Female urinary incontinence: perceptions and practice

A qualitative study from Amhara Region, Ethiopia

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To all the hard working women of rural Ethiopia

[1]

‘*No one is closer to me than my husband. He is a part of me, but I don’t even tell him’*

(45-year-old woman with urinary incontinence)

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[1] *Picture 1. Road outside Lalibela, heading towards the airport (private photo)*

Summary

The current study aims to add in-depth knowledge of how women living in rural and semi-urban areas of Northwest Ethiopia perceive and practically handle urinary incontinence. In several high-income settings, female urinary incontinence has been found to affect one in four women, and has been related to diverse reproductive health related factors, as well as to age and hard physical work. The experience of involuntary leakage of urine is found to severely influence physical, psychosocial and social well-being, and has also been found to have an economic impact on those who are affected. Perceptions and the handling of ill health conditions commonly differ considerably based on the socioeconomic and cultural context within which it is experienced. Limited research based knowledge is available on the experience of living with urinary incontinence in low-income contexts. Due to perceived challenges with limited access to water, to essential remedies and to health care services, the implications of urinary incontinence are thought to considerably differ from the ones experienced in more affluent settings.

The study was conducted in the North-Gondar zone of Amhara Region in Ethiopia in 2011, and included 26 informants; women suffering from urinary incontinence, health workers, a traditional healer and relatives of the women suffering from urinary incontinence. A qualitative approach was employed with in-depth interviews as the main data collection method. Informal talk with large numbers of individuals about the topic added important knowledge to the material. In the analyses of the data material 'Systematic Text Condensation' framework was applied.

The findings of the study illustrate how socio-cultural as well as practical and economical circumstances strongly influence on how the women perceive and handle the leakage. Limited access to water, soap, pads and spare clothes characterized the daily management of the problem. Shame, embarrassment and fear of being discriminated led to substantial efforts to hide the leakage. A majority of the women related the leakage to childbirth. Others held socio-cultural related explanations responsible. Although most of the women had been in contact with the health system, they usually did not seek help for or disclose the urinary leakage to health personnel. Religious or other 'traditional' remedies were frequently sought, although disclosure of the leakage rarely took place also in such settings. The discussion

briefly draws upon cultural- and critical theoretical approaches in medical anthropology to make sense of the study findings.

The thesis is based upon the current guidelines provided by the Centre for International Health, University of Bergen. The format chosen for the current study is the combination of an introductory thesis, followed by a paper presenting the findings of the study. The paper will be attempted published. It will be submitted to the International Urogynaecology Journal, May 2012.

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List of abbreviations

DABINCOP	–	The Dabat Incontinence and Prolapse Study
UI	–	Urinary Incontinence
SUI	–	Stress Urinary Incontinence

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Introduction

The current study explores the experiences of women living with varying degrees of urinary incontinence (UI) in the Amhara Region of Ethiopia. This first chapter introduces the topic of UI with reference to the existing literature.

Defining female urinary incontinence

In a recent joint report from the International Urogynecological Association (IUGA) and the International Continence Society (ICS) [1] standard terminology for female pelvic floor dysfunction was developed, aiming to enable accurate communication in clinical practice and research within the field. They describe a symptom as '*any morbid phenomenon or departure from the normal in structure, function or sensation, and an indicative of disease or a health problem*' [1]. The symptom of urinary incontinence (UI) is defined as the '*complaint of involuntary loss of urine*'. There are three main types of UI; Stress incontinence is defined as the '*complaint of involuntary loss of urine on effort or physical exertion, sneezing or coughing'*, urgency incontinence is defined as the '*complaint of involuntary loss of urine associated with urgency*', and mixed incontinence is defined as the combination of these two. In addition, and relevant for the context of this thesis, continuous urinary incontinence is defined as '*complaint of continuous involuntary loss of urine*' [1]. UI is also characterised by severity. One internationally acknowledged way of defining severity was developed and validated by Sandvik *et al* [2]. The severity index ranges UI from *slight, moderate, severe* to *very severe* for use in epidemiological surveys.

Risk factors of female urinary incontinence

From several European countries prevalence rates of UI among women has been found to be high and vary between 23 and 44 % [3, 4]. The prevalence of UI increases with age with rates of 10 – 30 % among young women, 30 – 40 % among middle aged women with a steady increase between 30 – 50 % in elderly women [3, 5]. UI is found to typically relate to women's reproductive history [6, 7], and vaginal delivery is associated with stress urinary incontinence (SUI) and mixed urinary incontinence [6]. Neglected obstructed labour can lead to diverse defects in the female genital tract, and may cause the condition of obstetric fistula [8, 9]. The most common type of obstetric fistula, the vesico-vaginal fistula, leads to a continuous leakage of urine [8]. Around 2 – 3 million women worldwide are suffering from obstetric fistula, and yearly 50,000 – 100,000 new women are affected, of whom the majority live in remote rural areas with limited access to emergency obstetric care [8, 9]. There are a number of other factors that also associates with UI, such as increasing age, high parity, excess weight, heavy lifting, family history of UI, childhood enuresis, chronic cough and a variety of chronic medical conditions [10].

Implications of female urinary incontinence

The excretion processes are among human being's the most intimate functions, and is commonly hidden from other people's view [11]. Irrespective of the type or severity of UI, the experience of involuntary loss of urine has been found to affect the physical, psychosocial, social and economic well-being of the ones affected and their families [4, 11].

Among middle-aged Australian women UI was found to be perceived as a 'normal' part of being female [12]. The symptom was linked to a sense of personal responsibility, and narratives of being unsocial, 'naughty' and bad for lacking control over the bladder were unveiled. The urinary leakage was explained by the affected women to be caused by multiple factors such as childbearing and menopause, and was furthermore linked to perceived personal failures such as lack of exercise and overweight. The symptom was experienced as 'dirty' and extremely bothersome among Moroccan and Turkish women living in the Netherlands suffering from UI [13]. They washed themselves as soon as possible after leaking urine, and to be able to handle such an event, they always carried with them extra underwear and pads. However, another study from the Netherlands revealed that women experienced insecurity despite wearing protective materials such as pads, and felt humiliated if noticed by others with bags of pads [14]. Being in need of a toilet at inconvenient moments was related to feelings of anxiety, and queuing up at public toilets was experienced as a 'nightmare' among some of the women. Certain sports and activities had been given up by many, primarily due to fear of other people noticing the urinary leakage.

Strong negative effects on the social life and increased anxiety levels among women suffering from SUI has been revealed in many European countries, as the majority of the women with severe SUI were found to be depressed, introverted and rigid to interpersonal relationships [15]. Use of creative strategies in order to gain control over the urinary leakage, and to be able to live as normal as possible was employed among both women and men in a German study [16]. One strategy involved being prepared for a situation of leakage by bringing extra cloths or pads when going out, staying close to a toilet at all times or by restricting the fluid intake. Another strategy involved looking for possible therapies such as medication, operation, bladder exercises or alternative methods through use of Internet or health counsellors. Some moreover formed a circle of trust with people who gave security, support and trust, usually closest family or close friends.

A study from several sites in United States found that urinary incontinence moreover had a significant economic impact on the ones affected, as women with severe UI had expenses of $900 annually for UI routine care such as supplies, laundry and dry cleaning [17].

Female urinary incontinence in low-income contexts

Several American studies have found UI to be less prevalent among African-American women compared to women of Caucasian origin, for unknown reasons [18, 19]. Limited data on prevalence of UI from African countries is yet available [20-22]. However, factors such as high fertility rates, limited access to emergency obstetric care as well as daily physical hardships for women living in low-income settings suggest that UI and other pelvic floor disorders may be prevalent among women in poor Sub-Saharan African countries. Despite also lacking in-depth knowledge about experiences of living with UI, it has been suggested that it more seriously impact women’s health and living conditions in resource poor settings compared to more affluent settings [22].

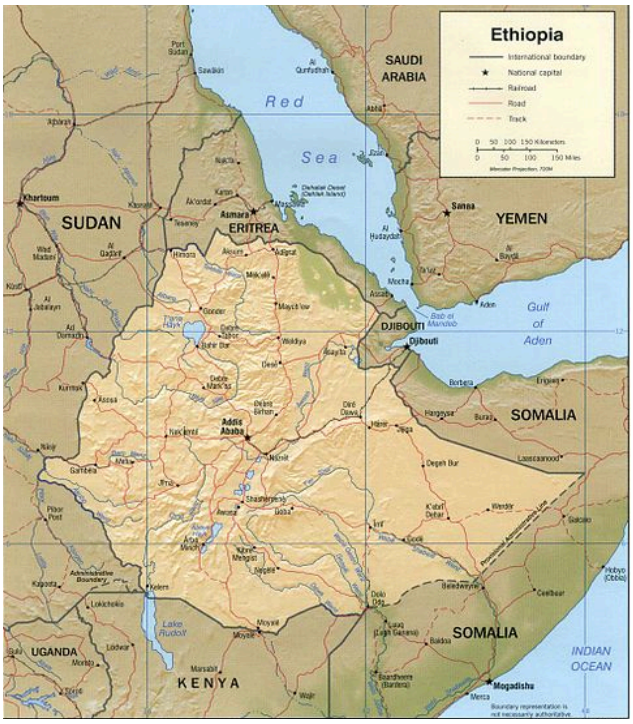
A review study from several low- and middle-income countries, including Sub-Saharan African countries, found that living with pelvic floor dysfunctions including UI is associated with embarrassment, shame, annoyance, frustration, depression and feelings of being alone or isolated [22]. For many women the greatest challenge was related to being able to perform religious practises. Among Muslim women, being unable to pray five times a day due to the obligation of ritual cleansing at times of prayer caused huge challenges, and among some resulted in feelings of sinfulness [22-24]. Practical aspects such as facing difficulties in performing housework were also revealed, as well as the experience of leakage during sexual intercourse with partner [22, 23]. Low self-esteem due to the symptom, often resulting in secrecy and isolation was commonly found [22-24]. In a study carried out among women with obstetric fistula in Ethiopia, it was found that for the majority the symptom caused divorce and was related to feelings of depression, often leading to social isolation and suicidal ideation [25]. The same study showed that fistula is associated with social poverty, exclusion and grief which make the urinary leakage, as well as other consequences related to fistula, a problem also for the women’s children and husbands.

While studies from low-income countries have provided a growing global knowledge concerning obstetric fistula, less attention has been given to women who suffer from milder and more prevalent degrees of UI [22]. Knowledge about prevalence, risk factors and especially in-depth understanding in resource poor settings of the experiences of living with UI, as well as of other pelvic floor disorders, is needed in order for the health care authorities to be able to plan sufficient prevention measures and health care services.

Background

Ethiopia - the context of the study

Ethiopia, situated at the Horn of Africa, is a multi-ethnic country with over 80 different ethnic groups and languages. It is estimated to be one of Africa's fastest growing and second most populous country in Africa with around 83 million inhabitants [26]. In a country characterized by a diverse landscape, from deep valleys to highland and mountains, 83 % of the population live in rural areas, and agriculture accounts for 85 % of the labour force in the country [27, 28]. Illiteracy levels of 75 % among women and 54 % among men, shows that education is not accessible to all, especially not to women [29]. 3/4 of urban women are literate, while only 1/5 of women are literate in rural areas [30]. The total fertility rate is 5.2 births per woman [28], and the life expectancy at birth is 54 years [26].



Picture 2. *Ethiopia, situated at the Horn of Africa [31]*

Ethiopia experiences a severe shortage of health workers, with a coverage of 2 physicians and 24 nurses and midwifes per 100,000 people, compared to the African region's average coverage of 23 physicians and 109 nurses and midwives per 100,000 people [26]. Only 3 % of births that take place in rural areas are attended by skilled health personnel, compared to 6 % overall in the country [26]. The high maternal mortality ratio of 676 deaths per 100,000 live births in Ethiopia has been linked to these low numbers of skilled health personnel during birth [32]. While around 25,000 women die due to pregnancy-related causes annually in Ethiopia, around 400,000 women experience pregnancy and birth related disabilities, including urinary incontinence [33, 34]. In Ethiopia, obstetric fistula is found in among 2 per 1000 women [35].

Even though there are several factors influencing women's decisions on whether to seek help or not when giving birth, access to a health facility with emergency obstetric care is often limited due to long distance, often with roads only accessible by foot in rural areas. Although the existing health system intends to meet the needs of the rural poor, and free health care is offered to the very poorest who can provide an official document stating this from their district, the health care system remains one of the poorest in Sub-Saharan Africa [36]. Early marriage arranged by elders and by abduction is still practised in some ethnic groups despite the fact that marriage before the age of 18 was made illegal by 2005 in Ethiopia [37]. Early marriage often leads to early start in childbearing, consequently reducing the educational and employment opportunities of women [37].

Theoretical approaches

In the later discussion of the findings from the current study, several aspects that influenced on how the women suffering from UI experienced and handled the problem are highlighted, based on the following theoretical approaches within medical anthropology.

Cultural aspects of health and illness

Helman [38] describes culture as *'a set of guidelines which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment'.* A person's cultural background is of great importance due to its influences on several different aspects in life, such as beliefs, behaviour, perceptions, emotions, religion, family structure and attitudes to illness or other forms of misfortunes. Culture should always be seen in its particular context, formed by its historical, economic, social, political and geographical elements [38].

