Mind The Gap

Health professional’s relation to Female Genital Schistosomiasis - Exploring perspectives, politics and practices during treatment on lower reproductive health problems in a schistosomiasis endemic area

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Acknowledgements

I have wanted to work with women and reproductive health as long as I can remember, although I had never guessed that my path would involve nursing in combination with equality studies and a master's degree in development studies[1]. Now I am incredibly grateful about this path, and I look forward to practicing this combination of knowledge in real life. The experiences from this journey have given me a deeper understanding of the world's many realities, and a greater humility. I would like to express my great gratitude to everyone who has contributed to this thesis.

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Prof. Emeritus Gundersen, Dr. Kjetland and I agreed that in order for me to explore this location for my thesis and stay at BRIGHT, I would assist in return. The idea is therefore that

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[1] I had rather pictured myself in midwifery, although it is never too late.

this thesis should become published, as my approach to FGS in social science might contribute to a more holistic view on FGS and help close a gap in the field of research.

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Abstract

The main objective of the study was to elucidate why there is a gap between medical research conducted on the neglected tropical disease *Female Genital Schistosomiasis* (FGS) and work-related knowledge about the disease amongst professional nurses in the Ugu District, South Africa. The study is based on qualitative field work in three local governmental clinics in this area, and the purpose is to explore why there is such a gap and why the development of knowledge concerning FGS seems to stagnate despite a relatively high level of awareness related to its "twin disease", *Urological Schistosomiasis* which is commonly referred to as *Bilharzia* or *Isichenene* in Zulu.

Nurses based at three local governmental clinics in the area made up the study population.
The empirical findings collected through interviews and observations at local clinics in the area are discussed against well-established research on FGS. This also took cognizance of the UN's sustainability goals (SDGs) with a focus on gender and sanitation, as well as control programs to prevent Schistosomiasis. The thesis is inspired by Institutional Ethnography and the work of IE is relevant here as it points out how discourses and texts of various types govern nurses' ability to provide health care, participate in decisions, and develop work-knowledge.

The study has showed that the reasons for the gap between local nurse’s work-knowledge and the medical research is complex. Among the main causes are skewed power relations, whereby the affected women live with low socioeconomic status in society while the larger power structures do not prioritize FGS due to other more obvious health problems in society. This leads the nurses ending up in a kind of "middle position" where they are responsible for society's health and the same time as they are governed by the texts/guidelines that form the basis of the institution of which they are a part of. Furthermore, the study showed that culture becomes an important assessment for nurses in consulting with patients, but that they themselves are part of a framework where their role as nurses is less dynamic. The thesis tries to point out potential for improvement by encouraging inclusion of more dimensions than just purely medical measurements in order to prevent FGS.

The thesis is written in the intersection between medicine and social sciences, whereby medical information is presented in order to understand the purpose of the approach in social studies.

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List of Acronyms

BREC	Biomedical Research Ethics Committee
CPD	Continues Professional Development
FGD	Focus group discussions
FGS	Female Genital Schistosomiasis
HBM	Health Belief Model
HIV	Human immunodeficiency viruses
IE	Institutional Ethnography
KZN	KwaZulu Natal
MDA	Mass Drug Administration
NSD	Norwegian Centre for Research Data
NTD	Neglected Tropical Disease
PBL	Problem Based Learning
SGDs	Sustainable Development Goals, by United Nations
SM	Syndromic Management
Stats SA	Statistics South Africa
STIs	Sexually Transmitted Diseases
TDR	Tropical Disease Research Program
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	The United Nations Development Programme
UoA	University of Agder
WHO	World Health Organization

1 Introduction

Female Genital Schistosomiasis (FGS) is a significant public health issue as well as a silent and neglected epidemic found in many tropical areas (UNAIDS, 2019) of which can appear acute and chronic. FGS defines particular damages that appear in the lower reproductive organs of women due to the infection created by the specific parasite *Schistosomiasis Haematobium* found in contaminated water (Kjetland, P. D. C. Leutscher, & P. D. Ndhlovu, 2012). FGS affects females who live under dire conditions, from the poorest parts of the world whom also carry the burden of HIV and cervical cancer amongst other reproductive problems (UNAIDS, 2019). Austveg and Christensen (2010) show that most people with such problems come from poor rural areas where the roads to the nearest health facility are difficult and this constitute obstacles to accessing the health facility. These poor areas are also strongly associated with gender inequality which disfavours females. The brief by UNAIDS (2019) highlights how the global health and development community have sworn not to forget these people by improving their quality of life, but how they paradoxically remain forgotten and with increased social as well as health related issues.

Thus, FGS illustrate and exemplifies how women and girls continue to be marginalised, as they cope with multiple and intersecting challenges concerning health, sociocultural, environmental and economic issues. This thesis aims to explore how professional nurses in South Africa relate to the women affected by this neglected tropical disease, *Female Genital Schistosomiasis* (FGS), and how action patterns, gender relations and culture can fit into the development of knowledge. Therefore, the purpose is to elucidate why there is a gap between the nurse's work-knowledge and the established research concerning FGS, and how this can create challenges. The problem statement of this thesis is consequently:

"How do local health professionals in South Africa relate to the neglected *Female Genital Schistosomiasis* and why does the work-knowledge seem to be stagnating?"

Austveg and Christensen (2010) and Smith (2005) state that there are many medical interests among the poor population, but less focus on the actual organization of the management of development in `health´ and organisation of care. Institutional Ethnography is still a fairly unknown approach within the social sciences, yet IE was used as an entry point to research in social science as I think it has a lot to add. An important objective is to see the link between research and politics and how discourses/texts guide the work of health workers - and vice versa. With help of the three following research questions, the thesis aims to provide answers to the problem statement:

- What and who has the power to decide which health conditions should be given priority?
- What role does action patterns and culture play and to what extent do this seem to incorporate into the development of knowledge concerning patient care, medical treatment and preventive measures regarding FGS?
- What barriers do nurses possibly face when trying to increase knowledge around FGS?

Through interviews with and observations of professional nurses at local clinics in the Ugu District of South Africa, the above questions were answered. The empirical findings were seen in the light of secondary data of previous medical research on FGS, theories of global guidelines by multilateral institutions and the methodology of inquiry, *Institutional Ethnography* by Dorothy Smith.

Delimitation

The research has been inspired by a feminist paradigm, both in accordance to Institutional Ethnography and due to its topic concerning female reproductive health. Yet, it was important for me to meet my informants regardless of gender, as both male and female health professionals may provide proper care to females with reproductive issues. However, in accordance with Interview 15, \`nursing´ is a female-dominated profession in South Africa, thus the proportion of male informants has been limited. At the same time, it is important not to forget men, especially in light of equality, as this thesis also emphasises.

It is important to note that this thesis is not a complete Institutional Ethnographic analysis, as I have not used the tool's full potential but rather a few concepts and dimensions. However, IE in relatively simple features [compared to its full potential] is used throughout the master thesis.

Choice of topic

There are several reasons why the theme was chosen. When FGS in South Africa was introduced as an opportunity, I became enthusiastic because I saw an opportunity to study a combination of dimensions that I am really passionate about, being *gender equality, reproductive health, tropical medicine* and *development studies.*

Personally, I am a registered nurse and know how texts in the forms of procedures and routines, doctor's orders, governmental regulations as well as patients' needs [which constitutes power and ruling relations] regulate the doings and being of registered nurses. I find my background as an important pre-understanding in meeting with the health service in South Africa. My understanding is that South African and Norwegian nurses are educated differently because we have different social, environmental and health related needs, as well as different educating systems. However, our professions are based on resembling health facilitating systems and our visions are to provide patient care with reliable human to human relations.

Relevance to the field

There has been little qualitative social science research on FGS, and therefore parts of this thesis can be referred to as an inductive and exploratory. As a registered nurse with a desire to see what disease does to society and what society does to disease, I have chosen to use this interest in favour of this thesis, which is prepared interdisciplinary, in the intersection between two disciplines, (*bio)medicine* and *social sciences*. The benefit of this interdisciplinary focus is to be able to understand the impact of health on society and on the people living and working in it. Simultaneously, I will explore diverse power relations that govern people's room for manoeuvre and aim to gain a deeper understanding of how one best can organize care when many health care measures seem to be exclusively medical without taking special account of cultural and socio-economic conditions. Hence, I aim to gain a deeper understanding of how the health sector can develop more sustainably while implementing social dimensions, instead of operating "fire-fighting" with the most detectable diseases.

Research in social science has a lower status than medical research, and as already mentioned, Institutional Ethnography (IE) is still a fairly young and unknown methodology within the social sciences (Smith, 2005). Nevertheless, IE has a lot to add as it starts out in the actual doings of people, rather than in theory, thus questioning the power of institutional captures, aiming to unveil the links also between research and politics and how discourses and texts guide the work of health workers and vice versa. Austveg and Christensen (2010) state how there are many medical interest organizations among the poor population, but a lack of focus on the actual organization of the management of developments in health.

Clarifications of terms

I will now give a brief presentation of my interpretation of the different terms connected to Schistosomiasis:

- The term *Female Genital Schistosomiasis* may also be referred to as *Genital Bilharzia/Schistosomiasis.* Although FGS is the core in this study, the term was unknown to most of my respected informants. Hence, terms describing the link between female genital morbidity and schistosomiasis was very rarely used in consultation with informants (thus rarely used in chapter "6 Empirical Findings") – this rather caused confusion when mentioned during interviews, as the phenomenon seemed to be unknow.

- *Bilharzia* on the other hand was well-known amongst my respected informants. Although "Bilharzia" is an umbrella term for diseases caused by the different parasites in the "Schistosomiasis family", it was implicit that the term referred to *urological*[2] morbidity. My interpretation of the Bilharzia became confirmed during all the interviews conducted at the clinics. At the same time, it turned out that their word for Bilharzia [implicit urological morbidity] is the *isichenene* in Zulu.

- *Urogenital Schistosomiasis* is the term recommended by the WHO because it covers both genital and urological morbidity due to Schistosomiasis Haematobium. Thus, this term would be recommended to use, but since this was unknown on a par with FGS, this was not referred to either.

