- Where and how often is the information given?
- Are you the one informing women about prolapse?

4) Where do you think women with prolapse and incontinence normally seek help?

Potential probes:

- What type of treatment received?
- Distance from home and transport method?
- When? (in relation to when the problem started)
- Why? (free choice, advice from others, pressure from others)
- Disclosure? (do they tell anyone, do they have company)

5) Is there anything else you would like to share with us regarding prolapse and incontinence or other women health issues in your community?

Interview guide for local healers in the community

- 1) Can you please share with us your title and what you do in your work?
 - What kind of conditions/diseases do you typically treat?
 - What is the main use of healing method
- 2) Can you please tell us what experience you have with women seeking help for pelvic floor disorders such as prolapse and urinary/faecal incontinence?
 - Frequency
 - Severity of the conditions
 - Typical age groups
 - How the women typically describe their condition
- 3) Can you please tell us what kind of treatment you offer women with such problems?
- 4) Have the women typically been elsewhere searching for treatment before reaching you?
- 5) Based on your believe, what do you think cause women to suffer from such conditions of prolapse and incontinence?
- 6) Do you typically get to know wether the treatment that you offered was successful or not?
- 7) If it was not successful, what do you typically do?
 - Continue the treatment
 - Try another treatment
 - Refer to somewhere else. If so, to where?
- 8) How much does a patient usually have to pay for being treated by you?
- 9) Is there anything else you would like to add?

Interview guide for stakeholders in the districts

- 1) What is your position and work description?

- 2) Can you explain how your organization is involved in community mobilization of women's health, especially concerning conditions of prolapse and incontinence?

- 3) Recently women with prolapse have got free treatment at Gondar Hospital, can you explain what role you play in this process?

- 4) What is your opinion about women with prolapse being included for free treatment?

- 5) Can you tell us about your experience and role in the campaigns?
Potential probes:
 - Well organization?
 - In your opinion, does it focus on an important health issue?
 - Any feedback from people?

- 6) Can you tell us about your collaboration with other actors / stakeholders in this relation?
Potential probes:
 - With Health Centre, Health posts and health care workers
 - Government offices
 - NGO actors

Focus group discussions with women suffering of prolapse

Introduction: Information about the study and why they have been selected and informed consent. Oral consent is acceptable.

1. Topic to be discussed:

Causation of illness in your community

Key question:

How do people in your community typically explain the reason behind illness?

Probing: Do they e.g. think it is caused by Gods anger; spirits anger; evil eye, lack of food; overwork etc.

Follow up questions:

- Ask for explanation behind what comes up. E.g. how is God / spirits / evil eye/ lack of food / overwork etc. related to getting sick?
- What is typically believed to be the cause of women's disease, such as prolapse or incontinence?

2. Topic to be discussed:

Common practices in your community related to health seeking behavior

Key question:

Think back about your relatives, neighbors or friends in your community who in the recent years faced mild to severe illness. What did they do or where did they go to seek solution/treatment?

Probing: Did they go to e.g. health post, health clinic, hospital, holy water, awaki bet etc?
Did they e.g. beg the spirits at home or do certain rituals?

Follow up questions:

- Where do people tend to go first?
- Is there a difference in where women and men seek help?
- Is there a difference related to what illness people have to where they choose to seek help?
- Health institution (health post / clinic or hospital):
 - o What kind of illnesses makes people choose to go there?

- What are the typical reasons if people choose not to go there? (e.g. belief, type of sickness, financial means, harsh handling, disclosure, exposure, etc)

- Holy water:
 - What kind of illnesses makes people choose to go there?
 - Is it acceptable among people to combine holy water with treatment from the health clinic or hospital?
 - Do people tend to disclose their condition among each other or to the priest at the holy water site?

- Jebal hakim:
 - What kind of illnesses make people typically choose to seek help there?
 - Is it accepted among people in your community to seek help there?
 - What kind of treatment / relief is commonly given by the jebal hakim?

- Awaki bet:
 - Is it a certain belief that makes people choose to go there – can anyone please explain this belief?
 - Is it accepted among people in your community to seek help there?
 - What kind of illnesses makes people typically choose to seek help there?
 - What kind of treatment / relief / advice is commonly given by the awaki?
 - If someone goes to awaki bet, is it normally something one would tell to others? Why not?

Appendix V

V

To whom it may concern

Your ref

Our ref
2014/589

Date
25.08.2014

Confirmation;

I hereby confirm that the project “Experiences and health seeking behaviour among women living with pelvic floor disorders in low-income contexts: The case of Dabat, North-West Ethiopia.”, by project manager Janne Lillelid Gjerde, University of Bergen, is reviewed and approved by the Regional Committee for Medical and Health Research Ethics, Western-Norway.