According to Kleinman [39] shared understandings, based on both the personal and social meaning, influences the experience and action taken in relation to an illness in a particular setting and in a particular social group. Members of a community are socialized into a set of guidelines that tell them how to behave, how to respond towards other people and supernatural forces, as well as how to see the world [38]. In the current study I explore the women's experiences of UI with reference to the socio-cultural context found in Amhara Region, as the particular settings found at particular times will influence on how the symptom of UI is perceived, handled and acted upon.

Plural medical systems

People's lived experience of ill health is commonly located in contexts where several therapeutic health systems co-exists within the same cultural setting [38, 40]. Kleinman [41] distinguishes between three sectors that differ with regards to perception and treatment of ill health. The *popular sector* is an arena of the individual, family and other social surroundings. It is the non-professional and non-specialist domain of the society and includes all the therapeutic options that people use without payment, such as self-medication, self-treatment, advice from friends, family or neighbours. The *folk sector* is also non-professional, and commonly includes a substantial variation of folk healing options. Broadly speaking the local healers tend to deal with 'the whole' body, and includes assessment of the natural environment, social relationships and supernatural forces when scrutinizing physical and emotional symptoms. This sector may be especially large in 'non-Western' societies, although the alternative sectors of healers have strongly increased its position also in the more affluent parts of the world. The *professional sector* is dominated by biomedicine, and is currently the dominant form of healing worldwide, but it also includes other officially blessed treatment options such as Ayurvedic medicine, acupuncture and other larger medical systems [41]. It is of interest to learn how the women in the current study related to the different health sectors, in order to enhance the understanding of their health seeking behaviour in relation to their experience of the urinary leakage.

Health and illness within critical medical anthropology

In attempts to understand perceptions and practices of health and illness it is important to also see beyond the cultural dimension. The World Health Organization's definition of health as '*a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity'* [42], has within critical medical anthropology been criticised for not considering the barriers of achieving well-being, such as social inequality, class, gender, discrimination or poverty [43]. An alternative definition of health is '*access to and control over the basic material and non-material resources that sustain and promote life at a high level of satisfaction'* [43], where emphasis is placed upon evaluating health in a larger socio-cultural context. Considering the importance of economic factors and processes of marginalisation as causes of particular patterns of illness, disease and suffering in a society has influenced the work of many medical anthropologists. Singer, Farmer, Scheper-Hughes and others [43-45] emphasise how conditions of poverty, powerlessness, marginalisation and institutionalised hopelessness influence how certain categories of individuals become sick in a society.

Increased attention has among medical social scientists also been drawn to how a person experiencing illness manifests or gives meaning to disease or distress [43]. Scheper-Hughes and Lock [46] have contributed to the development within this field through the concept 'mindful body'. The two authors distinguish between three relevant 'bodies' in health. The 'individual body' which represents the lived experience of a person; an individual's image, meaning and subjective experience of his or her body, whether in the state of health or illness. The 'social body' which represents a constant exchange of meanings between the 'natural' and the social worlds, by regarding the body as a 'natural symbol' which relates to nature, society and culture. The 'body politic' refers to structural factors and to the regulation, surveillance and control of the individual and the collective bodies in most relations of life. The 'three bodies' are overlapping units of analysis, simultaneously representing different arenas of experience of suffering. It seems relevant to explore how the 'three bodies' outlined by Scheper-Hughes and Lock can be briefly drawn upon in an attempt to enhance our understanding of how the suffering from urinary leakage was experienced by the women in the current study.

Rationale of the study

The current study was part of a larger collaborative research project between the University of Bergen, Norway, and the University of Gondar, Ethiopia, entitled the Dabat Incontinence and Prolapse (DABINCOP) study. The DABINCOP study aims to establish prevalence rates and risk factors of urinary incontinence, faecal incontinence and symptomatic pelvic organ prolapse in an Ethiopian female population through various quantitative research components, and furthermore aims to explore factors related to women's experiences of these conditions through various qualitative research components. A pilot study was carried out in Dabat District in 2011 in order to assess the feasibility of the questionnaire addressing the topics of urine and faecal incontinence and pelvic organ prolapse. Pelvic examinations were additionally carried out among the study informants in attempts to validate and adjust the questionnaire and to identify risk factors. The pilot study was organized and run through the Dabat Research Centre; one of the official surveillance sites in Ethiopia, run by the University of Gondar. Demographic data from a population of about 50,000 from 10 villages in Dabat District is registered every six months.

Current knowledge on the topic of UI has primarily been based on the experiences of women living in high-income contexts, while less knowledge is available about how women living in more resource poor settings experience and handle the symptom. This study was carried out as a sub-study within the DABINCOP pilot study, and aimed at exploring diverse aspects of women's experiences of living with various degrees of UI regardless of aetiology in rural and semi-urban Ethiopian settings, and thus aimed to add knowledge in an area yet limited explored. The practical handling of the leakage, its social implications, perceptions of reasons for the symptom and health seeking behaviour linked to the urinary leakage were particularly explored. A further aim of the study is to contribute to a strengthening of the DABINCOP study's tools. An overarching aim is to generate knowledge about UI that can inform coming treatment- and prevention measurers in Ethiopia.

Objectives

General objective

- To explore the experiences of women suffering from various degrees of urinary incontinence in rural- and semi-urban settings of the Amhara Region, Ethiopia

Specific objectives

- To explore the practical handling of urinary incontinence as well as conditions of hygiene and sanitation

- To explore social implications of living with urinary incontinence with an emphasis on relations with partner, family and neighbours

- To explore perceptions of urinary incontinence as well as health seeking behaviour among women suffering from urinary incontinence

Methods

Study setting

Ethiopia has nine ethnically based administrative regions that are divided into zones (*zonə*), further subdivided into districts (*woredas*). The current study was carried out within the district of North Gondar zone of Amhara region in the northwest part of Ethiopia. Amhara region is the second most populous region in Ethiopia, with over 17 mill inhabitants [27]. The North Gondar zone is furthermore one of the most populous zones within the Amhara region, with a population of 2.9 million [27]. The large major ethnic group within the zone is the Amhara. A variety of other ethnic groups are also present, such as the Tigrinya and the Oromo. The first language spoken by over 98 % of the population within the zone is Amharic, the official language in Ethiopia. However, there are also a variety of other spoken languages in the area such as Tigrinya and Afaan Oromo. Ethiopian Orthodox Christianity is practised by over 95 % of the population in the region, while other religions practised are among others Islam and Protestantism [47].

Figure 3. *Regions and zones within Ethiopia. Amhara region shown in green* [31]

The study took place in two settings within the North Gondar zone. A health facility-based component was located at Gondar University Hospital; a leading referral hospital with a range of specialities located in the city of Gondar in the centre of the Amhara region. Gondar District has a population of around 195,000 [36], but Gondar University Hospital serves a population of about four million people from within and beyond the region [48]. The hospital holds the capacity of around 400 beds, and has a range of specialities including paediatrics, gynaecology, surgery, HIV care and outpatient clinics [48]. The data for the current study was collected at the gynaecology ward and at the outpatient clinic of the hospital.

A community-based component of the study took place in Dabat District, located around 75 km north of Gondar city. Dabat District is one of 16 districts within the zone, and has a population of around 145,500 inhabitants. There are around 31,000 households in the district, the majority living in rural areas, with an average of 4.7 people per household [49]. The large majority of the people in the district belong to the ethnic group Amhara, speak Amharic and practise Ethiopian Orthodox Christianity [49]. The data for the current study was collected in three different villages (*kebeles)*, the smallest administrative units in Ethiopia, within the district;

- A semi-urban village: a relatively urban area with 1600 households
- A low-land village: a remote rural area located in the lowlands accessible by foot, with 950 highly spread out households
- A high-land village: a rural area in the highlands more or less accessible by car, with 924 households [50]

Picture 4. Landscape and households in the rural lowland village (private photo)

Study design

A qualitative research approach aims to create in depth understanding of various social phenomena based on explorative information about individuals and situations [51]. Moreover, the approach has been described as the best way to gain an 'insider's perspective', as well as an assessment of the socio-cultural context [52]. By focusing on the meaning of illness and illness related behaviour, the understanding of why people handle illness and suffering in the ways they do is enhanced. Qualitative methods draw upon theories of human experience (phenomenology) and of the interpretation of human experience (hermeneutics), and will commonly involve the systematic collection, organising and interpretation of material from conversations, observations or written sources [53].

A qualitative design was chosen for the current study due to the aim of gaining in depth information about women's experience of living with UI. An additional important factor for the choice of study design was an aim of integrating the findings from the current study with the epidemiological part of the study in a manner that would enhance the overall comprehension of the study topic. In studies of sensitive topics it is particularly useful to include qualitative research components, thus components of more explorative kind, as the flexibility of the design allows for the dwelling and probing in a manner that will enhance the understanding of what is at stake for the study participants. In such studies employing qualitative methods may reach high degree of validity, and will in the same vein strengthen the validity of the findings from quantitative closed-ended surveys [52].

Different qualitative research methods produce different varieties of qualitative health knowledge [54]. A phenomenological approach has been inherently drawn upon in the current study in the planning process through development of the protocol and the interview guides, throughout the fieldwork process, as well as in the process of analysis. This tradition seeks the personal experiences of the study participants, and views all experience as fundamentally reflective and contextual [54]. In the current study the experience we sought can be characterized as knowledge of historical and culturally situated health experiences. The approach thus aims to answer questions regarding how people living in or embedded in certain historical and cultural situations experience health and illness [54].

Study participants and their characteristics

As described above, the study participants were recruited from both a health facility setting and from a community setting. A total of 26 informants were included in the study, with women experiencing various degrees of involuntary leakage of urine making up the large majority of the study participants.

The informants recruited in the health facility-based component at the Gondar University Hospital included women admitted to the hospital for obstetric fistula, a husband of one of these women and health personnel at the gynaecology ward and at the outpatient clinic for gynaecological conditions. The admitted women came from different districts within the North-Gondar zone, including the districts of Chilga, Debarq, Metemma and Telemt. The health personnel were people from the surrounding area working at the hospital.

The informants recruited in the community-based component in Dabat district included women living with various degrees of UI, one sister of one of these women, health personnel and a traditional healer. The women were living in three different villages of the district, in semi-urban as well as rural areas. The health personnel were employed at the health centre in the semi-urban village. The traditional healer was also living in the semi-urban village. Since the main emphasis was placed on the community-based component, most of the material drawn upon in the current study is from the community.

Table I. Overview of the informants in the study

Health facility component	**(N = 7)**	**Community component**	**(N = 19)**
Women admitted to hospital	4	Women in semi-urban area	5
Health personnel	2	Women in rural highland	5
Husband	1	Women in rural lowland	4
		Health personnel	3
		Traditional healer	1
		Relative	1

The 18 women interviewed who experienced involuntary leakage of urine were between the age of 24 to 60 years. Among these only one was literate. The women living in rural areas of Dabat District were all married and were primarily engaged in house related work. Two of the women living in the semi-urban areas of Dabat District were divorced or widowed and were working as housemaids or were unemployed. Three of the women in the health facility-based component were divorced and were engaged in farming or worked as housemaids. The majority of the informants were first married at the age of around ten years. More than half had experienced at least one divorce. Except two of the women in the health facility component who had no live children, the remaining informants had an average of six live children each. The large majority gave birth for the first time before the age of 18.

The health workers enrolled in the study at the Gondar University Hospital included a female midwife working at the gynaecology ward and a female midwife working at the outpatient department for gynaecological conditions. The health workers in the community based-component included a female and a male nurse, as well as a female health officer employed at the local health centre in the semi-urban village. The traditional healer was living in the semi-urban village, and treated people for common health complaints in her home. She explained that she had previously been registered as a traditional healer by the government and frequently had meetings with health personnel in the area.

The degrees of urinary leakage experienced by the informants varied greatly, and even though it was not feasible to follow an index measuring the severity of the leakage in the current study, an attempt was made to classify the degrees in order to clarify the severity of the symptoms. The degrees of urinary leakage were in the current study defined as ‘mild’, ‘moderate’, ‘severe’ or ‘continuous’, based on the informant’s own explanations of the severity of the problem.

Table II. Frequency of involuntary leakage of urine

Mild leakage Women with involuntary leakage of urine once or up to a few times a month	2
Moderate leakage Women with involuntary leakage of urine once or up to a few times a week	6
Severe leakage Women with involuntary leakage of urine on a daily basis	5
Continuous leakage Women with involuntary continuous leakage of urine	5
Total number of informants with UI	**18**

Some of the informant’s also experienced faecal incontinence or pelvic organ prolapse. However, an exploration of the experiences of living with these conditions is not included in the current thesis.

Recruitment of study informants

Purposeful sampling was used in the recruitment process in the current study, with the aim to recruit informants suffering from UI and with diverse experience. Diversity among the study informants potentially leads to varied information, which gives the opportunity to grasp more nuances around the topic in question [53]. The principle behind the number of informants recruited followed the general principle of ‘theoretical saturation’ [53], which means that the recruitment stopped when no major new topics emerged.

In the health facility-based component, a key-person in the quantitative part of the DABINCOP study team assisted with the contact to a nurse at the relevant ward who assisted in identifying potential informants for the study as well as an appropriate setting for the data collection. At the gynaecology ward a small staff room was allocated for use, while an office was used at the outpatient clinic.