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[2] S. haematobium was originally referred to as *urinary schistosomiasis* because blood in urine, painful urination and increased risk of bladder cancer are the most apparent symptoms (Kjetland et al., 2012).

Outline

This thesis is divided into eight chapters. I will now present the main lines in each chapter and provide an overview of the structure of the thesis.

Chapter 1 – Introduction
Provides an introductory description of topics and issues, which research questions will contribute to answering the problem statement and why the topic, as well as why this problem have been chosen.

Chapter 2 – The Study Area
Provides some historical lines of South Africa as a nation and their situation in recent years, as well as the geographical setting, KwaZulu Natal and its burden of reproductive health.

Chapter 3 – Literature Review
Refers to important background information about the disease *Female Genital Schistosomiasis*, including medical research and social dimensions. This is an important angle to include due to understanding the disease's impact on society its influence on professional nurses.

Chapter 4 – Theoretical Framework
Refers to guidelines issued by multilateral institutions, which at the same time points to overall power structures and international "rules". Theory regarding Institutional Ethnography by Dorothy Smith are to be presented, which is also used as a tool for entering social research. Finally, the learning method Problem Based Learning is presented, which is used by `nursing education´ in South Africa.

Chapter 5 – Methodology
Describes the method used to obtain the empirical data. Research methodological approaches are described, as well as the advantages and disadvantages that has emerged along the process.

Chapter 6 – Empirical Findings
Presents the empirical findings obtained through the collection data presented. This includes quotes and descriptions from mainly professional nurses, but also an expert on FGS and some informal informants who have helped increase knowledge.

Chapter 7 – Discussion and Analysis

This section discusses and analyzes the empirical findings against the literature review and theoretical framework, especially in the light of Institutional Ethnography. This involves a discussion of barriers that can be met by health professionals, dimensions related to gender differences and what might contribute to the neglection of FGS amongst nurses. Finally, power relations are discussed, especially with a focus on nurses. Through this analysis, attempts are made to answer the problem statement and research questions.

Chapter 8 – Concluding remarks

This section gathers threads and concludes with the thesis' most important findings and remarks. The chapter concludes with reflections on further research and personal considerations for reflection. Lastly, measures proposed in order to increase awareness on FGS is presented as well as a bibliography and following appendices.

2 The Study Area

Although the thesis deals with the nurse's relation to FGS, it is still important to consider the geographical area of the study site. In this chapter, historical features will be presented in order to understand the area's development up to the present day. The historical lines provide an insight into the changes many of the inhabitants have witnessed over the years, both in South Africa as a current nation and Kwa-Zulu Natal as a province. The coming pages will therefore briefly present historical features from the 1400s until today. Furthermore, quantitative data from secondary sources and statistics by *Statistics South African* will be presented as a pointer to South Africa development in current `living conditions´. The chapter will end with presentation of some main reproductive health problems among women in the research field.

2.1 Brief historical lines

The area known today as South Africa, was originally composed by `hunters and gatherers´ of several different groups of people. It is proven that today's province of KwaZulu-Natal hosted some of the first Iron Age settlements globally, thus humanity in this area goes far back in time. In the 1400s, the area was "discovered" by Portuguese sailors who used the area as a stopover on the sea route to Asia. At the same time, goods were exchanged between locals and visitors as the journey to Asia was long and challenging. Over hundreds of years, by exchanging goods and knowledge (concerning nature, hunting and cattle farming) and in the light of `supply and demand´, mutual dependence developed between European people and indigenous people. This exchange and interaction have contributed to the social complexity of South Africa as a nation. In 1652, the first Europeans arrived to settle in the area. As a result, the indigenous population was driven away from their own areas and resources and were forced to give way to the settlers. This contributed to a distinct (and literally black and white) distortion of power based on human appearance (biology) and background (ethnicity). Not least, the European approach led to increased disagreements between existing indigenous groups, as the Europeans embraced the strategy of `divide and conquer´ in order to accelerate their own development due to global industrial competition. Systemized racism developed in which the `white´ minority claimed biological, culturally and political superiority, and where `black´ majority turned out marginalized. This resulted in racially divided cities and geographically defined areas. In 1910 South Africa became united into one state under white rule (Eriksen & Millstein, 2016).

After World War II, South Africa's chose to go in the opposite direction of global recommendations, both by United Nations and other multilateral institutions, whom addressed the fight against colonization and racism. In 1948 South Africa developed an even stricter program of systematic and political racial suppression; a direction known as `apartheid´ (Eriksen & Millstein, 2016). Before apartheid, nearly every formally educated black South Africans were taught by European missionaries, including Nelson Mandela, as foreigners were eager to both Christianise and Westernise natives. Under apartheid, *Bantu Schools* where built by the government to teach black South Africans basic metrics and agriculture as the current government saw no need to teach black South Africans science, history nor civics (Noah, 2016).

During apartheid, communities were held together by women as men (fathers) were either sent to prison, in exile fighting, or working in the mines, only able to come home during the holidays (Noah, 2016).

> *`Wathint' Abafazi Wathint' imbokodo!' was the chant they would rally to during the freedom struggle. `When you strike a woman, you strike a rock'. As a nation, we recognized the power of women, but in the homes they were expected to submit and obey* (Noah, 2016, pp. 46, reffering from Xhosa communities).

Not surprisingly, reactions to the suppression appeared. After decades of both silent demonstrations and uncompromising strikes from opponents, South Africa gradually gained international attention. The formalised system of apartheid ended when Nelson Mandela[3] became the first black president in 1994. After the this first democratic election in South Africa, Desmond Tutu together with Mandela developed the ideology of the "Rainbow Nation" to describe the post-apartheid period. The ideology aimed to emphasise the diversity of people living in South African, purpose of peace (Naik, 2020). In 1996 a new constitution was introduced with promises of equality and human rights acts. The constitution divided South Africa into nine provinces, approximately 300 municipalities and announced 11 public languages, whereas 22,7 % speaks *Zulu*; 16,0 % speaks *Xhosa*; 13, 5 % speaks *Afrikaans*; 9,6 % speaks *English*; 9,1 % speaks *Northern Sotho*; 8% speaks *Tswana*; 7,6 % speaks *Sotho*; 4,5 % speaks *Tsonga*; 2,5 % speaks *Swazi*; 2,4 % speaks *Venda*; 2,1 % speaks *Ndebele*; 2,1 % speaks other languages (Eriksen & Millstein, 2016). However, it is one thing to politically abolish a formal racially discriminatory system, and another thing is to build a culture where the country's inhabitants' practice that the system is abolished. Three waves of anti-foreigner violations 2008, 2015 and 2019, pointing to fear and hostility towards foreigners where the term "xenophobia" frequently have been used in discourses related to violence (Naik, 2020).

2.2 South Africa in recent years

The shift with ANC in politics has strengthened the black majority in multiple ways. ANC have provided increased infrastructure; increased provision of housing; more welfare arrangements (such as social security, pensions and other forms of public support); increased job creation for the black majority and better wages; increased access to clean water, sanitation and electricity; and increased participation in school and education (Eriksen & Millstein, 2016). However, according to *Men, Women and Children Findings of the Living Conditions Survey 2014/15* there are still large poverty figures in the country, which is

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[3] Nelson Mandela (Xhosa speaking) spent 27 years in prison on Robben Island because he was an anti-apartheid revolutionary and political leader. He representing the African National Congress (ANC) (Eriksen & Millstein, 2016).

perceived as executive. Approximately half (49,2%) of the adult population (18 years and older) live under the upper-bound poverty line (UBPL). Nation-wide, 35,1 million people are considered poor; 52 % of the population are adult female; 16,9 % more female headed households live under the poverty line compared to male headed households. Poor households headed by females had better access to housing and electricity (95,2% compared to 91,4% male-headed households) but where less likely to have full access to water and sanitation (69,6% compared to 71,7 % of male-headed households) (SA, 2019). All things considered, women experience greater burden of poverty compared to their male counterparts and have less access to adequate hygiene despite of their greater need for intimate personal hygiene, as during menstruation (Stothard, Odiere, & Phillips-Howard, 2020).

In the post-apartheid period, the social and economic inequalities between the racially defined groups of the apartheid era have moderated, but this is mainly due to the emergence of a small black elite and growing middle class in the cities. On the other hand, differences between rich and poor people in society have increased utterly, and for most people it does not help that a rising proportion of the rich are no longer of white skin of colour. The poorest 20% accounted just four per cent of the total consumption in 2011, while the richest 20% accounted for over 60 %. According to extensive reports on the concentration of wealth both nationally and globally, the two richest men in South Africa have a fortune equal to the total wealth of half the population (Eriksen & Millstein, 2016). Thus, despite many positive elements which benefits the black majority post-apartheid, a tense relationship with the government seems to be under development. The country is now suffering from high unemployment (Naik, 2020) and many have to drop out of elementary school and higher education (in 2013, only 15 % completed their bachelor’s degree in South Africa). At the same time, the authorities are known for high levels of corruption. The poor population is deprived of rights by the government taking what they cannot afford to pay (such as rent, electricity or water), leaving them downgraded instead of supported. Consequently, civil mobilisation and protests have led to violence and conflicts with the police, hence increased crime and the use of violence (including xenophobia due to foreign competitors crossing the border to South Africa) (Eriksen & Millstein, 2016).

At the same time, South African women carry the largest burden of HIV / AIDS epidemic globally (Magaisa, Taylor, Kjetland, & Naidoo, 2015; UNAIDS, 2019). Furthermore, South Africa is characterized by dissolved families, prostitution along the transport routes and a macho culture with sexualized violence within and outside the household (Eriksen & Millstein, 2016). All of which may challenge the females feeling of self-agency and have an immense impact on risk sexual behaviour, which again may increase female reproductive health problems and morbidity (Galappaththi-Arachchige et al., 2018).

2.3 KwaZulu Natal

The province KwaZulu-Natal (KZN) is an area that today extends between the east coast, towards the Indian Ocean, and the inland Drakensberg mountain range. Originally, the area was called the Zulu State, with King Shaka kaSenzakhona as a legendary leader known for having assembled the Zulu into one kingdom in 1816 (Eriksen & Millstein, 2016, pp. 40-43).