Best regards



Øyvind Straume
Committee secretary



Rfe. R/C/SN/P/05/ 315 /2015

Date: February, 02, 2015.

To **Ms. Janne Lillelid**
University of Gondar

Subject: - Ethical Clearance

Your research project proposal titled “**Experience and health seeking behavior among women living with pelvic floor disorders in low-income contest: North-West Ethiopia.**” has been reviewed by the Institutional Ethical Review Board of University of Gondar for its Ethical soundness, and it is found to be ethically acceptable.

Thus, the Research and Community Service Vice President Office has awarded this Ethical Clearance for the above stated study to be carried out by **Ms. Janne Lillelid** as Principal Investigator and **Dr. Mulat Adefres, Prof. Astrid Blystad, Prof. Guri Rortveit, Dr. Mulu Muleta** as Co-investigator as of January 30, 2015.

These investigators are expected to submit their research progress report to the Vice President for Research and Community Service Office of the University of Gondar.

Best Regards

Dr. Tadesse Guadu Delele

**Delegate, Vice President for
Research & Community Service**



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P.O. Box 196
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Gondar, Ethiopia

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Cable A.A.U. PH.
Fax - 251-058-114 1240
058 114 1233
058 114 123 Research & Community Service Core Process
URL Address:- WWW.ugondar.edu.et

Telephone PBX
President office
V/P/for A/ & Research

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Appendix VI

VI

Request for participation in the following research project:

“Experiences and health seeking behaviour among women living with pelvic floor disorders in low-income contexts: The case of Dabat, North-west Ethiopia”

The following information to be read aloud to the potential informant:

Background and purpose of the study

This is a request for you to participate in a research study that intends to explore different aspects of living with pelvic floor disorders among women in rural Ethiopia.

There is today limited information about pelvic floor disorders, and the consequences it has for women living in low-income countries such as Ethiopia. This study is a part of research team that aims to establish prevalence rates and risk factors of common pelvic floor disorders, as well as explore experiences of living with such conditions among women in Ethiopia. It is a collaborative study named the *Dabat Incontinence and Prolapse Study* (DABINCOP) between partners at the University of Gondar, Ethiopia, and the University of Bergen, Norway.

What does the study entail?

In the study we wish to conduct in-depth interviews with the aim to explore different aspects of living with different pelvic floor disorders. The interviews will be conducted in Amharic by my collaborator and myself.

Potential advantages and disadvantages

Your participation in the research project will be valuable as it contributes to informing health care planners in Ethiopia about the needs of Ethiopian women regarding pelvic floor disorders. This will make it possible to make important steps towards the improvement of treatment and prevention of such conditions in Ethiopia.

Potential disadvantages of your participation in the study include the time you will spend on the interview. Any economical loss due to participation in the study will be replaced.

What will happen to the information about you?

The data from the interview will be tape recorded upon your consent, and notes will be taken during the interview. The data that are registered about you will only be used in accordance with the purpose of the study as described above. All the data will be processed without name, ID number or other directly recognisable type of information. A code number links you to your data through a list of names. Only authorised project personnel will have access to the list of names and be able to identify you. It will not be possible to identify you in the results of the study when these are published.

Voluntary participation

Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time without stating any particular reason. Withdrawal from the study will not have any implications for potential ongoing treatment. If you wish to participate, sign the declaration of consent on the final page. If you agree to participate at this time, you may later on withdraw your consent without your treatment being affected in any way. If you after the interview wish to withdraw your consent or have questions concerning the study, you may contact the project leader of this study; Janne Lillelid Gjerde on the following number 0945952455, situated at the University in Gondar during the project period.

Consent for participation in the following research project:

**“Experiences and health seeking behaviour among women living with pelvic floor disorders in low-income contexts:
The case of Dabat, North-west Ethiopia”**

I am willing to participate in the study.

(Signed by the project participant, date. NOTE: If the study participant is illiterate he/she will give his/her oral consent, and the research collaborator will note the consent and date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

በዚህ ጥናት ላይ ለመሳተፍ ፍቃደኝነትን መዘየቅያ ቅፅ

በሰሜን ምዕራብ ኢትዮጵያ ዳቦት አካባቢ ባሉ ገዥቶች የኑሮ ደረጃ ላይ የሚገኙ የሚሆኑን መክከለኛ አካባቢ ያለ የጤና ችግር ያለባቸው ሴቶች ያለባቸውን ችግሮችና ስለሚከሰደላቸው የጤና እርዳታዎች

ከዚህ በመቀጠል ያለውን መረጃ ተሳታፊ እንዲሆኑ ለማዘየቅት ግለሰቦች አንጠላቸው

የጥናቱ አላማ

ይህ ቅጽ በገጠሪቷ ኢትዮጵያ ክልል ውስጥ ከሚሆኑ ጋር በተያያዘ ችግር ያለባቸው ሴቶችን በሚመለከት ስላሉት የተለያዩ ጉዳዮች ላይ በሚደረገው ጥናት ውስጥ ተሳታፊ እንዲሆኑ መዘየቅያ ነው