In the community-based component potential informants were identified through the quantitative part of the study. Women from the three villages had in the survey been randomly selected through the Dabat Research Centre’s database. 400 women over the age of 15 were selected to answer a structured questionnaire about urinary incontinence, faecal incontinence and pelvic organ prolapse. In addition, they were asked to have a clinical examination at a health post that was temporarily set up in the three villages by the research team. The women identified through the structured interviews or through the clinical examinations to have any degree of UI were eligible for participation in the current study. When more informants than needed were available through the quantitative part, potential informants for the current study were selected based on a strategic or purposeful selection, aiming at a widest possible variety in age and degree of UI among the informants to search for diversity in the data obtained. A few women who became informants in the current study approached the health posts on their own initiative, as they had heard from others about the research team. These women were offered pelvic examination and referral to hospital if needed, and were only included in the qualitative part of the study. The informant’s homes were primarily used for data collection, interview were also carried out inside or outside of the health posts depending on practical circumstances. An examination room at the health centre was allocated for use during interviews with health personnel.

Picture 5. Health Centre situated in Dabat town, North Gondar zone (private photo)

Inclusion criteria

The inclusion criteria for the women participating in the study were the following:

- Women at the hospital suffering from involuntary leakage of urine
- Women in the community suffering from involuntary leakage of urine revealed during the structured interview, if UI was confirmed at the pelvic examination or if they approached the team complaining about urinary leakage
- Women in both locations were only included if they were above the age of 16

The inclusion criteria for other informants in the study were the following:

- Health personnel at the hospital with experience from work with women suffering from UI
- Health personnel in the community with more than six months work experience from the health centre
- Relatives of women with involuntary leakage of urine whom the woman had disclosed to and consented to their participation
- A traditional healer was included on the basis of meetings with women with gynaecological problems

Data collection

The data collection was conducted during fieldwork lasting from 1st of March to 20th June 2011. The data collection started and ended in the health facility-based component in Gondar where a total of ten days were spent at the hospital including two days of observation at the gynaecology ward prior to the data collection. The community-based component in Dabat district lasted for 18 days, including time spent in all three villages. This part of the study took place simultaneously and was carried out in close collaboration with the quantitative part of the DABINCOP pilot study.

In the current study, semi-structured in-depth interviews were used as the main method, as it gives the opportunity to explore individual's thoughts and feelings concerning a certain topic [53]. In addition, the fieldwork with the duration of four months allowed for the observation of women's living conditions in the community and a large number of informal talks with a variety of people taking place throughout the time of the fieldwork. These informal talks added substantial information, which was further explored in the interviews. Also it substantially enhanced the knowledge about the socio-cultural context within which the study was conducted.

The semi-structured in-depth interviews in this study were based on an interview guide. The interviews were explorative in kind and the majority of relatively long duration, between 30 to 90 minutes. The informants were encouraged to reflect and speak at length with minimum guidance and interruption, but with relevant probes and follow-up questions asked for clarification and attempts to get as much in-depth information as possible. These aspects and to be open and not judgemental is important in the interview setting to avoid steering the conversation towards information already known to the interviewer and to contribute to openness in the interviews [53, 55]. A few questions were added, reformulated and erased during the first phase of the data collection in order to improve the tool of the interview guide. In addition, written notes of relevant situational and non-verbal communication during the interview were conducted. The interview guides were developed prior to the fieldwork. As there were different groups of informants, separate guides were made for each group. All interview guides were translated into Amharic. The English version of the interview guide is attached (cf. **appendix 4**).

Research assistance

Three people gave assistance in the process of conducting the study; a research assistant was translating during the interviews, while two other people conducted the transcription and the translation of the interviews. Additionally, a research assistant was contacted prior to arrival in the field through the department of Social Anthropology at the University of Gondar. She assisted in the adjustment of the interview guides, making the questions as relevant as possible to the socio-cultural setting they were to be employed in.

The main research assistant was a female nurse from the area. She became such an essential part of the study that a preferred term when referring to her in the following text is the 'research collaborative partner'. As the study involved a sensitive topic it was of importance that the research collaborative partner was a woman who had excellent communication skills as well as substantial knowledge of local codes and customs. To fully involve her in the study, a thorough introduction to the background, purpose and the objectives of the study was given. She was additionally thoroughly trained in the qualitative research approach and the method chosen for the study prior to the data collection, as she had no previous experience within research-related work. She worked full-time with the study throughout the data collection phase of the fieldwork both in the health facility- and the community-based component of the study. Continuous evaluation and discussion with her throughout the fieldwork period, both before, during and after the interviews was essential for gaining detailed knowledge of good quality.

Two staff members at the Department of Social Anthropology and the Department of Psychology at the University of Gondar assisted with translation and transcription of the data material while in the field. However, due to practical circumstances, a third person from the Department of Social Anthropology was later engaged in order to complete the comprehensive task. The first assistant from the Department of Social Anthropology additionally translated all interview guides and the consent form from English to Amharic prior to the data collection, while the head of Department of Social Anthropology assisted in proofreading the translations of these documents.

Reflections on the researcher's position

In lack of any available Ethiopian female student who could carry out the qualitative part of the pilot study, the DABINCOP study team invited me to join the project. With background as a Registered Nurse as well as a Bachelor Degree in Social Anthropology in addition to previous hospital placement in southern part of Ethiopia in 2008, I considered myself to have some advantage despite being an 'outsider' in the current study setting. Throughout the time I spent in the field, I emphasized participating in the local social life as well as learning as much Amharic as possible. Amharic language lessons were taken through the research period as well as in the period following the fieldwork.

Data analysis

Analysis of the data has been a continuous process throughout the research period in the current study, followed by a systematic and rigorous analysis of the data after completion of the data collection. The aim in qualitative method is to intertwine the data collection and the interpretation of the material. However, after the data collection is completed, an analysis-phase takes place, aiming at finding material that can answer the research questions [51, 53].

Data transcription and translation

The qualitative research process involves transforming reality from conversation or observation into written text. However, it is important to be aware that the text is not the reality itself as it might lose several of the non-verbal cues, and can only give a limited picture of what is being studied. The text thus becomes an indirect representation of certain aspects of the reality, collected from a certain perspective [53].

In the current study the process of conduction of the in-depth interviews evolved and changed over the period of the data collection. The research collaborative partner led the conversation with the informants through the use of the Amharic version of the interview guide. Throughout the interviews we took continuous breaks where she translated the informant's stories to me. After conducting a few interviews, I was carrying out the interviews in English with continuous translation into Amharic, which allowed me to follow the conversation more closely and ask continuous follow-up questions. In the final phase when we became acquainted with the task and were quite united in our approach and thoughts concerning the topic, we both asked follow-up questions. This allowed for a necessary flow in the conversation with the informant's that was important, especially when talking about sensitive issues, e.g. feelings of shame or challenges of intimacy with partner.

Upon permission from the informants, a tape-recorder was used during all the in-depth interviews in order to facilitate a recapitulation of the exact content of the interviews through transcription of the material. The process of transcription and translation started immediately after the first interview was conducted, and early transcriptions and translations allowed for valuable evaluation of both the content of the interviews and of the research approach. The interviews were transcribed word by word to Amharic, followed by a translation into English. Due to practical circumstances some of the data was directly translated into English. All three transcribers / translators added valuable socio-cultural contextual explanations or clarifications in the text where they regarded it as important for my understanding. The research collaborative partner and myself reviewed the majority of the translations from the transcriptions to clarify misunderstandings and add additional contextual information, securing that the content of the translations were as close as possible to the meaning that we perceived was expressed by the women.

Systematic Text Condensation

The analytical framework chosen for this study was the 'Systematic Text Condensation'; a method inspired by Giorgis phenomenological analysis [56], but modified by Malterud [53]. The framework was found useful for the development of descriptions and perceptions related to experiences of involuntary leakage of urine. Four essential steps of the method were followed.

The first step of the method involved obtaining a '*sense in the whole'* [53]. The entire material was thoroughly read to get an overall impression of the content. Recurrent themes, as well as nuances were noted down, and a 'brainstorming-map' was developed from this process. The main themes emerging from the text were naturally similar to the themes brought up in the interview-guide, however new topics and nuances emerged. The major themes emerging in this phase were: 'making sense of the UI', 'feelings related to living with UI', 'social implications of the UI', 'practical handling of the UI', 'health seeking behaviour in relation to the UI' and 'situations in which UI is most challenging'. While reading through all the interviews, a table was made to gain an overview of general demographic background as well as some major patterns of conduct related to the condition.

The second step of the method involved *‘identifying meaning units’* [53]. This phase is important in order to separate relevant information in the text needed to answer the research question from more irrelevant information. A time consuming and systematic review, sentence-by-sentence, paragraph-by-paragraph, of each interview was conducted. The content was ‘coded’ based on the themes that emerged from the first step of the method. The themes were coded with a certain number (e.g. ‘1’) and underlined (with a colour pen) representing the theme on the left side margins, while the more detailed nuances of the empirical material, the sub-themes, were coded with another number (e.g. ‘1.1’ or ‘1.2’) and underlined (with a colour pen) at the right side of the margins.

The third step of the method involved what Malterud refers to as the ‘*transformation and abstraction of meaning units*’ [53]. During this phase the meaning and the content of each of the coded groups were sought condensed and summarized into fewer and broader meaning units, leading to a small re-categorization of the initial themes and sub-themes. Three new categories were used as meaning units: ‘experience of living with UI’, ‘practical handling of UI’ and ‘understanding and making sense of UI’. All categorises had several sub-groups. For example, the category ‘practical handling of UI’ had the sub-groups; ‘protecting from leakage and smell’, ‘managing to keep clean’ and ‘health seeking behaviour’. Each sub-group’s main content were summarised in own words and relevant quotes were used to highlight the recurring topics and patterns as well as nuances within the sub-group.

The forth step implied to ‘*synthesise (the material) into a consistent statement’* [53]. The insights from the condensed meaning units that at this point consisted of categories and sub-groups were integrated and described, reflecting patterns or strong factors 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. Finally the categories were referred to as ‘keeping clean’, ‘fear and embarrassment’, ‘hiding the leakage’, ‘experience of support’, ‘making sense of the leakage’ and ‘seeking help’. Throughout the writing process, original transcripts were frequently re-checked; making sure that loyalty to the informant’s own words were retained, and to ensure that the text was continuously located within its broader context.

Ethical considerations

Ethical approval for the study was obtained from the Regional Ethics Review Board in Western Norway prior to arrival in the field (cf. **appendix 1**). Ethical approval was also obtained from the Institutional Ethical Review Board at the University of Gondar (cf. **appendix 2**).

Prior to the start-up of the data collection in the health facility-based component, the Dean and the Clinical Director at the Gondar University Hospital were informed about the study and gave their approval for the study to be carried out at the relevant departments at the hospital. In the community-based component the data collection was carried out alongside the quantitative part of the study, run through the Dabat Research Centre. The DABINCOP study received an ethical clearance from the Institutional Ethical Review Board at the University of Gondar.

A consent form translated from English to Amharic was read out loud and was also given to all the informants. Depending on literacy status, written or oral consent was obtained from all informants. The consent forms were kept confidential. Both the English and the Amharic versions of the consent form are attached (cf. **appendix 3**).

The principles of voluntary participation, confidentiality, anonymity and the right to withdraw at any time without stating any reason were emphasized and explained thoroughly to each informant, both by reading through the consent form as well as explaining it in informal terms, ensuring that the informants understood the given information. One person did not wish to participate in the study. All informants consented to use of a recorder during the interview.

Ethical principles based on the 'Declaration of Helsinki' [57], were followed by both the research collaborative partner and myself throughout and following the fieldwork. All the data obtained from the participants, both the oral and written material were retained confidential. Numbers indicating the type of informant and in what setting the interview took place were created in order to differentiate between the informants. Information about the informant's addresses in the community-based component was kept safe and separately from the notes and transcriptions throughout the study. All confidential material from the study is to be deleted by latest 31st Dec 2013.

Synopsis of the study findings

Merely a brief synopsis of the study findings is presented here. More findings are presented in the paper manuscript following this introductory thesis.

The large majority of the women involved in the study experienced limited access to necessary remedies for keeping themselves clean, such as water, soap and extra clothes. None of the women used pads bought from the shop to protect from the urinary leakage. Most of the women did not use underwear, leading to free leakage underneath their long skirts and dresses. Some used homemade pads made out of cotton fabric commonly available in the household. Use of toilet and cleaning of the body for females should take place during the early morning or in the late evening hours according to socially acceptable norms, restricting the possibility to freely urinate and bathe during the daytime.

Independently of the severity of the symptom, most of the women had great fear of other people noticing the leakage, as it was found to be shameful and embarrassing, and regarded as unnatural and uncommon among adults. Great efforts were thus made among the women to keep the leakage hidden from husband, friends, family, neighbours and others. In addition to the fear of embarrassment, many women did not expect to be supported or understood by others if the symptom was disclosed. Some had however disclosed to a person in whom they trusted. These individuals commonly were supportive and emphatic. Others experienced discriminative behaviour, most often from neighbours and strangers. Women with continuous urinary leakage often were divorce and experienced social isolation due to their condition.

Most of the women related the involuntary leakage of urine to their reproductive life. However, others held socio-cultural explanations responsible, such as being possessed or beaten by bad spirits. Although most of the women had been in contact with the health system, they usually did not seek help for or disclosed the symptom to health personnel. If they did, it was often done as a last option after religious and traditional remedies were sought.

Discussion

This chapter starts with a section discussing the major findings of the study, where the aim is to highlight both socio-cultural and economical aspects influencing the women's experiences of living with UI, based on the theoretical approaches briefly presented in the introduction. In the second section the methodology employed for the current study is discussed and reflected upon.