> *The Zulu man is known as the warrior. He is proud. He puts his head down and fights. Then when colonial armies invaded, the Zulu charged into battle with nothing but spears and shield against men with guns. The Zulu were slaughtered by the thousands, but they never stopped fighting. The Xhosa, on the other hand, pride themselves on being thinkers* (Noah, 2016, p. 3).

In 2016 there were registered 11,1 million people living in KZN (SA, 2020a) [4](up to date numbers are not to be found). In this province, **Ugu District** is located, covering 5866 km^2. The district is a predominantly rural with an estimated 700 000 people, out of which 84% of the people lives in rural areas, and the majority speak isiZulu. 51% of the population are under 20 years of age, and 55% are female (Hegertun et al., 2013, p. 2).

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[4] As in many countries, the informal sector in South Africa is high and it is difficult to obtain good numbers of material. Therefore, one should consider the statistics with a critical gaze.

Figure 1: Map of KwaZulu Natal (KZNTopBusiness, copyright 2020)

2.3.1 Kwa-Zulu-Natal: a province with significant reproductive health issues

The province KwaZulu-Natal hosts a third of most poor adults in South Africa, with 60,7 % (after Limpopo 67,5% and Eastern Cape 67,3%) (SA, 2019). Poverty are closely linked to health problems, thus KZN is significantly influenced by reproductive health issues, especially amongst teenage girls. Factors like teenage pregnancy (one third female have received a child by the age of 20), HIV epidemic, sexually transmitted diseases (STIs) and Female Genital Schistosomiasis (FGS) are characteristics. Furthermore, reproductive factors like these affect the women's attendance at school and therefore their possibilities for employment and earning. At the same time, this will affect their children, who will be born into poverty, which might lead to a vicious circle difficult to break out of (Galappaththi-Arachchige et al., 2018).

South Africa in its entirety carry the highest burden of HIV worldwide, with approximately 18% (7 million) of the worlds 36,7 million HIV-infected. Furthermore, KZN have the highest burden of HIV prevalence in South Africa, which is understood to be related to poverty. It is the young women (15-24 of age) who carry the heaviest burden. In a gender perspective, female prevalence of HIV in KZN is roughly four times higher compared to their male peers, and they contract HIV at a much younger age (Galappaththi-Arachchige et al., 2016). Although this master's thesis does not emphasise HIV, this information is relevant because HIV and FGS are closely linked[5].

According to Magaisa et al. (2015), the first case of urological schistosomiasis in South Africa was reported in 1863, only 12 years after Bilhartz discovered Schistosomiasis Haematobium in Egypt. Case studies between the year of 1864 and 1899 reviled infection in boys primarily, between the age of 3 and 16 years. The transmission was connected to recreational water activity in rivers and dams, and the symptoms observed were blood in urine (haematuria).

South Africa in its entirety, "harbours over 25.7 million people at risk of schistosomiasis, with an estimated 4.5 million infections annually» (Magaisa et al., 2015, p. 3). Today, studies conducted in KZN have found significant prevalence of S. haematobium, but today it included female reproductive tract problems. Research by Galappaththi-Arachchige et al. (2016) have confirmed an "association between self-reported unsafe water contact and urogenital schistosomiasis in young women (age 16-22)" (p. 9).

Finally, in this section, I would briefly address some statistics concerning piped water in KwaZulu Natal, since activity in contaminated water and FGS endemic prevalence are related: "According to the South African census of 2011, in KwaZulu-Natal 63.6% of the households had access to piped water in their dwelling or yard, 22.4% had access to piped water on a communal stand and 14.1% had no access to protected water" (Galappaththi-Arachchige et al., 2016, p. 2). South African statistics today (05.07.2020) points to an progress, as the statistics in KZN show that 73,9 % of the households have `improved sanitation´, 21,5 % of the household have `other sanitation´, while 4,7 % of the household have non sanitation (SA, 2020b). Giving to the two different statistics (2011 and 2020), this appears to be a development over the last decade. Which may indicate that fewer people [women] in South Africa use rivers and dams for everyday household chores, compared to earlier.

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[5] Sources referred to in this thesis argue that when females acquire FGS at an early age, it makes them more vulnerable to additional infections [referred to as "superinfections"], and that this may explain why girls in eastern and southern Africa "acquire HIV 5-7 years earlier than their male peers" (UNAIDS, 2019, p. 10). These are numbers that should be reacted and acted upon.

3 Literature Review

All literature referred to is characterized by specific concepts and a given way of writing in the medical field, and in the following chapter it will be the medical perspective that is of interest. This chapter will present the literature used for this master thesis and which has served as an important background for my work. For the unfamiliar reader to gain an understanding of the Female Genital Schistosomiasis (FGS), I will begin this chapter by presenting the cause, the symptoms, the diagnostic methods and the prognosis of the disease.

3.1 Attention on Female Genital Schistosomiasis

Several sources point out that FGS has not been an unknown disease among larger institutions and organizations, whereupon "Gender Task Force of the Tropical Disease Research Programme (TDR) of WHO included FGS in a list of scientific areas that deserve higher research priority" in 1997 (Christinet, Lazdins-Helds, Stothard, & Reinhard-Rupp, 2016, p. 396), in order to improve women's health and prevent further infections. And in October 2009, World Health Organization (WHO) recommended to rename *urinary schistosomiasis* to ***urogenital*** *schistosomiasis* (Stothard et al., 2020, p. 410). The purpose behind the change of term and attention was to emphasize that the parasite destroys both the urinary tract and the genital tract (in female and male) and highlight the relation between FGS and other sexually transmitted infections. Whereas 75% of the girls infected with S. haematobium seams to live with lesions in the womb (uterus), opening into the womb (cervix), vagina or the external part of the female genital (vulva) (Kjetland et al., 2012; Magaisa et al., 2015; Stothard et al., 2020; UNAIDS, 2019).

3.1.1 Cause of FGS

The reason why people become infected by this disease, is because they come in skin contact with contaminated water that is infected by the parasite called Schistosomiasis [in this case, the focus is on the subgroup *Schistosomiasis haematobium*]. The parasite has a very special cycle that has major consequences for those who become infected: in the water there are small larval flakes (*cercariae*) which are related to a special form of freshwater snails (*Bulinus snails*). The larval flakes drill in through the human (or animal) skin, while in contact with the infected water. Further they enter the bloodstream where the parasites mature into adult larvae’s, mates and lay eggs (fifty to hundreds every day). These eggs will then intend to exit the body, in order to find their way back to a new Bulinus snail in the water. In order to do this, the eggs leave the bloodstream, by drilling through the internal tissues and find a form of elimination route (such as urine, faeces, vaginal discharge, semen). When this body fluid/mass exits the body in water (for example by urinating in the water, or performing personal hygiene), the eggs will find their way back to a Bulinus snail and start the cycle all over again (Bruun & Aagaard-Hansen, 2008; Magaisa et al., 2015; Norseth et al., 2014; UNAIDS, 2019).

It is the eggs that causes great harm to the human being as they exit the body through bodily tissue, not necessarily the larvae’s living in the bloodstream. As Expert Informant 11 explained, the eggs can be compared to a thorn in the finger, only that the egg becomes the "thorn" in the tissue. It becomes a problem when the eggs are foreign to the body, as the body will resist it by creating an inflammatory reaction, and consequently will lead to damages (lesions) in the tissue (Kjetland et al., 2012). In this case it concerns the reproductive organs, although the parasite can (or will) affect other organs as well; according to Christinet and colleagues (2016, p. 395) “eggs can be found throughout the body in variable amounts, other clinical and pathological diseases can be found in the heart, lungs, brain and spinal cord as well as in the genital organs of both genders” (p. 395).

Figure 2: Schistosomiasis Cycle (Norseth et al., 2014, p. 4):

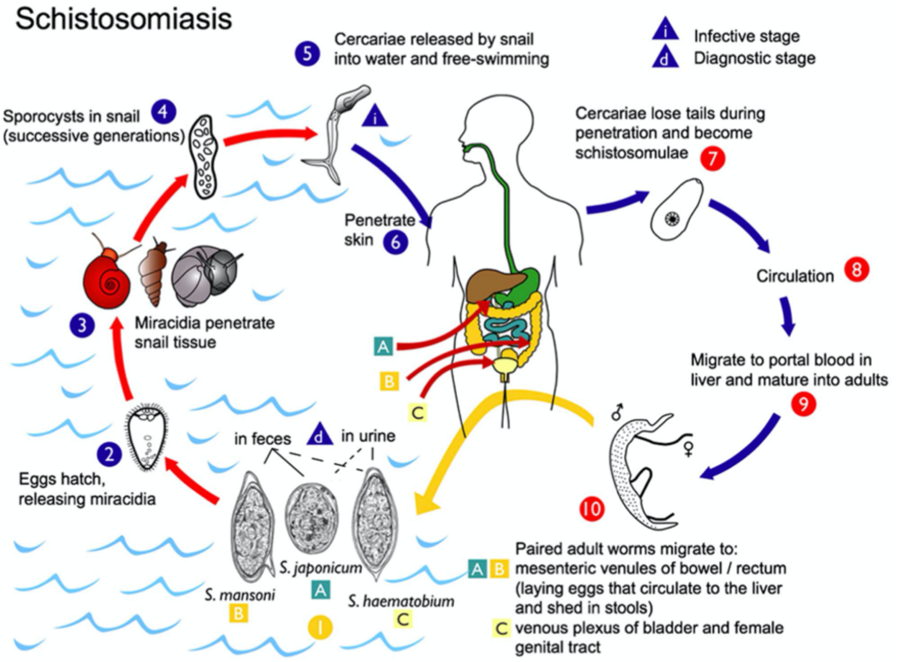

Figure 2. Schistosomiasis life cycle. The most common species found to be pathogenic to humans; and *Schistosoma (S.) haematobium, S. mansoni, S. japonicum* [73]. Eggs are excreted through faeces, urine and possibly through vaginal discharge from infected individuals, may hatch if they come in contact with water, releasing miracidia that infect fresh water snail hosts where they multiply, producing free-swimming cercariae that eventually may penetrate the skin of human hosts. The cercariae mature in the portal vein and migrate to venules draining the intestines, or the urinary and genital tracts, where they may deposit up to 300 eggs every day. Some of these eggs will be trapped in the tissues inducing a localised host response, while others will penetrate the vessel wall and the mucosa of the intestines, the bladder or the genitals, subsequently excreted in faeces, urine or vaginal discharge into fresh water in order to continue the parasite life cycle. This figure shows the venous plexus of the bladder only; however, the venous plexi surrounding the genital tract is also affected. (Source: CDC-DPDx, Atlanta, United States).
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3.1.2 Symptoms