በአሁኑ ሰአት በሚሆኑ መክከለኛ ላይ ስለሚከሰት ህመም በቂ የሆነ መረጃ የለም እንዲሁም ችግሩ ገዥቶች ገቢ ባላቸው እንደ ኢትዮጵያ በመሰሉ አገሮች ውስጥ በሚኖሩ ሴቶች ላይ ስላለው የተለያዩ ጉዳዮች በዝርዝር

አይታወቅም፡ ይህ ጥናት ስለ ችግሩ መዘኛ እና የተጋላጭት መስጠቶችን ለማወቅ እና እንዲሁም በኢትዮጵያ ውስጥ ከችግሩ ጋር የሚኖሩ ሴቶችን ተግባራዊ ለማድረግ ያደረገ ነው ይህ ጥናት በጎንደር ዩኒቨርሲቲ እና በ በርገን

ዩኒቨርሲቲ በጋራ ጥያቄ የሚደረግ ሲሆን *dabat incontinence and prolapse study (DABINCOP)* የሚል ስያሜ ተሰጥቶታል፡ ይህ ጥናት በምን ጉዳይ ትኩረት ያደርጋል?

በሚሆኑ መክከለኛ ላይ በሚከሰት የተለያዩ ህመሞች እና ከእነዚህ በሚሆኑ መክከለኛ ላይ በሚከሰት የተለያዩ ህመሞች እና ከእነዚህ ሁኔታዎች ጋር የሚኖሩ ሴቶችን የተለያዩ ተግባራዊነትን ለማወቅ ከተሳታፊዎች ጋር በሰፊው

ለመገናኛት እንፈልጋለን፡፡ ቃለ መጠይቆቻችንም እኔ እና ባልደረቦቼ በአሚኒኖ ቋንቋ እናካሂደዋለን፡፡

ስለ ጥቅሙ

በዚህ ጥናት ላይ መሳተፋችሁ ለኢትዮጵያ ጤና ሪፐብሊክ አርቃቂዎች ከችግሩ ጋር የሚኖሩትን ሴቶች የሚከሰደላቸውን ነገሮች ላይ በቂ መረጃን በመስጠት ለጉዳዩ በቁ ትኩረት አደርገው ችግሩን ለመቅረፍ አስፈላጊውን እርዳታ እንዲያስጡ ከፍተኛ የሆነ ጥቅም ይሰጣል፡፡

በዚህ ጥናት ላይ ስትሳተፉ በቃለ መጠይቁ ወቅት የተወሰነ ሰአት ለባክንባችሁ ይችላል፡፡ በጥናቱ ላይ በመሳተፋችሁ የተሳሳ ከገንዘብ ጋር በተያያዘ የሚጋጥሟችሁ ከሰራ ካለ ተመልሽ ይደረግላችኋል፡፡

የተሳታፊዎችን ማንነት በተመለከተ

በቃለ መጠይቁ ወቅት በእናንተ ፍቃድ ላይ በመመዘኑ ደምግችሁን የደምጭ መቅጃ መስርያ በመዘየቅም እንቀዳለን እንዲሁም እንዳንድ ወይይቶችን በፅሁፍ እናስፍራለን፡፡ ከእናንተ የምናገኘውን መረጃ ከላይ እንደተገለፀው ለዚህ

ጥናት ብቻ ነው የምንጠቀሙ የምስጢክ መረጃዎች ሁሉ ስንጠቀሙበት ከስሞችሁ ወይም ከመቃወሚያ ቁጥሮችሁ ጋር በፍፁም

እናገነኘንም፤ የምክብር ቁጥር ተሰጥቶት ነው የሚመዘው የተወሰኑ ሃላፊነቱ የተሰጣቸው ሰዎች ብቻ ናቸው ስለ እናንተ የሚመዘኑት እና እናንተን ለያገኙባችሁ የሚሹሉት፡፡ ይህ ጥናትም ለህጎች ሰበቃ ማም ሰው ለሊዮችሁ እንዳይችል ተደርጎ ነው፡፡