Discussion of the findings

As was established in the introduction, the loss of control over the excretion of urine can, not surprisingly one may argue, affect several aspects of life, and may make everyday practises and social interactions challenging [4, 11]. In a Canadian study it was indeed found that urinary incontinence was among the three chronic conditions that had the most negative impact on an individual's health-related quality of life, especially among young adults [58]. The major findings from the current study illustrate that UI, clearly depending on the severity of the symptom, has substantial impact on the lives of the women suffering from it.

Shared understandings of urinary incontinence

Kleinman [39] writes how shared understandings in a particular setting and within a social group influences the experience and the understanding of an illness. In the current material, shared understandings of UI did emerge. Understandings based on common socio-cultural norms and perceptions in the community.

Bathing and urinating is something that in most societies is perceived as appropriate to do in private, hidden from other people's sight [11, 59]. For the women suffering from involuntary leakage of urine urinary in the current study, bathing or washing the body and urination should be hidden, not only from others, but also from daylight. The reasoning behind this custom may be linked to the fact that processes of cleaning as well as of going to the toilet in this setting takes place outdoor, and daylight increases the risk of being seen by other people while undressed. Some of the women found solutions while at home, but found it more challenging when away from the home, where creative strategies had to be used in order to minimise the risk of the leakage being discovered.

Urinary leakage is in most settings a socially inappropriate topic of conversation, a taboo, which makes it difficult to disclose it to spouse, family and friends [59, 60]. This applies also in the current setting. The difficulty of the situation is enhanced by the fact that the experience of involuntary leakage of urine was regarded as something uncommon and unnatural among most of the women. Lack of formal education or other avenues that would reveal that UI is indeed quite common, made women think that they were suffering from a highly unusual and unnatural condition. Women could thus not easily access informed information about the symptom of UI, what it is commonly caused by and how it can be treated, either through education or due to the secrecy from fellow women.

The lack of knowledge about UI led to diverse explanations regarding the cause of the symptom among the women. Most of the women related the problem to their reproductive health, which is indeed a known risk factor of UI [6]. Many of the informants emphasised a lack of support at the time of delivery, as well as a lack of proper nutrition during the time following the delivery as potential factors that may have caused the symptom. The women did however also present other cause factors for their problem. The perception that evil spirits had caused the involuntary leakage of urine was commonly expressed. Some feared for example that they had been 'beaten' by evil spirits while urinating outdoor in a place where the soil had been or were heated up by the sun. This finding is also recorded in other studies [61]. Excess heat from the sun is moreover explained to cause disease in Ethiopia, and sun shining on soil moistened by urine is believed to cause disease to the genital organs [62]. The perception of contracting disease by evil spirits thus put additional restrictions on the women's possibility of urinating during daytime. Evil spirits were also related to the house spirits that several informants were worshiping in order to avoid misfortunes. Many thus related the cause of the urinary leakage to not having succeeded in sacrificing to the house spirits in a satisfactory manner. Some further regarded the urinary leakage as a punishment from God. These are all typical characteristics of local aetiology in Ethiopia, where perceptions that God, evil spirits and sorcerers may cause disease are common [61].

Health seeking behaviour

The perceptions of UI are of great importance also for the understanding of how the women acted in relation to the symptom. According to Kleinman [39], the personal and social meaning created of an illness through the shared understandings in a setting or in a social group influences not only the experience of the illness, but also the actions taken in relation to it. As the women lived in settings where several therapeutic health systems co-exist, it is useful to distinguish between these systems when looking at factors influencing the women's health seeking behaviour.

What Kleinman [41] describes as the *popular sector* seemed to be of relatively limited importance for the women in the current study. The strong taboo attached to the symptom of UI led many of the women to keep quiet about their problem and deal with the leakage as secretly as possible. However, those who did disclose to a person close to them explained that they did receive support and encouragement. The individuals disclosed to were commonly close relatives. Also other studies have revealed that many women living with UI hesitate to disclose their problem to others, often due to fear of embarrassment, consequently leading some women to never seek help or treatment [59, 60].

The perception of evil spirits causing the urinary leakage led many of the women to seek advice and help at *awakis* and at the holy water *(tsebel).* Both of these forms of healing fall under what Kleinman [41] refers to as the *folk sector.* The *awaki* is closely connected to the belief in the house spirits, and he has the ability to assess the situation, and may give advice in relation to what needs to be sacrificed to please the spirits in attempts to heal illness and suffering. The holy water is commonly used for healing within the Ethiopian Orthodox Church in relation to all sorts of ailments, and is partly based on the belief that the drinking or washing the body with large amounts of holy water may force evil spirits to leave the body and cause healing [61]. Often the same person sought both these types of healing, and this did not seem to imply contradictions. What was noteworthy was however that neither of these healing alternatives did involve disclosure of the symptom, as disclosure was not an obligation for receiving help. This meant that the women could continue to keep the urinary leakage hidden with the implication of lack of support.

The health care facilities within the district of where the interviewed women lived, as well as at the hospital in Gondar must be located within what Kleinman [41] refers to as the *professional sector.* The fact that the majority of the women had been in contact with the official health care system at one point or other revealed certain experience with the biomedical health system. However, a number of barriers were revealed in relation to decisions of seeking help at a health care facility. An important barrier in this connection was the fear of disclosing the symptom, also to health personnel, due to its strong relation to shame. However, some of the women did disclose their problem to health workers and were presently under treatment at the hospital, but these were merely the ones with the severe forms of UI that could not be hidden from the public, and which had long since been disclosed.

Three levels of experience

Scheper-Hughes and Lock's [46] concept of the 'three bodies' can possibly be drawn upon briefly to illustrate different levels within which to gain enhanced understanding of the dynamics at hand. The symptoms of UI may be made sense of in relation to the women's own personal experience, in relation to other people and in relation to the women's structural conditions. The three levels overlap, and cannot be understood as entirely separated from each other. However, they nonetheless seem to represent three different and important arenas in relation to how the women experience living with involuntary leakage of urine.

The *individual body* [46] is in this relation employed to evaluate the women's own image of the UI, the meaning she gives to the problem and her subjective experience of her body suffering from it. Feelings of discomfort and being dirty due to the urinary leakage were expressed among informants across all degrees of the symptom. Feelings of shame and embarrassment were furthermore prominent among all informants. However, when the women were asked about how the urinary leakage made them feel, the question often needed to be modified, rephrased or further probed in order for the informants to understand and respond to what we sought information about. Studies have revealed that some women tend to use silence as a strategy to handle the stress and embarrassment associated with UI, and moreover to avoid feelings of guilt for causing reactions of disgust in others and being rejected from the society [59, 60].

Experiences of discomfort, shame and embarrassment are thus impossible to solely include in the *individual body,* as these feelings are influenced by the socio-cultural norms emerging in the context in which they are experienced. There was an important distinction however between the ones who had disclosed and those who had not. For the women who had disclosed, usually the ones with the most severe degrees of UI, the shame and embarrassment was commonly a direct consequence of the discrimination they were exposed to. Often these women also experienced feelings of sadness, hopelessness and loneliness. For the ones who had not disclosed their urinary leakage to anyone, the shame and embarrassment was related to a fear of being discriminated against. The fear led to great efforts to hide the problem, which can be regarded as a strategy employed by the women in order to maintain everyday life and their roles in the household and in the community. The close confidants and supporters for some of them seemed to ease these women's lives enormously.

Although the *social body* [46] has dimensions beyond the ones just touched upon, it is difficult not to point to the roles women have in the communities in question and the relevance of this contextual factor for the handling of the urinary leakage. In very general terms the status of women in Ethiopia is low, as women are generally poorer and less educated than men, with limited decision-making power [29]. Many of the women in the current study had married around the age of 10 years, which for the majority had led to no education as well as early pregnancies, increasing the risk of obstetric complications due to childbirth before reaching physical maturation [37]. The contextual situation the women live in expose them to severe physical burdens, leading to potential nutritional depletion and poor health, which actually leave women in high risk of contracting UI during life. Their marginal situation vis a vis their husbands thus leaves them without time, support or money to improve the situation.

The married women in the current study were usually responsible for all household chores, and did not access the household's money or leave the household without the husband's approval or company. This moves us quickly to the *body politic* [46] which is here employed to look at how economic and structural factors in the current context may further hamper the daily handling of the UI. As we have seen, severe limitations or restrictions were placed upon the possibilities the women in the current study had for preventing and improving the urinary leakage. Access to enough water to keep bodies and clothes clean was severely limited due to the common long distance to the water source. The lack of access to soap and pads due to their limited access or affordability prevented many from buying such remedies and increased the difficulties of properly handling the symptom. Lack of underwear or clothes for change added to the challenge at hand.

Structural factors beyond the lack of means to keep clean were moreover found. The very high levels of illiteracy among the interviewed women led to limited knowledge about UI and the possibilities to improve the situation. The long distance and limited access to a well functioning health system, including emergency obstetric care, partly explains the high numbers of pregnancy and birth related disabilities in rural Ethiopia as well as the lack of a sense of potential help found within the official health system. The health personnel in the semi-urban area indeed were found to have limited experience with women seeking help for milder types of UI and moreover explained that they had little to offer if women sought help.

The above discussion indicates that aspects related to the individual, the social and the political body have to all be taken into account in attempts to make sense of UI in the current setting.

Reflections of the research methods

It is essential with proper research methods to ensure quality of the research data. Various ways of improving validity in qualitative research have been suggested. Some suggestions from Mays and Pope [63] on how to improve the credibility of findings in qualitative research will here be briefly reviewed in relation to the current study.

By use of *triangulation* [63] in qualitative research, one compares results from different data collection methods or data sources, with the aim of finding corresponding and diverging patterns to develop an overall interpretation. The assumption is that weaknesses in one method to some extent may be compensated by strengths in another. Comprehensiveness and reflexive analysis of the data may thus be improved. The use of focus group discussions was initially planned for the current study, however, due to the topic's highly sensitive character it was not considered feasible to employ such a method in this particular study setting. However, different data sources were employed. The inclusion of women experiencing different degrees of UI gave insights into wide spectres of a highly diverse phenomenon. The inclusion of health personnel, relatives and a traditional healer gave insights to differently positioned actors with experience of UI, and added valuable and often confirmative information when comparing to the findings from the women who were suffering from the symptom. This may have added validity to the study. Furthermore a large number of 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.

Personal and intellectual biases, through prior assumptions or experience make up a threat to the credibility of any qualitative research project. *Reflexivity* [63] is therefore of enormous importance to enhance the credibility of the findings. This involves being sensitive to how the researcher and the research process have shaped the material collected. In the current study, both the research collaborative partner and myself being nurses could of led us to be associated with the professional health sector resulting in a restriction of shared information from the informants. However, it was made clear to the informants that we did not work at the hospital or at the health centre, in order to possibly limit this association. Being females was most probably an advantage, since the topic in question was sensitive and highly gender specific. Our young age might however have influenced the openness negatively, especially among the older informants. Coming from a different social and cultural context with limited language skills in Amharic undoubtedly had an impact on how the informants perceived me, which could create a gap between the informants and myself. In attempts to limit the gap, I strived to be sensitive towards local social and cultural norms, e.g. by following the socially acceptable dress code for women in the area, greet people in a social acceptable and respectful manner and learn useful phrases in Amharic. There may moreover be aspects of being a 'foreigner' that eases people's will to speak about sensitive topics that are regarded as taboos and stigmatised, as the outsider is considered less of a treat to the informant.

A *clear exposition of the process of the data collection and the analysis* [63] is additionally important in qualitative research due to the influence the methods have on the objects of inquiry. The interviews were mainly situated at the women's home in the community setting, assuming that it would be a relaxing atmosphere for the woman to speak freely in as she would be in her own safe environment. However, interviewing in the their homes did create some challenging situations where curious children, neighbours or family members disturbed the conversation, and possibly influenced the atmosphere of the interview setting by making the woman worried about people around listening in on the conversation. Efforts were made to limit these disturbances by talking to everybody in the household prior to the interview, which usually gave fewer interruptions and a more relaxed atmosphere.

Since neither I, nor the research collaborating partner transcribed the data, there was a potential for the translations to contain misunderstandings. However, the careful review of the transcriptions by the research collaborating partner helped limit this potential pitfall. The analysis of the material was primarily carried out by myself, but was assisted by continuous discussion and follow-up, first with my research collaborative partner in the field and later by the main supervisor of the study.

An important aim for qualitative research is that the findings will have *relevance* and be *transferrable [63],* and thus possibly be of relevance by others in similar settings or groups. These aims can be reached through thorough and critical reflection and discussion of the method and analysis [53, 63]. As urinary incontinence is a topic yet limited researched in low-income settings, there is scarce knowledge to compare the findings of the current study with. However, this reinforces the initial aim of adding to existing knowledge within the topic-area. 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 likely that the findings from the current study may have relevance for similar settings within Ethiopia, but also to some extent for other low-income settings.

Conclusions

Through the stories of women living with urinary incontinence in these particular rural and semi-urban areas of northwest-Ethiopia, valuable information of a possibly highly prevalent and strongly tabooed, yet scarcely researched topic in the area was obtained. Recognizing the limitations implied by the severely restricted opportunities of keeping clean, of lack of access to knowledge about the symptom they suffer from, and of a health system that can offer little remedy is vital in any attempt to understand the embarrassment and shyness of the women, the local aetiology and the attempts of healing outside of the official health system. Only a fundamental recognition of the context of the women's suffering makes it possible to grasp why the majority of the women in the current study who suffers of urinary incontinence chose to keep the problem to themselves, and instead secretly employ strategies to handle their situation in order to continue daily tasks and maintain social relations.