The most recognised location is in the urinary tract [referred to as “urinary Bilharzia” or “isichenene” in isiZulu] where the most apparent symptom is blood in the urine (haematuria) and experience of difficult urination (dysuria) (Bruun & Aagaard-Hansen, 2008). In case of infection, the eggs of the larvae’s will find its way to exit the body through vaginal discharge, may lead to abnormalities such as bad smell and discolour, genital lesions[6], contact bleeding (when penetrating the vagina), ectopic pregnancy (fertilization outside the womb), repeatedly spontaneous abortions, infertility, amongst other health problems. These symptoms can be easily misinterpreted with sexually transmitted infections since the symptoms are similar. Overall, the damages created in the reproductive tract may increases the risk of further

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[6] The lesions may be identified as sandy patches; homogenous yellow sandy patches; abnormal mucosal blood vessels; rubbery papules; genital ulcers; tumours (swelling lumps); a thick white layer (leukoplakia); and/or red skin. FGS would be diagnosed due to the presence of any characteristics mentioned above, found through gynaecological colposcope inspection (visual examination) of the cervix, vagina and vulva (Norseth et al., 2014).

infections (superinfections) such as HIV and other Sexual Transmitted Infection (STIs) (Christinet et al., 2016; Galappaththi-Arachchige et al., 2018, p. 3; Hotez et al., 2019; Kjetland et al., 2012; Eyrun F Kjetland et al., 2006; Eyrun Floerecke Kjetland et al., 2008; Norseth et al., 2014, p. 2; UNAIDS, 2019).

3.1.3 Diagnostics

Female Genital Schistosomiasis might be difficult to diagnose. In the following text, it is illustrated how the infection develops unpredictable and different in each individual, so it becomes problematic to capture (the clusters of *S. haematobium* eggs). Furthermore, I will explain recommended diagnostic methods.

One might manage to diagnose FGS with Pap smears (collecting cells from the cervix) but Pap smears have proven a sensitivity of less than 15 % (Kjetland et al., 2012, p. 12). One may test and analyse urine by filtrating the schistosomiasis eggs, but Norseth and colleagues (2014) whom have conducted research in endemic areas (such as in South Africa, Malawi, Tanzania and Madagascar), have indicated that less than 60 % of women with FGS excrete eggs through urine. The eggs might rather be excreted through vaginal discharge, making it unadvisable to diagnose FGS via urine samples (Norseth et al., 2014, p. 2). Otherwise, one can try PCR (polymerase chain reaction – mapping the DNA), and serum analysis (blood test), but none of which have a 100 % credibility due to diverse biomedical variables (Kjetland et al., 2012, p. 12). However, mentioned diagnostic tools will become extra challenging when the health facility has limited resources, such as lack of equipment's and trained staff.

Although The Joint United Nations Programme on HIV/AIDS (UNAIDS) currently recommend FGS to be diagnosed simply from a specimen collected during a gynaecological examination (UNAIDS, 2019), an `FGS consensus meeting´ held in Copenhagen October 2010 recommend different. The meeting compared and conferred clinical findings from several African countries and concluded that visual examination in itself is an adequate diagnostic method, thus no requirement for a biopsy specimen. One argument behind this was that the tissue sample which is removed during a biopsy might fail to include the S. haematobium eggs as the eggs accumulates in small clusters inside the tissue (Kjetland et al., 2012, p. 63).

Numerous of researches and experts advise to train health professional to identify lesions, especially in low-resources settings where expensive diagnostic equipment's are unavailable (Bruun & Aagaard-Hansen, 2008; Christinet et al., 2016; Hotez et al., 2019; Kjetland et al., 2012). Furthermore, UNAIDS present a proposal for the future, an innovative mechanism such as `telemedicine´, where one uses a smartphone to perform diagnostics in the genital tract. This is increasingly available because more people use smart phones, including health workers in developing countries. The same mechanisms have already been used to diagnose cervical cancer, henceforth it may gradually include FGS "through capture and interpretation of characteristic lesions indicative of the disease. In all situations issues pertaining to confidentiality, dignity and privacy are of ethical concern and must be respected" (UNAIDS, 2019, p. 20).

3.1.4 Medical Treatment

Clear indications suggest that it is advisable to start anti-Schistosoma treatment (Praziquantel) as early as possible in life (infanthood), and repeat treatment every three to six months as long as one is exposed to infected water or live in endemic areas. Hence, use the treatment as a prophylactic measure to prevent irreversible chronic damages and reduce the possibility of reinfection[7]. Furthermore, it is advisable to medicate the whole family, if proven by one of the members. This is because one member is most likely to share water (contact) with his or her family members and thus be at risk of transmitting the infection via shared water (Hegertun et al., 2013, p. 6; Kjetland et al., 2012; Norseth et al., 2014).

For the best possible result of the medication, it should be given when it is the lowest season for infection. Norseth et al. (2014, p. 2) refer to a study of systematic investigation of Urinary Schistosomiasis in children, where lesions in the urinary tracts resolve within two to six months post-treatment. There is a high likelihood that anti-Schistosoma treatment (Praziquantel) works best on children, because the treatment will kill the worms before they have managed to create grave and chronic lesions - comparable to how it has been observed in many adult patients (Magaisa et al., 2015, p. 3). Untreated FGS is likely to cause irreversible damage to the genitals and can therefore continue to cause diverse health problems in women throughout life.

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[7] When the treatment is taken regularly, the worms will not be able to develop too deep wounds, and thus the wounds will have more time to heal before the next infection occurs (which depends on the interval in individual water contact) (Hegertun et al., 2013, p. 6; Kjetland et al., 2012; Norseth et al., 2014).

3.1.5 Prognosis

The parasite may stagnate the growth of children and pubertal development of adolescence, leading to decreased fertility through life. Rapports indicate that early suffering from Schistosomiasis (as for children living in endemic areas) appears to end up with hormonal disturbance (Norseth et al., 2014, p. 2). Likewise, the infection results in loss of blood (anaemia), leading to stagnation physically (also growth in children) and intellectually. It may result in concentration difficulties, learning disabilities, attention deficit disorder, altogether reduced leaning potential. In an early stage of life, this can affect attendance at school and lead to dropouts from school and higher education (Magaisa et al., 2015, p. 4). Outcomes such as reduced school and educational participation may stand in the way of the district's development. It can also contribute to a stagnation of the general level of knowledge.

3.1.5.1 Female morbidity

In KwaZulu Natal, sexual transmitted infections (STIs) seem to be overrepresented amongst sexually active young women, leading the ladies into a morbid kind of discrimination. With infections such as Chlamydia, Gonorrhoea, Trichomonas and syphilis. Many STIs occur *without* significant symptoms, which might leave the women untreated[8] (Galappaththi-Arachchige et al., 2018). In sub-Saharan African countries, there is anticipated 3 % relative increase in HIV prevalence per 100 individuals infected with S. haematobium. According to several epidemiological studies, FGS increases the risk of HIV/AIDS. "FGS causes lesions in the cervix and vaginal mucosa in young women, creating ideal conditions for HIV transmission due to "contact bleeding" during sexual intercourse" (UNAIDS, 2019, p. 13). Consequently, "FGS is responsible for up to a three- to four-fold increase in horizontal transmission of HIV/ AIDS" (Hotez et al., 2019, p. 1). These conditions of sickness will further lower the woman's position in society, by weakening and depriving her of opportunities she would otherwise have been able to bear if she were completely healthy. Like spoiling girls' opportunities for school and higher education. When enough of the female population end up in a similar situation, this could be detrimental to the development of a society - as women do not get the same opportunities to join, compared to the male population. Consistently, genders can have different benefits and positions in society, contributing gender inequality.

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[8] Consequently, untreated STIs might lead to pelvic inflammatory diseases (PID), increased risk of fertilised eggs outside the womb (ectopic pregnancies) and infertility (Galappaththi-Arachchige et al., 2018)

As both mentioned and illustrated through “Figure 2” the most apparent symptoms of Bilharzia/Schistosomiasis are blood in urine, thus Schistosomiasis has not been recognised as a genital disease until relatively recently. Another explanation seems to be that the damages in the genital tracts often hide behind or gets mistaken with other diseases, such as HIV, STIs or HPV/cervical cancer (Galappaththi-Arachchige et al., 2018). When an infection adds to another, it is called *a superinfection*. Kjetland et al. (2012, p. 60) describes a characteristic prognosis in women whom are sexually active; “Genital changes are breaches in the mucosal surface, open wounds, perhaps susceptible to superinfection by bacteria and viruses such as human papillomavirus (HPV) or other sexually transmitted diseases”.

Primary health care facilities may easily misdiagnose, thus fail to offer praziquantel treatment because the signs and symptoms are similar to sexual transmitted infections (STIs)[9] or cervical cancer. One of the reasons for this is argued to be the use of s*yndromic management* (SM), which is an algorithm used by nurses in order to diagnose on the basis of detectible signs and symptoms, and SM may cause confusion amongst the patients and nurses when the treatment does have any effect. In such cases, counselling, help and support would be necessary (Stothard et al., 2020, p. 411). Consequences by FGS (including miscarriage and infertility) may affect women’s mental health and social status, as it can lead to taboo, stigmatisation and social exclusion in many cultures. Moreover, “misdiagnosis can lead to multiple visits to health-care professionals, with an increased burden on the patient and the health-care system” (UNAIDS, 2019, p. 8). All mentioned factors contribute to complexity concerning the neglected disease. When healthcare professionals lack of knowledge about FGS, because it is (globally) neglected, failures are determined to occur. These failures, such as incorrect medical treatment or failure to provide proper treatment (praziquantel), will lead to increased morbidity in the female population. Because the problems that arise, such as infertility or “contact bleeding” during sexual intercourse, are closely linked to the stigma and taboo. It will then lead to an unfortunate [morbid] discrimination against women.