የመከተፍ ፍቃድ

በዚህ ጥናት ላይ የምሳተፊት ፍቃድ ከሆናችሁ ብቻ ነው፡፡ በፈላጊነት ጊዜ ምክንያታችሁን መጠለፅ ሳያስፈልጋችሁ ተሳትፎችሁን ማቋረጥ ትችላላችሁ በሚቋረጣችሁ የተነሳ ምንም ዓይነት ነገር አይደርስባችሁም፡፡ ለመከተፍ ፍላጎታችሁ ከሆነ ከዚህ በታች በተዘጋጀው ቅጽ ላይ ፊርማችሁን አኑሩ፡፡ ለመከተፍ ፍላጎታችሁን ከገለጻችሁ በኋላም በሆነ ተሳትፎችሁን ማቋረጥ እና ብዙሪብ መጠየቅ ነው፡፡ ቃለ መጠይቅ ከሰጣችሁ በኋላም ማቋረጥ ብርፅህናት ወይም ማኖሪያም ዓይነት ጥያቄ ካላችሁ የዚህ ጥናት መሪ የሆነችውን Janne Lillelid Gjerde በግጥም ቁጥር 0945952455 ላይ ልታገኙባችሁ ትችላላችሁ ጥናቱም እስከጠናቀቅ ድረስ የጥናቱ መሪ በጎንደር ዩኒቨርሲቲ ውስጥ ትቆያላችሁ፡፡

በዚህ ጥናት ላይ ለመስተፍ ፍቃድ ማግለጫ ቅጽ

በሰሜን ምሪብ አገልግሎት ዳይሬክቶሬት አካባቢ ባሉ ገዛቶች የኑሮ ደረጃ ላይ የሚገኙ በተዘነፈ የሚጠቀሙ ማጠቃለያ አካባቢ ያለ የጤና ችግር ያለባቸው ሴቶች ያለባቸውን ችግሮችና ስለሚከናወኑት የጤና እርዳታዎች

በዚህ ጥናት ላይ ለመስተፍ ፍቃድ ነኝ

(ተሳታፊዎ ማረጋገጫ አለበት/ ቀን ይጠቅሙ) መከታተያ ተሳታፊው/ዋ ግለሰብ ማረጋገጫ እና መገፍ የሚያስፈልገው/ትኛል ከሆነ በታላቅ ይነበብ/ላት ከዛም የጥናት አስተባባሪ ቀኑን እና ፍቃድ ማስገኘት/ታን ይገፍ

ለዚህ ጥናት ሚጃ መስጠቴን እገልጻለሁ

(ይፈረም ቀን ይገፍ፣ በጥናቱም ላይ ያለውን/ላትን ሃላፊነት ይገለጽ)

Appendix VII

VII



☎ 251-011-123 97 52
☎ 251-011-123 97 74
251-011-123 98 00

Fax:251-011-123 97 68

✉ 1176 አዲስ አበባ ኢትዮጵያ
Addis Ababa Ethiopia

E-mail: poffice@aau.edu.et

Date: February 12, 2015

Ref.No: PR/5.5/354/07/15

The Immigration and Refugee Affairs Authority
Addis Ababa.

Subject: Request for Residence Permit

Mrs. Janne Lillelid Gjerde is a Norwegian national with Passport No.30230162. She is an expatriate scholar affiliated to The Institute of Ethiopian Studies, Addis Ababa University.

This is, therefore, to request your esteemed office to issue her residence permit from February 10th, 2015 to February 10th 2016.

Thank you for your cooperation,

Sincerely,

Admasu Tsegaye (Ph D)
President



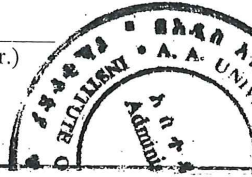
Appendix VIII



Addis Ababa University
Institute of Ethiopian Studies
Researcher's Identity Card

Name: **Ms. JANNE LILLELID GJERDE**
 Position: Researcher
 Duration: One Year
 Valid: Until February 12, 2016 only

Ahmed Hassen
 Ahmed Hassen (Dr.)
 IES, Director




የኢትዮጵያ ፌዴራላዊ ዲሞክራሲያዊ ጠቅላይ ሚኒስትር ጽ/ቤት
 የሥነ ምግባርና የሥነ ምግባር ጽ/ቤት
 የጥገና ጽ/ቤት

FEDERAL DEMOCRATIC REPUBLIC OF ETHIOPIA
 Security, Immigration and Refugee Affairs Authority
Temporary Residence ID

የዘ/ግ/አ/ቤት/ስም / Surname: GJERDE
 የዘ/ግ/አ/ቤት/ስም / Given Name: JANNE LILLELID
 የዘ/ግ/አ/ቤት/ስም / Nationality: NORWEGIAN
 የዘ/ግ/አ/ቤት/ስም / Date of Issue: 17 FEB 15
 የዘ/ግ/አ/ቤት/ስም / Date of Expiry: 10 FEB 16

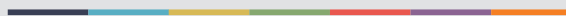
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 የዘ/ግ/አ/ቤት/ስም / Sex: F
 የዘ/ግ/አ/ቤት/ስም / Date of Birth: 09 JAN 84

የዘ/ግ/አ/ቤት/ስም / Bearer's Signature: *Janne Lillelid Gjerde*





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