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Paper

Silently waiting to heal

Experiences among women living with urinary incontinence in Ethiopia

Janne Lillelid Gjerde[1]

Abstract

Introduction: The aim of this study was to gain in-depth knowledge of women suffering from urinary incontinence (UI) in rural and semi-urban settings in Ethiopia.

Methods: A qualitative study based on semi-structured in-depth interviews of 18 women experiencing the symptom of urinary leakage. The study was conducted in Northwest Ethiopia, and was part of the Dabat Incontinence and Prolapse (DABINCOP) study.

Results: Limited access to water, soap, pads and spare clothes characterised the daily management of the symptom. The consequences for the marital relation and social life were of great concern to the informants. Shame, embarrassment and fear of being discriminated led to huge efforts to hide the urinary leakage. Among the informants who were not able to hide it, humiliating comments and discriminative behaviour was commonly experienced, sometimes leading to divorce and self-isolation. On the other hand, women who had disclosed their symptom usually had a person who supported them. Women with UI regarded it as an unnatural and uncommon condition. Most of them did not take action to improve the situation.

Conclusions: The findings differ considerably from research from more affluent countries, underlining the importance of addressing contextualised and socio-cultural dimensions of UI to reveal the conditions that may hamper the opportunities for proper handling of the symptom.

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Keywords

Ethiopia – Experience – Perception – Practice – Reproductive health – Urinary incontinence

Abbreviations

DABINCOP	The Dabat Incontinence and Prolapse Study
UI	Urinary incontinence

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Introduction

Urinary incontinence (UI), defined as the complaint of involuntary loss of urine [1], affects around 25 % of women in European countries such as Norway and the UK [2, 3]. UI is a common symptom that impacts on several aspects of women's life, from the physical to the psychosocial and social well-being [3-7]. UI may also have economic implications [8]. A qualitative study from Germany found that UI influenced partner relationships as well as social, cultural and sportive activities, and that informants used complex strategies to regain control [5]. A study from the Netherlands showed that fear of people noticing the condition, embarrassment, fear of bad smell and loss of confidence in doing daily chores were common among women with UI [6].

Due to enormous differences in the living conditions between high- and low-income settings, some of the implications related to UI reported from high-income contexts are, however, not readily transferable to or relevant in a poorer context. While studies from low-income countries have enhanced the global knowledge on obstetric fistula, less attention has been given to women who suffer from far more prevalent, although milder forms of incontinence [9]. A review study as well as other recent studies from low- and middle-income countries regarding pelvic floor dysfunctions, suggest that the consequences and the effects on the quality of life for women suffering from UI in low-income settings is more severe than for women suffering from the same symptom in more affluent countries [9-12]. The knowledge of the implications of living with UI for women in low-income contexts is still very limited. The current study was designed to contribute to such knowledge.

The symptom of UI is found in European studies to be typically related to women's reproductive history, childbirth being one of the major risk factors among women under 65 years [13, 14]. The fertility rate in Ethiopia is 5.2, and only 6 % of all births are attended by skilled personnel [15, 16]. Both of these factors have been linked to the high Ethiopian maternal mortality ratio of 676 deaths per 100,000 live births [17]. Annually 25,000 Ethiopian women die due to pregnancy-related causes, and 400,000 women experience pregnancy and birth related disabilities [18]. Health facilities are often scarcely equipped and have limited emergency obstetric services. The facilities are moreover often located far away, and are often accessible only by foot [19]. Ethiopia has a severe shortage of health workers, with coverage of 2 physicians and 24 nurses and midwives per 100,000 people [15].

The current study is part of the DABINCOP (Dabat Incontinence and Prolapse) study, a collaborative research project between the University of Bergen, Norway, and the University of Gondar, Ethiopia. The DABINCOP study aims at establishing prevalence rates, risk factors and exploring the experience of living with various pelvic floor disorders. To enhance the quality of the research, close links between the qualitative and the quantitative research components is sought. The current sub-study, grounded in medical anthropology, aimed to explore the practical handling of UI, its social implications, the perceptions of the symptom and the health seeking behaviour among women suffering from involuntary leakage of urine in this particular low-income setting.

Materials and Methods

The current study was conducted in the Amhara Region, Northwest Ethiopia, and consisted of two parts: I. A health facility-based component conducted at the gynaecology ward and at the outpatient clinic at the Gondar University Hospital in Gondar city. II. A community-based component conducted in three villages (*kebeles* - the smallest administrative units in Ethiopia); one located in a semi-urban area and two located in rural areas, all three settings located in the Dabat district (*woreda*) about 75 km north of Gondar city.

The major ethnic group within the zone is the Amhara, and Amharic is the first spoken language. The majority of the population in the area are Ethiopian Orthodox Christians, while around 4.3 % are Muslims [20]. The fertility rate in the Amhara-region is 5.1 child per woman, 75, 6 % of the women are illiterate, and the region has the lowest median female age for first marriage of 14.4 in the country [21].

A qualitative design was employed, and in-depth interviewing through semi-structured interview guides was the main method employed for the collection of the data. The interviews were explorative, aiming to let the informant speak at length with minimal guidance and interruption. A female research collaborator, a nurse from the area who was well acquainted with the language and culture, was essential for the implementation of the study. The collaborator was introduced to and trained in a qualitative research approach prior to the data collection. Observation and informal talks throughout the time spent in the field enhanced the understanding of the phenomenon studied. The data collection was conducted between March and June 2011.

A total of 26 informants were included in the current study with the major emphasis placed on women with UI (**Table I**). Data collection took place in the health facility prior to the community. Purposeful sampling, with the aim of finding individuals with the relevant experience and who were differently positioned vis-à-vis the study topic, was employed to recruit informants. Health personnel identified potential informants in the health facility. The interviews took place in a separate room at the ward. In the community, potential informants were identified based on findings from the structured interviews or the clinical examination that were conducted by the quantitative part of the DABINCOP pilot study. The interviews primarily took place in the women's homes, but some were carried out inside or outside of the village health posts, depending on the woman's wish. The interviews with health personnel took place at the hospital and at the health centre in the semi-urban area. After data collection, the informants with involuntary leakage of urine were categorised according to the frequency of their symptoms (**Table II**). The women interviewed at the health facility all suffered from continuous leakage possibly due to obstetric fistula, while the women in the community suffered from urinary leakage ranging from mild to continuous.

The research collaborator translated continuously during the interviews, giving the researcher the opportunity to ask relevant follow-up questions. She also asked follow-up questions herself, especially when the topic was sensitive and it was important to maintain the flow of the conversation. A digital recorder was used to record the interviews. The data material was transcribed in Amharic, and was later translated from Amharic to English. Parts of the transcribed and translated data material was later reviewed to secure that the full content was retained with an emphasis placed on retaining the culturally embedded expressions and explanations.

The analysis process was based on the 'Systematic Text Condensation', a method inspired by Giorgi's phenomenological analysis [22], but later modified by Malterud [23]. A manual process took place, including a thorough review of the full material followed by a rigorous and systematic process of searching for core themes running through the material. Nuances in the material were systematically sought, including potential ambivalences and contradictions to gain a sense of the recurring themes and patterns as well as ambiguities within the data.

Ethical approval for the study was obtained from the Institutional Ethical Review Board at the University of Gondar and from the Regional Ethics Review Board in Western Norway. The aim and purpose of the study, as well as the consent form was read out loud to the informants, and a hard copy of the information was handed out to all informants. Written or oral consent to participation was obtained depending on literacy status. The main principles of the Declaration of Helsinki [24] were explained thoroughly to each informant and were attended to throughout the study.

Findings

Keeping clean

All informants with urinary leakage strongly emphasised a focus on trying to keep as clean as possible. Water and soap was not easily accessible for any of the informants, and the majority described walks of one to two hours, usually twice daily, to fetch water by the use of jerry cans (holding 20 – 30 litres). As the fetching of water is a female duty, mothers and daughters are responsible for this chore. Despite the long distances and heavy loads the women did not express much complain about this. Lack of soap was more often mentioned as a limitation for managing to keep clean. *'I would prefer cleaning with soap to avoid the smell, but the market is far away and we face shortage of money'* (woman, 30 years, moderate leakage). It was acceptable for the women to use the toilet and wash their bodies only early in the morning or in the evening when it was dark outside, as washing the body and sitting down to urinate or defecate during the day when somebody could observe them was explained to be inappropriate as well as unhealthy for females when the sun was strong. The smell of urine was experienced as unpleasant both to the women themselves and to others in the household if they did not manage to keep clean and to get outside in time of leakage. The women's households commonly shared a small latrine with other households, or used backyard or surroundings of the home as a toilet. Most informants lived in houses with an earthen floor. Dried cow dung was commonly used on the floor to keep insects away, as well as to keep the floor clean and nice. *'For me it is not a problem, but when people come to have coffee at our home I tell her [the wife] to clean, put water on it, or cover it [the urine]. She cleans it by covering it with cow dung, as we have this in our surroundings'* (husband to 27 years old woman with continuous leakage).

Most of the informants did not use underwear, and they let the dress or skirts absorb the leakage until they reached an appropriate place to sit down. *'Usually I will rush out of my home, holding it in my dress'* (woman, 38 years, continuous leakage). *'If I feel that it flows when I'm at a feast I will try to manage to control it by tightening my clothes and then leave* *the area, as if I am going to collect firewood'* (woman, 35 years, moderate leakage). For some it was a challenge to find remedies to protect from the leakage. *'I don't have anything that I can employ to prevent from the leakage'* (woman, 30 years, moderate leakage). None of the informants used sanitary pads from shops, but some made pads from cotton fabric. *'I will put some cloth on allowing it to drip'* (woman, 60 years, mild leakage). The pads would normally be tied around the abdomen or be placed underneath them when sitting or laying down. *'I put it on when I sleep and when I sit. When I stand and walk around it falls off. I frequently wash it and use it again'* (woman, 38 years, continuous leakage). Some informants also used a thin plastic sheet on the chair and bed. Another common strategy practised was to limit and control intake of fluid. '*The problem will be when I go far away or to a mourning place. At this time I will not take any food or drink so that I can avoid the consequences. It is in this way that I manage to control the problem'* (woman, 48 years, continuous leakage).

Fear and embarrassment

The women strived to keep the urinary leakage hidden from others. *'Even though the problem is serious, I prefer to keep it as a secret and I haven't told anybody about it' (woman, 34 years, severe leakage).* There was a fear of other people knowing among most of the women. *'I fear that the problem will occur in public, and I wonder what people would have said about it. I feel embarrassed of what they might think about me'* (woman, 60 years, mild leakage). The urinary leakage was thus related to embarrassment and shame among the majority of the women. *'Since it happens also during social gathering I feel discomfort and ashamed. I see myself as dirty because of the smell of my body and clothes'* (woman, 40 years, severe leakage). Many of the women talked about how the leakage felt unnatural. *'We get it late after we are born, so it is not natural'* (woman, 40 years, severe leakage). *'Us mothers talk among each other about what we are going to do if a child urinates while sleeping. We frequently say that we will punish them...being a mother and not able to control your urine is embarrassing. It flows when I laugh as if I am a kid'* (woman, 35 years, moderate leakage). Another informant explained that if people knew about her condition they would make fun of her and say that she '*urinates while standing like a man'* (woman, 45 years, moderate leakage). Many of the women also revealed worry, sadness or hopelessness. *'I worry about the future, what will happen to me…I don't know what I can do. The only thing I do is feeling sad'* (woman, 35 years, moderate leakage).

Hiding the leakage

The women feared embarrassment and humiliation, and the ones who were able to hide the urinary leakage strived to keep it a secret even to their closest relatives. *'It is difficult to tell about this to one's mother, let alone a husband, because this is a difficult issue'* (woman, 45 years, moderate leakage). Most of the informants were living with their husband, meanwhile hiding the symptom. '*No one is closer to me than my husband. He is a part of me, but I don't even tell him'* (woman, 45 years, moderate leakage). The reasons for not disclosing were usually related to feelings of shame. *'Though I have a child with him, I am ashamed to tell him about the condition. I know the consequence will be embarrassment'* (woman, 35 years, moderate leakage). Another common explanation was the fear of not being supported. *'I don't think he will say something bad, but I don't think he will help me either…he would not be supportive. He would probably say; "I have many children to support and I am not going to support you too"* (woman, 45 years, moderate leakage). Some women, however, found it difficult to hide the urinary leakage from their husband. Often these difficulties were related to intimacy. *'Recently it began to flow [during sexual intercourse], and it is becoming a serious challenge. He has never noticed it, as I hold it in my dress and wipe it if it flows'* (woman, 45 years, moderate leakage). Another informant who leaked during nights explained how she hid the urinary leakage from her husband; *'as the children sleep in the same bed as me, I blame the wet bedclothes on them'* (woman, 30 years, moderate leakage).