3.1.6 Prevalence of early genital problems in girls

The highest prevalence of FGS is found in areas with poor sanitation, because contaminated fresh water is the main source of infection. The infecting waters is both host to the *Bulinus snails*, whilst infected by human waste (urine, faeces, genital excretions which is infected

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[9] If a patient suffers from both FGS and an STI, but only receives treatment for her STI, then the "wrong" treatment can relief her current disorder of the STI / superinfection - even if it does not relief the underlying disorders of FGS (Kjetland et al., 2012).

with schistosomiasis eggs) (Magaisa et al., 2015). As mentioned above, Schistosomiasis may easily be acquired during childhood if one lives in endemic areas. In the following section, I will present something that challenges the mapping of FGS prevalence. Invasive gynaecological examinations in young girls, in order to tract vaginal or cervical Schistosoma, has not been systematically inspected because such intervention is unexpectable and controversial at a young age prior sexual debut - both due to culturally and medical reasons (Hegertun et al., 2013) [please read more in section *6.1.3.1 Diagnosing genital problems in young girls and cultural consequences*]. Therefore, young girls are partly excluded from research in general, which may be a contributing cause for why FGS remain underreported, thus a neglected disease (Stothard et al., 2020) – a dimension which can also be considered as culturally. Hegertun et al. (2013) on the other hand, have researched girls between 10-12 years of age, via interviews and examination urine specimens as main methodology. Also, Hegertun et al. (2013) conducted a study on 1057 schoolgirls between 10 and 12 year of age, spread across 18 randomly selected schools in both high endemic areas and low endemic areas. They interviewed the girls about (self-reported) genital problems and examined samples of their urine. The results found S. haematobium presented in one third of the schoolgirls (312/970, 32%). Through regression analysis, they found significant association between reported genital symptoms and presentation of S. haematobium and self-reported water contact. Thus, a higher prevalence among the girls from high endemic areas compared to the girls from low endemic areas. UNAIDS (2019, p. 31) suggest further research in order to adequately diagnose FGS without requirements of a proper gynaecological inspection, in order to include younger group of the population. By doing this, one might find numbers/variables that reflect a more credible prevalence of FGS.

3.2 Sociological factors

Through the document analysis, several social factors have emerged that I find important to include in order to achieve an understanding of the problem statement. In the following text, I will view some social risk factors connected to suspecting FGS, associations to gender, as well as global and regional FGS prevention agendas.

3.2.1 Water as the main risk factor

Growing up in endemic areas, the waters might be impossible to avoid as water is a natural part of the environment and people's daily behaviours. Water related activities are linked to domestic purposes (personal hygiene, household chores, collecting water, laundry, washing blankets, bathing), professional purposes (fishing, cultural or religious cleansing rituals), and recreational purposes (playing/swimming) or crossing. Most people in endemic areas may acquire schistosomiasis during an early stage in life, as water is essential for proper childcare. Thus, leading to a major public health problem as the health problems might begin during childhood (Hegertun et al., 2013; Magaisa et al., 2015). Another risk factor is personal hygiene with a need for water and sanitation, especially for girls experiencing menstruation health. SGD 6 (clean water and sanitation) support this by stating “unique needs of girls and women for sanitation” (Stothard et al., 2020). Paradoxically, female headed households have a statistically lower access to water and sanitation compared to male-headed households (SA, 2019). All in all, how exposed one is, depends on the individual’s contact with contaminated water and further their water activity pattern.

3.2.2 Other `at risk behaviour´

Social factors can put women at increased risk of disease transmission. According to Galappaththi-Arachchige et al. (2018) there are a number of social and behavioural factors behind the severe prevalence of lower reproductive tract problems amongst sexually active young women in the province of KwaZulu Natal. Through a perspective of public health, researchers have studied the relationship between female genital morbidity and “socio-demographic factors, socio-economic factors, sexual risk behaviour, substance abuse and knowledge about reproductive health” (p. 1). Risk factors were mapped such as early sexual debut; multiple sexual partners; the age difference between the sexual partners (if the male is older and more experienced than the female); the level of parental care and financial stability while growing up, because absence of support (not living with both biological parents) might lead young women into a higher level of transactional sex and substance abuse; socio-economic factors, which might decrease access to medical treatment (praziquantel); and if treatment for schistosomiasis have been previously received (p. 2).

3.2.3 Global planning and preventive mobilisation

World Health Organisation states that the schistosomiasis parasite “has the highest burden of disease among the 17 recognised neglected tropical diseases” (World Health Organization (WHO), 2016b cited in Christinet et al., 2016, p. 395). Despite of many efforts, UNAIDS (2019, p. 25) states that “Yet, to date, there is no targeted national programme for detecting people with FGS, informing patients, managing the chronic consequences, or actively preventing new cases of FGS». In 2001 however, WHO World Health Assembly (WHA) endorsed resolution number 54.19, which promotes regular chemotherapy[10] (praziquantel medication) through Mass Drug Administration (MDA). The target group is considered to be children and women of school age to reduce and prevent long-term morbidity as well as reinfection due to schistosomiasis and terrestrial worm-like parasites (helminths) by 2025. If Schistosomiasis is detected at a school, the medicine is distributed to school children without medical consultation beforehand (Christinet et al., 2016, p. 397; Magaisa et al., 2015, p. 1). Nevertheless, the first control program in KwaZulu-Natal (of helminths and schistosomiasis) had already been carried out October 1997 (Magaisa et al., 2015, p. 3), which indicates that the administration method was already an effective and good practice before the WHO chose to adopt it to its own guidelines.

Magaisa et al. (2015) suggest schistosomiasis control measurement to mandatory collaborate with primary health facilities and school health teams, including at the same time ensure adequate recourses such as a supply of praziquantel. Portable water should be provided in the communities to improve water and sanitation, and bridges or steppingstones may be constructed at sites where people need to cross rivers. Furthermore, educational programs should encourage and likewise prevent contact with contaminated water, such as recreational contact and household chores (p. 4). A brief of UNAIDS (2019) plants FGS on the agenda by suggesting that knowledge and awareness about FGS should be integrated in other programs emphasising health and rights connected to gender inequality, sexual and reproductive health; the epidemic of HIV; and the burden of cervical cancer[11].

3.2.4 Gender differences

Access to school and gender inequity amongst the pupils may affect access MDA. A report by UNESCO, stated that approximately half of the youth population between 15 and 17 years old in Sub-Saharan Africa were not attending school in 2016. Across the region, more than 93 million of the children in primary and secondary schools are out of school. Furthermore, there is a gender inequity in sub-Saharan Africa, where 9 million girls compared to 6 million boys

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[10] The drugs are recommended to be distributed with a frequency of 6 to 3 months interval, depending on weather it is high or low seasonal transmission (Kjetland et al., 2012, p. 63).

[11] FGS may be identified as a crucial cofactor to the HIV/AIDS epidemic in sub-Saharan Africa, MDA would be a highly cost-effective measure thus part of an important strategy in order to reduce the prevalence of HIV (Hotez et al., 2019).

will never attend school. Leaving 23% of girls compared to 19% boys out of primary school (UNAIDS, 2019, p. 9). Thus, the cure rate of MDA is far from adequate, as the mass treatment will fail to reach children whom are not attending schools. Furthermore, infected people will continue to excrete the Schistosoma eggs through bodily fluid/elimination in local water sources (rivers and dams), thus continue to infect the local population in the need for water. Even if one had received treatment before, reinfection rates will remain high (Bruun & Aagaard-Hansen, 2008, p. VIII).

UNAIDS (2019) highlights global measures such as The Conventions on the Elimination of All Forms of Discrimination Against Women which "established access to healthcare, including reproductive health, as a basic right" (p. 10). For women to experience equal rights, it will depend on stakeholders, policymakers and the governments will initiate action, ability to fulfil promises, and work structurally. One should take into account that men, women, boys and girls have different starting points and therefore different risk behaviour factors associated with Schistosomiasis. Therefore, gender roles, including taboos and risk behaviour factors are important to analyse and understand, in each area with a rights-based approach.

3.2.5 Planning prevention in South Africa

According to Magaisa et al. (2015), there has been attempts to incorporate the management of Schistosomiasis controls programs (i.e. treatment, prevention and active surveillance of the disease). The Department of Health in South Africa have developed planning guidelines which easily can assist "(…) district and provincial health planners to help assess the unmet needs of their population and to draw up plans to bring services up to national standards". The document is titled "The Primary Health Care Package for South Africa – A set of norms and standards", with three key requirements:

> *1) recognizing the public health importance of schistosomiasis, (2) the political will and commitment to utilising local resources for control and (3) readily available public health facilities for the delivery and maintenance of control interventions (Magaisa et al., 2015, p. 3).*

According to Magaisa et al. (2015, p. 4) "the major obstacle has been limited access to praziquantel as well as unavailability of water, sanitation, environmental health infrastructure or the necessary resources to implement schistosomiasis control". Furthermore, the Department of Health in South Africa have taken these aspects and the strategical plan by WHO into consideration whilst developing a document containing guidelines for managing schistosomiasis. The document is titled *The Primary Health Care Package for South Africa – A set of norms and standards.* Magaisa et al. (2015) compliments that "The norms and standards were intended to be used as planning guidelines by district and provincial health planners to help assess the unmet needs of their population and to draw up plans to bring services up to national standards" (p. 3). The document also intends to guide integration of schistosomiasis management in South African primary health care systems. It includes guidelines for the treatment of the disease, the need for preventive measures and the primary health service's monitoring of the disease, especially the endemic areas of South Africa. With an aim to reduce morbidity; improve sanitation; create dialogue between the health personnel, teachers and parents; and increase children's leaning potential (Magaisa et al., 2015, p. 4).