Most of the informants kept quiet about the urinary leakage also to relatives, friends and neighbours. One informant explained that '*it is because we believe that the disease we face will not stay long and will get healed, so we don't tell others. We just wait to get healed'* (woman, 45 years, moderate leakage). Informants explained that many health issues could be discussed openly among women, but that leakage was not one of them. *'I've never heard about anyone with the same condition. Problems of pain we all discuss among each other, but not the problem of urine'* (woman, 45 years, mild leakage). The reason for the silence was mainly a fear of not being understood and of being discriminated. *'The problem is mine; there is no need to tell others. If they hear about it they will discriminate me and talk about me behind my back* (woman, 40 years, severe leakage). *'People will say; "Mr. X's wife is urinating while standing". Since we are all uneducated nobody would understand'* (woman, 45 years, mild leakage). Some of the women had, however, disclosed to one or few selected people who they trusted. Usually this was their mother, sister or a close friend. An informant's sister explained: *'It is not a big problem if she and I are alone, as I help to keep her clean and give her clean clothes'* (sister of woman with moderate leakage).

Experience of support

In the cases where the husband was aware of his wife's leakage of urine, some of the women explained a lack of support. *'My husband has slept in a separate bed during the last three or four years as he says it has a bad smell…I repeatedly ask him to send me to the health institution, but he refuses'* (woman, 48 years, continuous leakage). Some informants, primarily the ones with severe or continuous leakage, said that they were divorced due to the problem. '*It was after the problem occurred that I got divorced. After the leakage started he left me and married another woman'* (woman, 40 years, continuous leakage). Some did, however, experience support from their husband. A woman explained her husband's reaction after disclosing: *'He [my husband] said "go for treatment before it gets worse", but the problem is that we have shortage of money'* (woman, 45 years, moderate leakage). A husband, who had been disclosed to, explained: *'We are husband and wife. Whatever she has I will still have her with me. I don't discriminate her because this happened. I don't say anything'* (husband to woman aged 27 years with continuous leakage).

Most informants explained that it was particularly neighbours and strangers who behaved in discriminatory manners, while the closer family often showed more support. *'My relatives are worried about me; they sympathise with me and say "what a tragedy has happened to our sister"'* (woman, 27 years, continuous leakage). For some of the informants, especially those experiencing continuous leakage and who therefore could not easily hide their problem, living a normal social life was impossible. Lack of means to hide the smell of urine often led to the women living more or less socially isolated. *'After I began facing this problem I never went outside home anymore. I stopped visiting my relatives or any other people around. I lost a lot of things…I feel like a dead person'* (woman, 38 years, continuous leakage). Another informant explained how she experienced being around people in public: *'People abuse me, and use insulting words towards me. They also spit when I'm around, and tell me not to sit next to them'* (woman, 27 years, continuous leakage).

Making sense of the leakage

Most of the women related their problem to a delivery. The women with continuous leakage typically related it to a 'technical' delivery at the hospital that involved 'tools', 'cutting' or 'harsh handling' from the health personnel. Among the women with milder leakage, explanations often involved not having received enough help from other women at the time of delivery, delivery at a too young age, too many deliveries or having experienced a lack of food or support after delivery. Hard work, injury, rape and abortion were also factors mentioned as causes for the urinary leakage among the informants.

Other more socio-cultural related cause factors were also mentioned. Some informants explained that it was their house-spirit '*Kole*'; evil spirits who needs to be worshiped in order to avoid misfortunes and disease, that was causing the urinary leakage. *'We worship Kole, but it turned against us because I failed to slaughter a sheep when I first faced disease'* (woman, 38 years, continuous leakage). A nurse at the gynaecology ward at the hospital explained that she frequently heard patients expressing that their urinary leakage was a punishment from God, which is a common belief within the Ethiopian Orthodox Church. Some women expressed that having urinated in a hot place during the daytime caused urinary leakage. It was explained that urinating in the daytime in an open area where the sun was shining could cause *'mitat'* (being beaten by evil spirits), which could lead to health problems to the female genital organs, such as urinary incontinence. *'Sitting in a hot place or urinating in a hot place causes this condition. It doesn't have any relation to delivery. It is caused by hot things'* (woman, 45 years, moderate leakage).

The health personnel in the community brought up the practice of early marriages as an important cause factor for UI among women in the area. *'Early marriage is still practised in the area. Many do it secretly so that they can avoid being charged of crime. Early marriage will be followed by early age pregnancy which is the immediate cause of this problem'* (female health officer, semi-urban area). Health personnel at the hospital also mentioned factors such as pregnancy at young age, long distance to emergency obstetric care and people preferring to seek help other places before reaching the health centre or hospital, as potential cause factors for UI.

Seeking help

Most of the informants had been in contact with the health system, however, rarely for the symptom of UI. Among the informants in the community, only a few women had disclosed their problem to public health workers. All the informants in the health facility had previously been unaware of or unable to seek help at the hospital, but had recently been referred to the hospital for free treatment by health extensions workers.

Holy water (*tsebel)* was sought by most of the informants. Holy water is the most common mode of healing within the Ethiopian Orthodox Church, and is believed to have the power to cure any disease and erase bad spirits possessing the body. Fresh water in the form of springs or streams is considered holy when it is located inside or close to a church, and when a priest blesses the water by the use of a cross. Most of the women had not openly disclosed at the location of the holy water. *'I didn't tell my family members, let alone the people in the holy water area'* (woman, 45 years, mild leakage). Some of the women worshiped in their homes to please the house spirit, by preparing coffee, by wearing new clothes or by slaughtering chickens. An '*awaki',* a person who is considered to have a certain connection with the house spirit, would also be visited in attempts to seek remedy and cure. An '*awaki'* acts as a messenger between the house spirits and human beings, and informs the patient what needs to be addressed or worshiped in order to mend unfortunate health conditions. Some of the informants did, however, say that they had never sought help anywhere for the urinary leakage. *'It never came to my mind that I could get cured, so I never attempted to seek advice'* (woman, 27 years, continuous leakage).

Health personnel in the community-based component explained that they had limited or no experience with women seeking help for UI. *'They go to holy water or traditional healers. It is after exploring these options that they come to us'* (female health officer, health centre, semi-urban area). Another health worker explained what he believed prevented women from seeking help at the health centre: *'It is most probably due to not believing that they will get cured here, and also due to fear of being discriminated'* (male nurse, health centre, semi-urban area). They also explained that they had limited material and trained personnel in order to treat or assist women with UI, rather they would refer affected women to the hospital. The traditional healer explained that she offered help and remedies to females, males and children with health problems. She had once experienced that a woman came to her asking for advice regarding urinary leakage. *'I advised her to go to the health institution. I simply gave the advice and kept quiet about it. Their life is theirs, and not mine. I only give them the advice…they don't talk about it because they are ashamed about it. There is no one who talks about it'* (traditional healer, 62 years, semi-urban area). The health personnel at the outpatient clinic at the hospital frequently experienced women seeking help for UI. Most often it would be women with continuous leakage, who would be admitted for free treatment. Other and milder degrees of UI would usually not be prioritised for admission due to shortage of beds, though pelvic floor exercises was said to be provided at the outpatient clinic.

Discussion

Experiences of living with UI in an Ethiopian setting in the current study emerged in substantial contrast with experiences reported from women living in more affluent settings [5, 6, 8]. Our understanding of living with UI emerging from this low income setting may be enhanced by briefly drawing upon two major strands of theory within medical anthropology, theory in which cultural and structural conditions are given attention.

The main limitation of the current study is that the researcher has limited socio-cultural and language competence. This limitation was however partly compensated for by the close collaboration with the research collaborator with excellent communication skills and wide knowledge of local codes, customs and health related behaviour. The current sub-study was carried out in close collaboration with the quantitative part of the project that most importantly provided access to women with UI symptoms.

According to Kleinman [25], the perception, experience and action related to any symptom of suffering is dependent on shared understandings and meanings given to the condition within the particular historic and cultural setting. The ways in which UI was perceived, made sense of and handled by the women in this particular study setting did indeed emerge as partly culturally constituted. It is common in Ethiopia to make a connection between sun shining on soil moistened with urine and disease in genital organs [26], and perceptions of disease as caused by God's punishment for indiscretion are moreover commonly found [27]. This line of reasoning has obvious implications for women suffering from UI. Customary aetiology within the Ethiopian Orthodox Church commonly links illness with the work of evil spirits or sorcery [27]. Aetiology is closely related to the ways in which people seek remedy and care. In the current material we found that the women suffering from UI would commonly seek help from traditional healers (*awaki)* and through religious means *(holy water)* before considering seeking help from the official health care services. A strong experience of embarrassment due to the suffering from a symptom that is considered rare and shameful was moreover found within this study setting, often keeping the women from disclosing their symptom. The enormous struggle to maintain social ties while hiding the leakage thus characterised many of the women's stories. Among the ones who did not manage to hide the problem, experiences of discriminative behaviour leading to isolation and at times divorce were reported.

To gain a comprehensive view of women's experience of living with UI in this rural Ethiopia setting, cultural explanations do however have to go hand in hand with a scrutiny of the practical and structural conditions. The women in the current study were unable to absorb the urinary leakage in disposable pads, they spent hours daily to fetch water, and there was limited access and affordability to soap as well as to spare clothes. These conditions severely limited the women's possibility of keeping clean and thus keeping odour away. The smell of urine is related to being dirty and will cause reactions of disgust irrespective of society, however, Farmer, Scheper-Hughes and other scholars within critical medical anthropology [28-30] reveal the extent to which disease is constituted by conditions of poverty, powerlessness, marginalisation and institutionalised hopelessness. Long distances to a health centre and the fact that a health centres commonly have little to offer the women suffering from mild to severe UI makes it reasonable to search for care and cure elsewhere. The decision making power of women living in rural Ethiopia is moreover hampered by illiteracy and early marriage [19]. Early marriage is particularly widespread in the northern regions of Ethiopia, and lead to limited education and early pregnancies with high risk of obstetric complications [31].

A fundamental recognition of the limitations implied by the severely restricted opportunities of keeping clean, the lack of access to knowledge about the symptom one suffers from and the lack of access to a health system that can offer remedy is vital in our attempt to understand the embarrassment and shyness of the women, the local aetiology and the attempts of healing outside the health system revealed in our study. Indeed for the women in question there is little option beyond keeping silent and hoping that the leakage will heal by itself.

Acknowledgements

The authors thank all the study informants, not the least the women suffering from UI who shared their experiences with us. We thank Professor Yigzaw Kebede (PI of the DABINCOP study) and the rest of the engaged research team for close and valuable collaboration throughout the process. Sincere appreciation to Hanna Abebe, the research collaborator, for vital assistance throughout the fieldwork period. We also thank Hibste Mekonnen and staff at the Department of Social Anthropology at the University of Gondar for valuable assistance and collaboration throughout the data collection period.

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Table I. Overview of the informants in the study

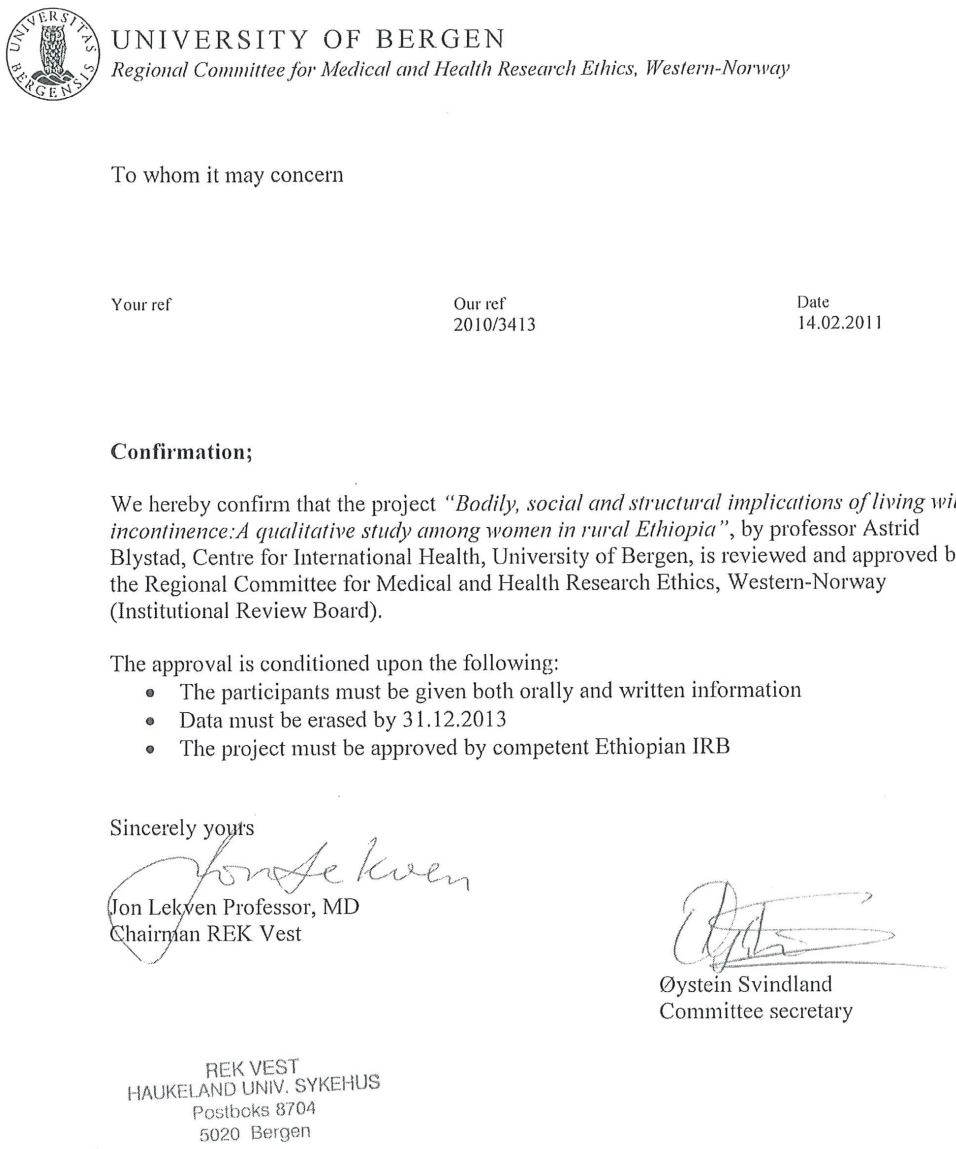
Health facility component	(N = 7)	Community component	(N = 19)
Women admitted to hospital	4	Women in semi-urban area	5
Health personnel	2	Women in rural highland	5
Husband (of woman admitted to the hospital)	1	Women in rural lowland	4
		Health personnel at health centre in semi-urban area	3
		Traditional healer in semi-urban area	1
		Relative (sister of woman in semi-urban area)	1

Table II. Frequency of involuntary leakage of urine

Mild leakage Women with involuntary leakage of urine once or up to a few times a month	2
Moderate leakage Women with involuntary leakage of urine once or up to a few times a week	6
Severe leakage Women with involuntary leakage of urine on a daily basis	5
Continuous leakage Women with involuntary continuous leakage of urine	5
Total number of informants with UI	**18**

Appendixes

Appendix 1: Ethical approval, Norway



UNIVERSITY OF BERGEN
Regional Committee for Medical and Health Research Ethics, Western-Norway

To whom it may concern

Your ref	Our ref	Date
	2010/3413	14.02.2011

Confirmation;

We hereby confirm that the project *"Bodily, social and structural implications of living with incontinence:A qualitative study among women in rural Ethiopia"*, by professor Astrid Blystad, Centre for International Health, University of Bergen, is reviewed and approved by the Regional Committee for Medical and Health Research Ethics, Western-Norway (Institutional Review Board).

The approval is conditioned upon the following:

- The participants must be given both orally and written information
- Data must be erased by 31.12.2013
- The project must be approved by competent Ethiopian IRB

Sincerely yours

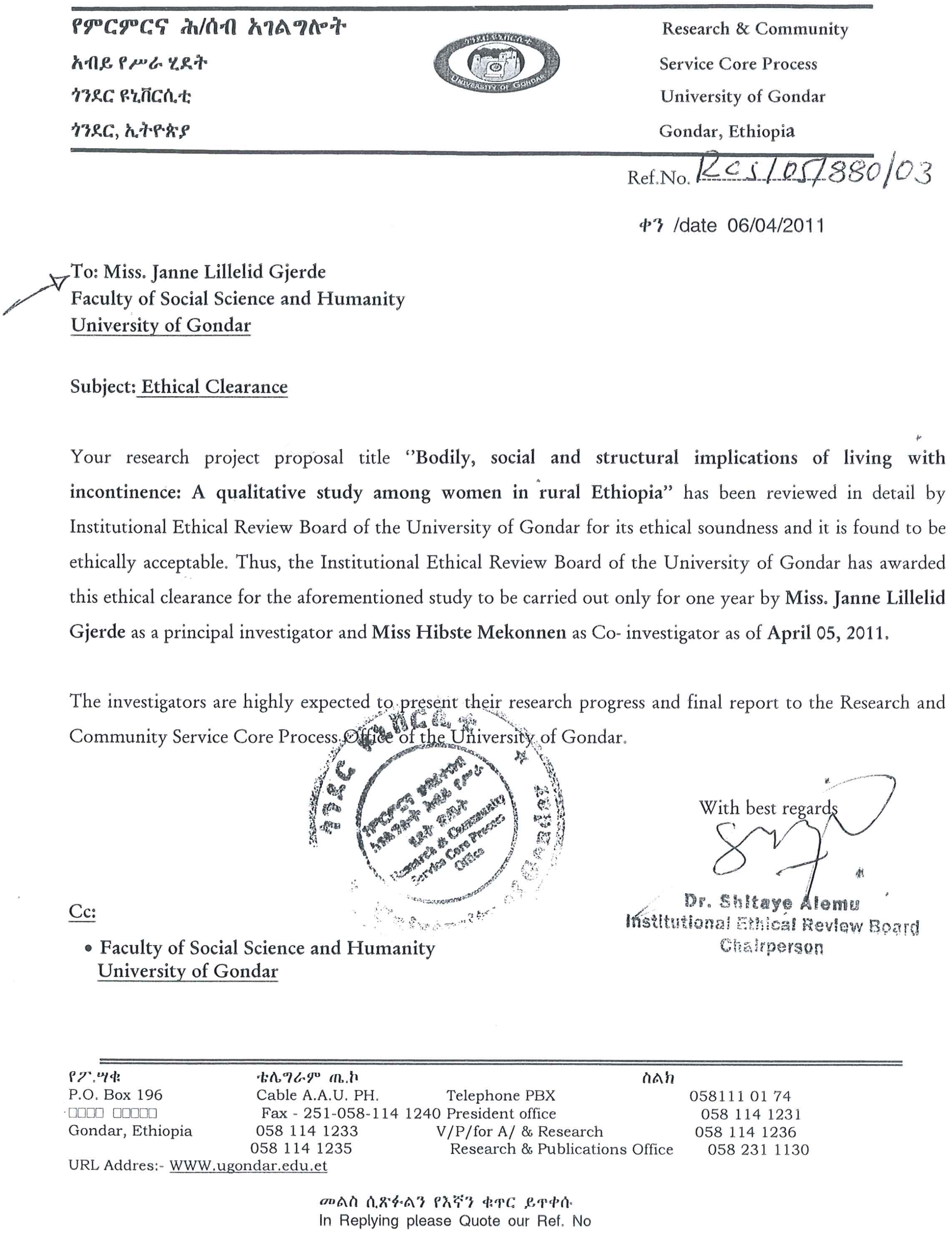
Jon Lekven

Jon Lekven Professor, MD
Chairman REK Vest

Øystein Svindland
Committee secretary

REK VEST
HAUKELAND UNIV. SYKEHUS
Postboks 8704
5020 Bergen

Appendix 2: Ethical approval, Ethiopia



የምርምርና ሕ/ሰብ አገልግሎት
አብይ የሥራ ሂደት
ጎንደር ዩኒቨርሲቲ
ጎንደር, ኢትዮጵያ

Research & Community
Service Core Process
University of Gondar
Gondar, Ethiopia

Ref.No. RCS/05/880/03

ቀን /date 06/04/2011

To: Miss. Janne Lillelid Gjerde
Faculty of Social Science and Humanity
University of Gondar

Subject: Ethical Clearance

Your research project proposal title "**Bodily, social and structural implications of living with incontinence: A qualitative study among women in rural Ethiopia**" has been reviewed in detail by Institutional Ethical Review Board of the University of Gondar for its ethical soundness and it is found to be ethically acceptable. Thus, the Institutional Ethical Review Board of the University of Gondar has awarded this ethical clearance for the aforementioned study to be carried out only for one year by **Miss. Janne Lillelid Gjerde** as a principal investigator and **Miss Hibste Mekonnen** as Co- investigator as of **April 05, 2011.**

The investigators are highly expected to present their research progress and final report to the Research and Community Service Core Process Office of the University of Gondar.

With best regards

Dr. Shitaye Alemu
Institutional Ethical Review Board
Chairperson

Cc:

- Faculty of Social Science and Humanity
  University of Gondar

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Research & Publications Office 058 231 1130

መልስ ሲጽፉልን የእኛን ቁጥር ይጥቀሱ
In Replying please Quote our Ref. No

Appendix 3: Informed consent form

English version:

Request for participation in the following research project:

"Bodily, social and structural implications of living with incontinence:
A qualitative study among women in rural Ethiopia"

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

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 urinary incontinence; faecal incontinence and pelvic organ prolapse among women in rural Ethiopia.

There is today limited information about incontinence and prolapse, and the consequences it has for women living in low-income countries such as Ethiopia. This study is a part of a larger umbrella project that aims to establish prevalence rates and risk factors of conditions of urinary and faecal incontinence as well as pelvic organ prolapse in Ethiopia. The University of Gondar, Ethiopia and the University of Bergen, Norway are responsible for this research project.

What does the study entail?

In the study we wish to conduct in-depth interviews, focus group discussions and case studies with the aim to explore different aspects of living with conditions of incontinence and pelvic organ prolapse. The interviews / focus group discussions will be conducted in your local language by my collaborator who will function as a translator 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 leakage and prolapse. This will make it possible to make steps towards the improvement of treatment and prevention of these conditions in Ethiopia.

Potential disadvantages of your participation in the study includes the time you will spend on the interview / focus group. 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 / focus group. The registered information will only be used in accordance with the purpose of the study. All the data will be processed without using your name, your ID number or other directly recognisable type of information. All data will be stored in a secure way, and only authorised project personnel will have access to the data. Data will be deleted by the end of year 2013 (Ethiopian calendar). It will not be possible to identify you in the published results of the study.

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 (only relevant for study participants receiving treatment at a health facility). If you later on wish to withdraw your consent or have questions concerning the study, you may contact Professor Yigzaw Kebede at the University of Gondar, College of Medicine and Health Sciences, who leads the study. Mobile number: xxxxxxxxxx.

Consent for participation in the study

I am willing to participate in the study.

(The study participant will give his/her oral concent, and the research collaborator will note the concent)

I confirm that I have given information about the study.

(Signed, role in the study, date)

Amharic version:

በሚከተለው የጥናት ፕሮጀክት ላይ እንዲሳተፉ የቀረበ ጥያቄ

“ሽንትና ዐይነምድር ለመቆጣጠር አለመቻል የሚኖረው አካላዊ፣ ማሕበራዊ እና መዋቅራዊ አንድምታ፣ በገጠሪቱ ኢትዮጵያ በሚገኙ ሴቶች መካከል የሚደረግ ጥናት”

መነሻና ዓላማ

ይህ በገጠሪቱ ኢትዮጵያ በሚገኙ ሴቶች መካከል ሽንትና ዐይነምድር ካለመቆጣጠርና ከዳሌ መንሸራተት የተነሳ የሚያጋጥሟቸውን ሁኔታዎች ለመዳሰስ በሚደረግ ጥናት ላይ እንዲሳተፉ የቀረበልዎ ጥያቄ ነው፡፡ በአሁኑ ጊዜ ዝቅተኛ ገቢ ባላቸው እንደኢትዮጵያ ባሉ አዳጊ አገሮች ውስጥ ሽንትና ዐይነምድርን ስላለመቆጣጠርና የዳሌ መንሸራተት ችግር በሴቶች ላይ ስለሚያስከትለው ጫና ያለው መረጃ ውስን ነው፡፡ ይህ ጥናት ብዙ ነገሮችን የሚሸፍን ፕሮጀክት አካል ሲሆን ኢትዮጵያ ውስጥ ስለሽንትና ዐይነምድር አለመቆጣጠርና ስለዳሌ መንሸራተት ችግሮች ተጠያቂ የሆኑ ሴቶች ብዛትና የችግሩ መነሻዎችን ለመወቅ ይጠቅማል፡፡ ጎንደር ዩኒቨርሲቲ ከኢትዮጵያ እና በርገን ዩኒቨርሲቲ ከኖርዌይ የጥናት ፕሮጀክቱን በኃላፊነት ያካሂዳሉ፡፡

ጥናቱ በምን ላይ ያተኩራል?

በጥናቱ ውስጥ ጠለቅ ያሉ ቃለምልልሶች፣ የቡድን ውይይቶችና ሽንትና ዐይነምድር መቆጣጠር በማይችሉ ሰዎች ግላዊና ዝርዝር ሁኔታዎች ላይ ያተኩሩ ጥናቶችን በማካሄድ ላይ ያለመ ነው፡፡ ቃለምልልሶቹ/የቡድን ውይይቶቹ በተርጓሚነት በሚያስተባብሩልኝ ረዳቱ አጋዥነት ጥናቱ በአካባቢዎ ቋንቋ የሚካሄዱ ይሆናል፡፡

ሊኖሩ የሚችሉ ጥቅሞችና ጉዳቶች

በጥናት ፕሮጀክቱ የሚኖርዎ ተሳትፎ ኢትዮጵያ ውስጥ ያሉ የጤና እንክብካቤ ዕቅድ አውጭዎች የሽንትና ሰገራን ያለመቆጣጠር የአካል መንሸራተትን ያለባቸው ሴቶች ምን እንደሚያስፈልጋቸው ለማሳወቅ ነው፡፡ ይህ ደግሞ ተጠቂዎች የተሻለ ህክምና እንድያገኙ እንድሁም አዲስ ተጠቂዎች ቁጥር ለመቀነስ ይረዳል፡፡ ምንአልባት ይህ ተሳትፎ ስራ ላይ ቢውል ገቢ ሊያገኙበት የሚችሉበትን ጊዜውን ተሻምቶት ይሆናል፡፡ እዚህ ጥናት ላይ በቃለ መጠይቅ ወይም በቡድን ውይይት ያሳለፉት ጊዜ ስራ ላይ ቢውሉ ሊያገኙት የሚችሉትን ገንዘብ ታሳቢ በማድረግ ማካካሻ ይሰጠዎታል፡፡

ስለራስዎ በሚሰጡት መረጃ ላይ ምን ይከሰታል?