4 Theoretical framework

The following chapter presents how multilateral institutions have made rules and regulations such as the millennium development goals and the SDGs to "elevate" the poor population and females in particular, with an aim for a more equal global society. It also presents how a paternalistic hegemony has come in the way for women's equal position in society and research through history, and how this has impacted and continues to impact women's health. Taking feminism as a standpoint, a presentation of Institutional Ethnography has also been provided, to demonstrate the "way of thinking" as a preparation for the analysis and discussion in Chapter 7.

4.1 Global guidelines and planning

The legacy of colonialism, imperialism and post-world war two as well as patriarchal norms and practices have contributed to a power asymmetry that has continued to plague global health (GH50/50, 2020). In the rapport "Our Common Future" ("Vår Felles Fremtid") directed by the United Nations (UN) in 1987, Gro Harlem Brundtland claimed the term *Sustainable Development.* The objective is to see what the current generation can do in order to hand over our planet to the next generations, no more destroyed nor polluted than it already is. The aim is to take care of the needs and opportunities of the present and the future generations (Austveg & Christensen, 2010, p. 84)

The analysis "Maternal health initiative: a global perspective"[12] (Norwegian title: “mødrehelseinitiativet: et globalt perspektiv”) by Austveg and Christensen (2010), refers to research on women and their reproductive health, as well as how their position traditionally has been neglected in favour of male-profiling discourses[13]. Dorothy Smith support this by fronting how a gender subtext of ruling relations has historical roots in patriarchy” (referred to in McGibbon, Peter, & Gallop, 2010, p. 1368). A lack of gender equality and diversity within global health organizations has been recognized, including positions of power and leadership. According to the Global Health 50/50 Rapport, 70% of CEOs and board chairs are men and only 5% are women from low- *and* middle-income countries, which insinuates that the poorest women are marginally represented in the development of global health policy. Furthermore, 85% of global organizations working on global health policy are headquartered in Europe and North America. Out of the leaders, 80% are from high-income countries, whereupon over 90% completed their education in economically rich countries (GH50/50, 2020). Which points to a strong inequality anchored in socio-economic conditions at an overall systemic level, which also makes it difficult to understand the poorest peoples, and therefore take their side in the fight against dire health burdens. At the same time, it reflects the differences between people who come from the global south and the global north, which is also recognized as the phenomenon of "race" as social construction.

The term "reproductive health" was confirmed by the UN in 1994, and includes health aspects related to sexuality, the reproductive organs and their function (including family planning; advice and guidance regarding sexuality; preventive measures and treatment of sexually transmitted infections; care for infertility; and care for pregnancy, childbirth and abortion) (Austveg & Christensen, 2010, p. 71). In the following text I aim to demonstrate how the marginalized position of women is an important background in order to understand why development within women's health is lowered, especially regarding reproductive health.

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[12] Note that the analysis of Austveg and Christensen (2010) primarily highlights *maternal health* within the spectre of “reproductive health”, furthermore how women have a lack of social as well as decision-making power.

[13] A *discourse* in way where “versions of reality are accomplished through language” (Bryman, 2016, p. 690). Discourses are intended as criticism of the socially constructed reality, as well as criticism of positivist thinking. With "gender discourses" as an example, it means that each individual will feel responsible for acting on the expectations assigned to their specific gender (role) in society. Therefore, gender is not necessarily seen as something personal, but rather as a role in a system; hence the statements «we are not gender; we do it» and «doing gender» (Alvesson & Sköldberg, 2018, p. 269)

Through the UN's Millennium Development Goals (from the year 2000 to 2015), the focus on female reproductive health increased as well as the focus on strengthening the position of women in society. But despite an increased focus, it became the least developed area (Austveg & Christensen, 2010). In 2003, current WHO Director-General Gro Harlem Brundtland highlighted the importance of increasing investments for the health sector, in order to gain economic development. Public actions and mobilising resources were required in order to succeed, maintain and improve public health. Brundtland emphasised how well-functioning public health system is a constituent component of development, because society will not be able to maintain neither dynamic nor structural functions unless the health of the people is satisfactory and taken care of. Hence, health and economic development are mutually directed (Ruger, 2003). Austveg and Christensen (2010) discuss how the health of females are unpredictable due to reproductive abilities, and that health facilities therefore should maintain an average good standard wherever there is female [worldwide]. Unfortunately, among less developed societies worldwide, it is common for health facilities to fail to meet quality goals due to a lack of priority and financial resources, as well as other barriers connected to culture. Contributing barriers to development process might be several; cultural factors, local values and traditions (Austveg & Christensen, 2010). According to Ruger (2003, p. 678), skewed power relations should be addressed during development, partly because income inequality and inequality among social positions may harm the health of the disadvantaged in society, furthermore contribute to marginalization by weakening their position due to vanished health. Women living in poverty in a male-dominated world have historically ended up disadvantaged and marginalized due to their low influence compared to their mail peers and people from higher social classes. Consequently, poor women have posed no threat to social security. Although, there are health differences among women according to which social class they belong to, on which spectrum they are based economically, politically. At the same time, what historical heritage they carry and in what way social order, cultural and structural frameworks shape women's everyday lives (Moss, 2002).

Political arrangements, citizens' right to vote and right to property, ownership, management of resources often seem to have been developed from a man's perspective, and throughout the ages, international politicians have not spoken out on behalf of poor women (Austveg & Christensen, 2010; GH50/50, 2020). It is not until recent decades that the interests around women’s rights and perspectives began to flourish. The UN Millennium Development Goals introduced in 2000 brought women's sexual and reproductive health onto the global agenda.

Despite increased commitment and engagement; lots of health-oriented intensives; increased research and aid; as well as growing feminist mobilization, there has been alarmingly little development regarding female reproductive health. Traditionally, men and male interest have ruled both research and global media (Austveg & Christensen, 2010; Smith, 2005; Sundby, 2019). This may have been a contributing factor to why women's health has been downgraded. Moreover, men have traditionally decided what to research in medicine, ignoring the difference in male and female, rich and poor health challenges. The Global Health Report 50/50 state that the colonial era has left its mark on medicine and global health. Most medicine was developed by the colonists for the colonists, in order to maintain military superiority and to support extractive industries. It resulted in a competition for knowledge and prestige more than reducing the gap between rich and poor, and thus there was little need to secure cooperation with indigenous people. When metropolitan societies flourished in the late 19th and early 20th centuries, urban development interventions became selective in the colonies. All in all, global history has shaped where the focus should aim, both in terms of people and which diseases should be prioritized (GH50/50, 2020)

Multilateral institutions such as the UN and WHO play an important role for the worlds well-being, by implementing and ensuring the states know the rules of the "global game" regarding trade, finance, aid, development (McNeill, 2006). The UN Millennium Development Goals (MDGs) were established in order to improve the well-being of people in developing countries by the year 2015, but without particularly impressive results for women's health. In 2015, the UN Sustainability Goal (SDG) came with the new "Agenda 2030" aimed globally, due to an acknowledgement of an increasingly interconnected world. The SDGs contain overall 17 goals, 169 targets and over 300 proposed indicators, in need of sufficient commitment and work in order to succeed. Simultaneously, three critical dimensions have been taken into consideration, regardless of country, being *climate and the environment*, *economy* and *social conditions* (Costanza et al., 2016, p. 350). Associated to Female Genital Schistosomiasis, following SGDs are highly relevant:

- SDG 1: No poverty – “end poverty in all its forms everywhere”.
- SDG 3: Good health and well-being – “ensure healthy lives and promote well-being for all at all ages”.
- SDG 4: Quality education – “ensure inclusive and equitable and promote lifelong learning opportunity for all”

- SDG 5: Gender equality – “achieve gender equality and empower all women and girls”
- SGD 6: Clean water and sanitation – “Ensure availability and sustainable management of water and sanitation for all”
- SDG 10: Reduce inequality – “reduce inequality within and among countries”
- SDG 11: Sustainable cities and communities – “make cities and human settlements inclusive, safe, resilient and sustainable”
- SDG 17: Partnership for the goals – “strengthen the mans of implementation and revitalize the global partnership for sustainable development” (SDGs, 2015).

The discussion in chapter 7 emphasises SDG 5 on “gender equality and empowerment for all women and girls”. This goal is important for the group of patients, but I have chosen to focus on the nurses and their room for empowerment [in light of the fact that nursing in South Africa is a female-dominated profession, as stated by Interviewee 15]. Access to information about the neglected FGS are available in research and through multilateral institutions, such as the WHO. If nurses get access to the “hidden knowledge” and room to reflect and act upon it, it might contribute to an empowerment amongst nurses as they would be able to carry out their role satisfactorily and sustainably. In such development of knowledge, implementation of SDG 4 and SDG 17 will also be relevant. In other words, discussion about empowerment, knowledge development and ruling relations is about *who is allowed to set the agenda,* as discussed above.

Global initiatives are defined as «*a transnational advocacy network* includes those relevant actors working internationally on an issue, who are bound together by shared values, a common discourse, and dense exchange of information services» (Keck and Sikkink, 1998 p. 2 quoted by Austveg & Christensen, 2010, p. 67). Within planning on a global level, it is measured how ideas and international norms affect the national states and their politicians' will regarding decision-making processes and choices of action. `Political will´ is achieved when international and national political leaders express determined concern about issues, when the multilateral institutions and political organs in which they lead, develop strategies to solve the problems and allocate resources that are corresponding with the size of the problem (Shiffman and Smith 2007 p. 1370, cited in Austveg & Christensen, 2010, p. 68). In such processes, it is important to recognize how investments in women's health can contribute to sustainability and be critically important for the development of society. Nevertheless, because women have a lower status than men, it may also explain the lack of political will aimed at improving women's conditions. Moreover, because the reproductive organs of women are frequently referred to as private thus embarrassing, it is recognized as taboo. Thus, reproductive health problems in women have proven to be a sensitive indicator of social injustice in many societies.