ለቃለምልልሱ የሚሰጡት መረጃ በራስዎ ስምምነት በመቅረጸ-ድምፅ ይቀረጻል፡፡ እንድሁም በማስታወሻ ደብተር የተመዘገበው መረጃ ለጥናቱ ዓላማ ብቻ እንዲያገለግል ይደረጋል፡፡ ሁሉም የመረጃዎች አሰባሰብ ሂደት ስምዎን፣ መታወቂያ ደብተርዎን ወይም ሌሎች በቀጥታ የሚታወቁባቸውን የመረጃ ዓይነቶች ሳይጠቅስ ይካሄዳሉ፡፡ ሁሉም መረጃዎች ደህንነታቸው ተጠብቆ ይቀመጣሉ፣ የጥናቱ በለሙያ ብቻ መረጃ መግኘት ይችላል፡፡ በ2013 ዓ.ም መረጃው ይሠረዛል፡፡ ታትሞ በሚጠጣው የጥናቱ ውጤት ላይ እርስዎ ጥናቱ ውስጥ መሳተፊዎን የሚፈልግ እንኳን ቢኖር ማወቅ መለየት አይቻለውም፡፡ ይህ ሁሉ የሚደረገው የርስዎን ደህንነት ለመጠበቅ ሲባል ነው፡፡

የበጎፈቃድ ተሳትፎ

በጥናቱ መሳተፍ በጎፈቃደኛነትን ይጠይቃል፡፡ በጥናቱ የመሳተፍ ፈቃደኛነትዎን የለምንም ቅድመ ሁኔታ ማቋረጥ ይችላሉ፡፡ ከጥናቱ መውጣትዎ ወደፊት በሚያገኙት ሕክምና ላይ የሚያስከትልብዎ ችግር አይኖርም (በጤና ተቋሙ ውስጥ ሕክምና ለሚያገኙት የጥናቱ ተሳታፊዎች ብቻ የሚያገለግል)፡፡ ጥናቱን በተመለከተ ቆይተው ፈቃደኛነትዎን ለመሰረዝ ወይም የሚያወሷቸው ጥያቄዎች ቢኖሩዎ ጥናቱን የሚመሩትን ፕሮፌሰር ይግዛው ከበደን ከጎንደር ዩኒቨርሲቲ ሕክምናና ጤና ሳይንስ ኮሌጅ በሞባይል ስልክ ቁጥር 0918 722268 ማግኘት ይችላሉ፡፡

[ኢትዮጵያ ውስጥ ባሉ ሴቶች መካከል ሽንትና ዐይነምድር አለመቆጣጠር ያለው አንድምታ] - ምዕራፍ ሀ እና ለ- [14/12-2010]

በጥናቱ ለመሳተፍ የሚደረግ ስምምነት

በጥናቱ ለመሳተፍ ፈቃደኛ ነኝ።

(የጥናቱ ተሳታፊ የራሱን/የራሷን የቃል ስምምነት ይሰጣል/ትሰጣለች፣ የጥናቱ አስተባባሪም ስምምነቱን ይመዘግባል)

ስለጥናቱ መረጃ መስጠቴን አረጋግጫለሁ።

(ፊርማ፣ በጥናቱ የነበረው ሚና፣ ቀን)

Appendix 4: Interview guides

1. Interview guide for adult women living with incontinence

Serial number of interview: ________________
Date of interview:________________________
Location:________________________________

Start by explaining the purpose of the study by carefully going through the *request for participation in a research project* form including the *consent for participation in the study* form.

Thank the informant so much for her collaboration to be interviewed.

Tell the informant that we would like to start with a few general 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 children (if any)
- Number of pregnancies (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.)

Brief introduction:

Start by discussing the challenges of incontinence as a substantial problem for women worldwide with the aim to ‘normalize’ the challenge / create an open and relaxed tone:

- The prevalence among women in high-income settings (The size of the problem of incontinence in the richer part of the world):
  - ➢ Urinary incontinence affects around 2-4 out of 10 women.
  - ➢ Faecal incontinence affects more than 1 out of 20 women.
- Studies from high-income settings (the richer part of the world) show that living with incontinence impacts several aspects of women’s lives:
  - o Physical and psychosocial impacts
  - o Economic challenges

- So far it is limited knowledge about the experience of women living with incontinence in low income contexts (African countries, such as Ethiopia)
- This study aims to increase this knowledge, so her participation is valuable.

1) Can you please tell us about your condition of incontinence? (General scrutinization)
    - (Let the informant speak at length - if possible without interruption - except for clarifications. Probes primarily based on the informant's story).

2) Can you please tell us when the leakage started and how it has developed? (Narrative exploration)
    - (Getting the story 'from beginning till end' with little interruption, except for clarifications).
    - Potential probes:
        - How often do you leak? (Several times each day, every day, once a week or more seldom? Here important to explore the ways she talks about frequency of leakage)
        - Sometimes able to control the urination?
        - When does the leakage occur? (When coughing, sneezing, lifting heavy items, when sudden and strong urge to void or all the time)
        - How long have you experienced the leakage?
        - Do you also have faecal leakage?

3) Can you please tell us what you think caused the condition? (Aetiology)
    - Potential **careful** probes: birth related, age related, rape, bad luck, people / spells, God, other?

4) Can you please explain in what kinds of situations or social events you experience the leakage as most problematic? (Assessment of main challenges)
    - Potential careful probes: At home, work related, prayer sessions, social gatherings, relation to neighbours, other?

5) Can you please tell us how the leakage makes you feel about yourself? (Phenomenological assessment)
    - Potential **careful** probes:
        - To what extent and in what way does it make you feel different from people around you?
        - How does it affect the way you experience your body?

6) Can you please tell us how the leakage affects your relationship with people around you? (Social assessment)
    - ➢ Potential probes:
        - In relation to your condition, how do you experience being around people? (Family, friends, neighbours, others?)
        - How do people behave towards you in relation to your condition? (Any experience of discrimination, isolation, etc.?)
        - In relation to partner - if any - (Is he supportive? If so, in what way? What about implications for the sexual relation?)

7) Can you please tell us how you handle the leakage practically?
    - ➢ Potential probes:
        - What do you use to protect from the leakage being visible? (Pads, other?)
        - What do you use to avoid the smell of urine or faeces? (smoke/fumes, incense, other?)
        - How do you manage to keep clean? (How do you get water, from where, how often is it collected?)
        - Do you have free access to use a place for urination and defecation? (A latrine? A toilet? The bush area?)

8) Can you please tell us what kind of help you have sought or received for your leakage from when it started, if any?
    - ➢ Potential probes:
        - Where and when did you seek help, and reasoning for the choice?
            - o Home-treatment, holy water, traditional healers, the official / private health system
            - o Location, how far from home? Why did you go to this specific place to get help?
        - What type of treatment did you receive? (Spiritual, herbal remedies, holy water, medication, other?)
        - The experience of the help / advice received?
            - o Any improvement after seeking help / advice?

9) Can you please tell in what ways the leakage affect your economy?
    - ➢ Potential probes:
        - Do you have any cost for soap, pads (if relevant), etc.
        - Do you think your condition has an affect on you income opportunities?
        - Travel costs in relation to treatment (if relevant)
        - Costs for treatment (if relevant)

10) Finally, can you please tell us what words that you or other people around you use for describing;
    - Urinary incontinence?
    - Pads? (and other remedies that are used to protect from leakage)
    - Words used in relation to the smell?

2. Interview guide for husband / close relative to women with incontinence.

Serial number of interview: ________________
Date of interview:________________________
Location:______________________________

Start by explaining the purpose of the study by carefully going through the request for participation in a research project form including the consent for participation in the study form.

Thank the informant so much for his / her collaboration to be interviewed.

Tell the informant that we would like to start with a few general questions about his / her background:

- Age
- Gender
- Ethnic group
- Religion
- Occupational status
- Educational status (can he / she read and write?)
- Marital status (at what age did he / she get married?)
- Number of live children (if any)

Brief introduction to incontinence (cf. interview guide 1.)

1) Can you please tell us about the kind of challenges your wife / close relative experience in relation to her condition of incontinence / leakage? (General scrutinization)
   - ➢ (Let the informant speak at length if possible without interruption, except for clarifications. Probes primarily based on the informant's story).

2) Can you please tell us when these problems first started, and how they have developed since then? (Narrative exploration)
   - ➢ (Getting the story 'from beginning till end' with little interruption, except for clarifications).
   - ➢ Potential careful probes:
     - Is the leakage continuous? (every day? More seldom?)
     - Does she also have faecal incontinence?

3) Can you please tell us what you think caused the condition? (Aetiology)
   - Potential **careful** probes: birth related, age related, bad luck, people / spells, God, other?

4) Can you please explain in what kinds of situations the leakage is most problematic for your wife / close relative? (Assessment of main challenges)
   - Potential careful probes: At home, work related, prayer sessions, social gatherings, relation to neighbours, other?
   - In relation to the husband?

5) Can you please tell us how you think the leakage affect the way your wife / close relative feel about herself? (Phenomenological assessment)
   - Potential **careful** probes: Experiences of being different, of not being in control over the body, of being dirty, of shame, of embarrassment, of fear? How the condition affects her self-confidence? Experience of loneliness?)

6) Can you please tell us how the leakage affects your wife's / close relative relationship with people around her, including yourself? (Social assessment)
   - Potential probes: in relation to partner (implications for sexual relationship), family members, other relatives, neighbours, friends, other? (Please give examples)
   - How do you think the condition affects her self-confidence in relation to people around her? Any experience of loneliness?
   - In relation to her condition, how do people behave towards her? (Any experience of discrimination, stigma or isolation? If so, from whom?)

7) Can you please tell us how your wife / close relative handles the leakage practically?
   - Potential probes:
     - What does she use to protect the leakage from running? (pads, moss etc.)
     - What does she or you use to avoid the smell of urine or faeces? (smoke/fumes, insense, other?)
     - How does she manage to keep clean? (Access to water?)
     - Does she have free access to use a place for urination and defecation? (A latrine? A toilet? The bush area?)

8) Can you please tell us what kind of help your wife / close relative has sought or received for her leakage from when it first started, if any?
   - Potential probes:
     - Where and when did she seek help?

        - Home-treatment, holy water, traditional healers, the official / private health system
        - Location, how far from home? Why did she go to this specific place to get help?
    - What type of treatment did she receive? (spiritual, herbal remedies, holy water, medication, other?)
    - The experience of the help / advice that she received?
        - Any improvement after seeking help / advice?

9) Can you please tell us in what ways her leakage has affected your economy?
    - Potential probes:
    - Cost for soap, pads (if relevant), etc.
    - Do you think her condition has an affect on you income opportunities?
    - Travel costs in relation to treatment (if relevant)
    - Costs for treatment (if relevant)

10) Finally, can you please tell us what words that you or other people around you use for describing;
    - Urinary incontinence?
    - Pads? (and other remedies that are used to protect from leakage)
    - Words used in relation to the smell?

3. Interview guide for personnel in the health facility / traditional healers

Serial number of interview: _________________
Date of interview:__________________________
Location:__________________________________

Start by explaining the purpose of the study by carefully going through the *request for participation in a research project* form including the *consent for participation in the study* form.

Thank the informant so much for his / her collaboration to be interviewed.

Tell the informant that we would like to start with a few general questions about his / her background:

- Age
- Gender
- Educational status
- Work description
- Ethnic group
- Religion

Brief introduction to incontinence (cf. interview guide 1.)

1) Can you please tell us what experience you have with women seeking help / advice for the condition of incontinence? (General scrutinization)
    - ➢ Potential probes: Frequency of women seeking help / advice, magnitude of conditions of incontinence, age groups etc.

2) Can you please tell us what kind of advice / treatment you offer women with incontinence at this health facility?
    - ➢ Potential probes:
        - Types of advice, treatment?
        - Long-term or short-term treatment?
        - Referral to other places if treatment fails? If so, to where?

3) Can you please tell us, based on your experience, what kind of challenges you think women experience in relation to incontinence?
    - ➢ Potential probes:

        - Bodily challenges: experiences of being different, of not being in control over the body, of being dirty, of shame, of embarrassment, of fear?
        - Social challenges: relation to family members, partner, relatives, neighbours and friends. How the condition affects her self –perception and self-confidence. Experience of loneliness, stigma or isolation?
        - Situational challenges: At home, work related, prayer sessions, social gatherings, other?
        - Practical challenges: Use of pads (which type?). Sanitary / hygienic conditions, other?

4) Can you please tell us, based on your experience, what you think typically cause the condition of incontinence? (Aetiology)
    - Potential probes: birth related, age, people /spells, God, other?

5) Can you please tell us where you think women with incontinence typically seek help for their challenges?
    - Potential probes:
        - Traditional healers, holy water or the official / private health system?
        - Type of treatment received? (spiritual, herbal remedies, holy water)
        - When and where (location / how far away from home)
        - How much does it cost?
        - Reasons for decision to seek help / advice at particular places?
        - The women's experience of help / advice received from the different places?
        - If she thinks the women have any improvement after seeking help / advice?

6) Can you please tell us in what ways you think economy prevents women from enhancing their situation of incontinence?
    - Potential probes: Travel related costs, costs for pads, costs for treatment, other?

7) Finally, can you please tell us any additional terms for the following?
        - Urinary incontinence
        - Pads (and other remedies that are used to protect from leakage)