4.1.1 The theory of *Health Belief Model*

The Health Belief Model (HBM) has been frequently used as a link between socialization and behaviour, as demographic characteristics (such as socio-economic status, gender, ethnicity and age) are associates with health related (risk) behaviour and the use of health facilities. The HBM target individuals by triggering them, thus motivate them to make a change in their own health-related conditions. Two aspects evaluated in the development of health promotion are the perceptions of *threat* and *behaviour*[14]. Education will increase the level of knowledge (and reduce fear) thus trigger and motive to act for a change. Moreover, to succeed, the individuals must believe in oneself and one's ability to handle the following challenge(s) and thus cultivate *self-efficacy*. However, limitations have been addressed with this model, as it might target the individuals in a general sense with little room for individual (cognitive) differences (Abraham & Sheeran, 2005). I will not go deeper into this model, nor the limitations, because HBM does not target the *nurse's relation* to public health issues. However, HBM is mentioned in the discussion because it is a model that is frequently used in health research, although it does not address power relations and structures such as Institutional Ethnography (IE). As most models, HMB approaches "top-down" [targeting to educate a group of individuals] even though the model itself seeks a "bottom up" approach putting the patients in the centre. In other words, this model does not help to bridge the gap between research and behaviour, both because it comes up with a solution rather than study the reasons *why*. Consequently, HBM constitutes an example of ruling relations, thus being a contrast to IE, as IE seeks to develop a theory instead of promoting one.

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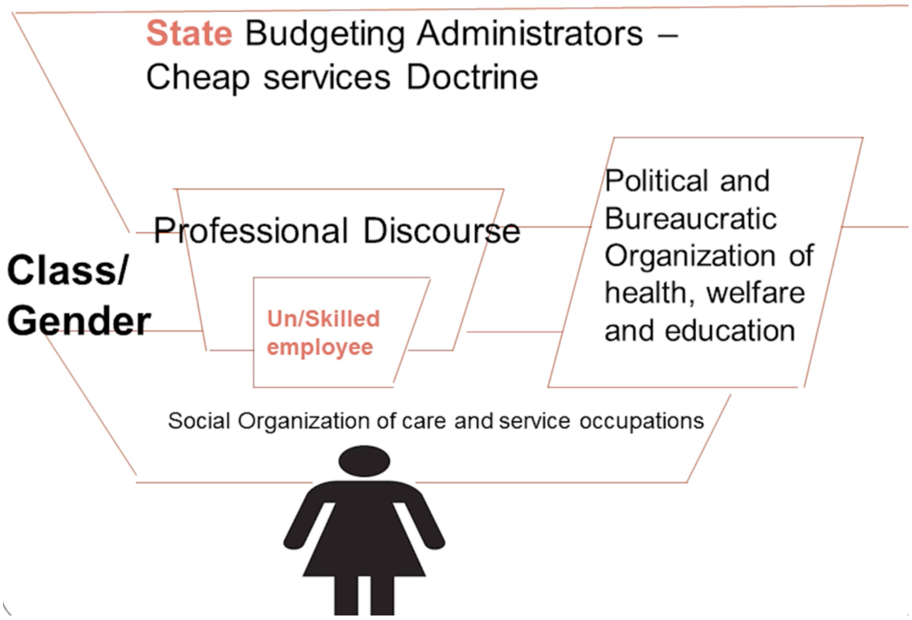
[14] Furthermore, the *perceived of susceptibility* (one's opinion of chance of being affected), the *perceived of severity* (the idea of how serious and harmful this condition might be) – and if there two perceptions result in a high score, it might trigger a feeling of threat which might motivate for change. Moreover, the *perceived barriers* (the cost and drawbacks) and the *perceived benefits* (how effective the advice action would be) – the score of the latter might determine the response after evaluating both pros and cons (Abraham & Sheeran, 2005).

4.2 Institutional Ethnography

I am inspired by Dorothy Smith (2005) and her presentation of *Institutional Ethnography* (IE), "…a feminist methodology that nonetheless relies fundamentally on people's experience. Not as truth, nor the objects of inquiry, but as the point d'appui [support] for social inquiry" (Campbell, 1998, p. 55). Smith invite us to "begin from the actualities of people lives" in order to understand them (Smith cited in Campbell, 1998, p. 56). By studying people's behaviour, activities and discourses and how these activities are coordinated with those of others, Smith seeks to address the gap between written text/theory and what people actually do (work knowledge). The *power* and *ruling relations* between the governing state, the organizations involved, and the employee is addressed in IE. The scriptural guidelines given (for the purpose of providing meaning and order, prevent conflict and add value, thus in line with bureaucracy) set requirements that shape the employee's room for manoeuvre and work knowledge (Smith, 2005). In this thesis, the link [or the "contract"] between the guidance provided by specific multilateral institutions; the South African Government; the three specific local health clinics; and the professional nurses are considered. Thus, and according to IE, several layers and dimensions of ruling relations "control" the behaviour and work knowledge of my respected informants' opportunities.

The drawing below illustrates the thinking behind IE and its way to consider *ruling relations.* It is considered through the paradigm of *feminism* on which IE is based, where the employee's behaviour and work knowledge are also shaped by the position and role in the society and at home (hence class, gender and race as *social constructions*).

Figure 3: Institutional Ethnography (NCRMUK, 2017)



Institutional Ethnography is a way of thinking (a tool) in order to get hold of the social field (an inquiry). IE is based on specific understandings of "the social" rather than being a category within sociology. This way of thinking is not often captured by traditional sociological theory, as theory is not a natural part of people's reality (Smith, 2005). According to Smith, the gaze and understanding of social scientists can be "captured" both by dominant discourses in society as well as by social science theory and concepts. "Captured" meaning that discourses, habits and routines freeze and lose its dynamic adaptation to other things around. Formal concepts and theories within social science are based on something objective and concrete, so that interested people are able to relate. At the same time, there are very close links between politics and research. Moreover, it is not only "practitioners" that can be captured by objectified understandings of the "truth", social scientists may also be captured. With the help of IE, one can try to move beyond such captures. I will now present a quote that describes Institutional Ethnography in an adequate way:

> *It is the problem of how sociology for the most part is put together, of how it looks at people from the point of the discourse and seeks to explain how their behaviour is shaped in return. There is a very different possibility of trying to develop a sociology that looks at the society from the point of the people and their experience of it. Institutional ethnography picks up this idea, to explore the institutional order and the ruling relations from the point of view of people who are in various ways implicated in and participating in it* (Widerberg, 2004, p. 183).

According to Austveg and Christensen (2010), it is the power relations that decide what within health should be prioritized and not. Power defines and creates concrete, physical, economic, ecological and social rights. Immanuel Kant said that "the possession and power unavoidably spoils the free use and reason" (cited in Austveg & Christensen, 2010, p. 72). Bent Flyvbjerg (1998, cited in Austveg & Christensen, 2010, p. 72) describes how rationality meets power, meaning that the rationalities of power have deeper historic roots than the power of rationality. In other words, many people today are preoccupied with logic and logical connections, but such rationalization cannot compare with the actualities of *power*. Practically speaking, rationality is always replaced by rationalization; that a plan will be broken up into smaller parts, and where each part will be part of a power struggle. Furthermore, professionalism and democracy will lose facing other forces. Smith points out how institutions are put together with action (what one actually does), texts (procedures and routines and so on) as well as discourses (how staff talk locally and about what). She is further concerned about *the gap* between what is written (the social structure/organization) and the people's actual activity/practice. In order to study this, she highlights how one have to look past the set of frameworks that organizes people's activity and linguistics, including these institutional power/ruling relations. Thus, to see what happens when we are controlled by texts, or vice versa; what happens when we are controlled by the culture at work (Smith, 2005).

4.2.1 Institutional Ethnography in nursing

I will now refer to an example where there is a gap between nurses' dependence on texts and their behaviour. McGibbon et al. (2010) refers to nurse's *occupational stress* where professional health personnel are daily exposed to multiple stress factors [I choose to call this “stressors”], which may increase the gap between what is expected of the nurses at work [what the institution require, thus many of these requirements are written down in the form of texts] and what is actually practiced [the nurses work behaviour]. Stressors[15] can occur due to limited “level of support from hospital management, under- or overutilization of staff, rigidity of hospital policies, and the need for professional development” (McGibbon et al., 2010, p. 1354). More accurately, stressors will negatively affect the nurses' ability to work and thus practice. McGibbon have studied occupational stress is in accordance to Institutional

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[15] Other stressors might be high staff renewal rate, “intense workloads, staff shortages, an aging nursing workforce, inadequate management support, uncompetitive remuneration, poor working conditions, a lack of resources to work effectively, limited career opportunities, limited educational opportunities, and unstable work environments” (Coetzee & Klopper, 2010, p. 235).

Ethnography by Smith (2005). Nevertheless, I have not conducted an in-depth study of `occupational stress´ in the following master's dissertation, but I have studied the gap between institutional, political and academic *texts* and nurses' *behaviour* regarding Female Genital Schistosomiasis. With Institutional Ethnography as an inquiry to social research, my research questions have asked "how things happen" rather than finding the answers to "why". I find it interesting to see how people work at medical institutions, how and by what they are guided in their work and how these guidance's impact and colour their well-being and care of patients.

In accordance to IE, people's activities and discourses are studied within a formal and authorized social context; an institution which are organized as a standardized system including written and unwritten rules, regulations, guidelines, officially authorized definitions, forms, protocols and directives (Smith, 2005, p. 188). However, IE is not only intended for use in formal institutions, it can also be used where human activities are governed by texts in general, but "for nurses, these texts include the multiple kinds of patient charting document, workload measurement grids that most nurses are required to complete on each shift, professional journals, educational textbooks, videos, and Web-based education" (McGibbon et al., 2010, p. 1356). The local language is key to a well-organized institution, and the people whom are involved relate to `social facts´ that are well incorporated on a general basis. An example of people who collaborate in such formal institutions are health professionals (or teachers or politicians) controlled by a standardized system. The individual health personnel alone are *not* in centre, but rather her/his preformed activities, possibilities and discourses which are *shaped by* the institutional organisation, including local and formal linguistic and documents/texts.

Health personnel can be considered as a *social actor*, and IE study how social actors within a standardized system interact with each other based on their professional role, various texts, established work culture, furthermore how this together constitutes `ruling relations´ within the institution (Smith, 2005). The nurses `self-agency´ is restricted by texts, work-knowledge and work-cultural behaviour, which also rationalise their professional role in contrast to their private role.

4.3 Gender Inequality

Historically, there have been limited opportunities for women and fairly open opportunities for men. In terms of medical research and training, women and the diseases that affect them have had (and still have) lower status than men and diseases that affect them. For example, reproductive diseases are considerably lower in status than cardiovascular and neurological diseases. Professor in Global Reproductive Health at the University of Oslo, Johanne Sundby, has come up with possible explanations. She says that health research traditionally is based on men, weighing 75 kilos, and that this knowledge has been transferred to women - without taking into account the biological differences between women and men. `Leading researchers´ in the field of medicine have historically also been men, and their interest may help to explain why women have not received much focus. Further she says that in medical research earlier, it was recommended not to do research on women due to possible negative consequences for the woman's reproductive opportunities. Thun, due to fear of making fatal mistakes, they stopped researching fertile women. Later, it has been mapped that there are large differences between women and men, and that there is much unexplained in women's health. E.g., we now know that men and women react differently to medication and show different signs and symptoms. Today, one should give solid reasons of why one should not include women in research, which was not the case before (Austveg & Christensen, 2010; Sundby, 2019).

UNAIDS (2019) and Galappaththi-Archchige and colleagues (2018) highlight how FGS fuel female morbidity and support the explanation of `why´ girls acquire HIV several years earlier than boys in Schistosomiasis endemic areas. Low socioeconomic status may result in poor living conditions, such as low access to school and education, support and a safe environment while growing up. According to South African Statistics, poor children are half as likely to have a safe play area, which means that there are still many vulnerable children in need of protection (SA, 2019). Lack of support from caregivers may lead to uncritical behaviour and/or increased consumption of drugs, and girls growing up in less safe or unsafe environment tends to seek older partners and/or several sex partners. Several reports suggest that violence amongst intimate partner increases HIV vulnerability amongst females. Especially in areas where HIV prevalence is high, such as in sub-Saharan Africa (Galappaththi-Arachchige et al., 2018). According to UNAIDS (2019, p. 8) “violence (or the fear of violence) is associated with lower treatment access rates, lower treatment adherence rates, and lower rates of viral suppression among women and girls”. Overall, FGS may reflect the “social inequality in health and lack of access to high-quality sexual and reproductive health services” (UNAIDS, 2019, p. 9). Thus, female morbidity lead to gender inequality in sub-Saharan Africa, capturing the women in a vicious circle.

Bruun and Aagaard-Hansen (2008) present environmental, biological/immunological, sociocultural, educational and socioeconomic variables that may reflect gender related biases and inequities. Henceforth, it may affect people’s schistosomiasis status. In a context where there are different expectations of women compared to men, where women ascribe a lower social position, female health problems might reflect a public health issue. These are issues globally, and are therefore anchored in global guidelines such as the UN Sustainability Goals (see SDG 3 and SDG 5 in Chapter 4.6) (SDGs, 2015). According to Bruun and Aagaard-Hansen (2008);

> *... errors can occur at a demographic and sociocultural level (women are underrepresented, either by lack of attention to the sampling of participants or to women’s sociocultural or economic circumstances, which may hinder involvement), or at a technical level (in terms of gender-related differences in sensitivity or specificity of diagnostic methods)* (p. 77).

Global initiatives such as UN Development Goals have increased their focus on women's health and position in society. However, Cornwall (2003, p. 1338) argue that “rather than the `add women and stir´ approach to addressing gender, what is needed is strategies and tactics that take account of the power effects of difference, combining advocacy to lever open spaces for voice with processes that enable people to recognize and use their agency”. Concurrently, modern feminism can be criticized for forgetting the interests of the poor women in the world. However, in order to reverse the trends of forgetting these women, it has been argued that women should be given priority in education so that they have the opportunity to dispose their own of time and money for their own benefit. It is argued to be central for them as education will raise their voice and strengthen their backbone to make own choices (Austveg & Christensen, 2010). Building knowledge in this way will be essential in order to close the gap between research and nurses' behaviour as well as work knowledge.

4.4 Problem based learning (PBL), a strength and a weakness in health education

A worldwide method of educating health professionals is Problem Based Learning (PBL), where students educate themselves in small groups. The students define their own learning objectives, such as a problem case or a scenario typical for that current context (local clinic or ward during internship/practice). Then they study this in-depth independently before they return to the group in order to discuss and improve learned knowledge. PBL does not solve problems per se but uses the problems to reflect as well as rehears on a typical illness or a medical case, until the day they will stand as independent health professionals themselves. By listening to other health personnel's experiences during `in service training´, using search engines and textbooks, they will somehow make their own teaching curriculum (Wood, 2003). The advantages here are that the students are forced to be solution-oriented, while critically assessing what should be prioritized, how and why. On the other hand, it can be difficult to develop new knowledge if the students rely on already established work knowledge. The reason why PBL is included in this theoretical framework is because it is actively used to train nurses in South Africa, with the aim of specializing nurses according to the needs shown in the area where they are sent to South Africa is a country with a lot of variations, and to cover everything, the problems must be divided into smaller parts that are distributed among the number of nurses so that it is possible to overcome. It may also explain why there is little focus on FGS, when students concentrate on already established issues among the clinics where they are trained. The nurses are thus good at the problems that are relevant where they are sent but can at the same time lack experience and knowledge if they apply for a job in a new place after graduation, whereupon the problems are completely different. The nurse may thus feel incompetent, as well as experience that s/he lag behind - which does not allow for further development, only an effort to keep up.

5 Methodology

Presented in this chapter are my methodological, strategic and practical choices which have guided my gathering of data and analytical approaches in research. Qualitative research methods have been used, with help from quantitative secondary data, and guidance by Institutional Ethnography as a tool in social research. This chapter discusses the different methods used to collect data, as well as describe both considerations and limitations of the methodological choices made along the way, to ensure transparency. The degree of trustworthiness of the conducted qualitative research will be discussed, as well as ethical guidelines and researcher's stance.

5.1 Social research strategies

The method and strategy in research are chosen carefully in accordance with the nature of the topic investigated. There are two main methods in research, which is often presented as a dichotomy of qualitative and quantitative methodology; "between data in numbers and data in words (and sometimes images)" (Blaikie & Priest, 2019, p. 181). Even though these two are represented as part of a dichotomy, a mix of the two methods can be beneficial as they may complement each other and emphasise a more holistic perception (Blaikie & Priest, 2019; Bryman, 2016). My research is mainly based on a qualitative approach, due to the nature of my problem statement. However, most of the research done on Bilharzia is medical and thus relying on quantitative approach. It is against this backdrop of quantitative research that I have done my field work. In the following text, I will give a brief presentation of both quantitative and qualitative research methods, with a profounder explanation of qualitative methods due to its relevance.

5.1.1 A quantitative approach

In quantitative methods, the main objective seeks to quantify what is being studied, through counting and statistically measuring aspects of social reality. The aim is to create a general explanation of the objective truth, by strictly assuring validity and reliability before publishing (Blaikie & Priest, 2019; Bryman, 2016). The most common strategy of collecting data in social science "are the self-administrated questionnaires and the structured interviews, both of which keep the researcher at a distance from the actual social situation and process" (Blaikie & Priest, 2019, p. 201). The quantitative methods pursue a *deductive* approach to research (a logic of inquiry), as the purpose is to test explanations/hypothesis with an aim to reach a logically definite conclusion - which again can be tested true or false. The ontological assumptions (nature of social reality) in quantitative research seek *objectivism* and the epistemological assumptions (how reality can be obtained) seek a *positivist* paradigm, meaning a set of ideas based on logical evidences (Blaikie & Priest, 2019; Bryman, 2016). More accurately, a positivistic researcher seeks one reality and are driven by given facts, patterns and real objects in order to systemise the world we live in. Hence, quantitative research is often favoured by natural and medical scientists - as one can recognize from the research articles referred to in chapter “4 Literature Review” of this master thesis, presenting primarily Female Genital Schistosomiasis.

5.1.2.1 Document Analysis

An important part of my research has been documents of quantitative research, as mentioned above. Document analysis are often included in qualitative studies to obtain information on the topic that concern the study's issues (Bryman, 2016, pp. 562-565). I have not carried out any in-depth analyses of each document independently, because this master thesis is primarily based on data collected from interviews and observation. Nevertheless, biomedical research and public management documents has been explored in order to navigate and map concerns regarding female reproductive problems in Schistosomiasis endemic areas. It has become clear to me that FGS requires interdisciplinary research and collaboration, as well as a willingness to understand the interplay between medical considerations, people's everyday lives, political structures, global guidelines - and this altogether *in practice*.

It is important to take into consideration that secondary data and public documents can also be subjective and biased, based on the researchers or the authorities interests and purpose. Therefore, Bryman (2016, p. 553) “suggests that causation is necessary in attempting to treat them as descriptions of reality”. Accordingly, I have read the documents as normative and instrumental guidelines rather than the “absolute truth”. Nor have I acquired the documents with subjective interpretation because several documents fall under a positivist [medical] paradigm and concrete goals for increasing knowledge [as well as putting women's health more in focus].

It should be noted that none of the documents I have used are written *for* this thesis. The documents used in this thesis have been carefully selected with the aim of achieving credibility and a degree of relevance. The purpose while reading each document has been to select out relevant and necessary information that is of interest to the thesis. My assessments while reading each document have had an impact on the validity (relevance of the data material) in this study, thus the researcher's assessments of what is relevant may have consequences for the result. Overall, the documents have increased the reliability of the thesis, by confirming parts of the information that emerged from the interviews - while also showing me that there is a large gap between knowledge regarding biomedical research and the work knowledge of the professional's nurses, including their practice. Thus, a gap has been discovered in the field of research regarding FGS, where qualitative social science research is lacking.

5.1.2 A qualitative approach

The main objective in qualitative research is to seek an understanding of the subjective reality of each individual met in the field of research. The aim is to produce discursive descriptions through scrutinising and exploring social actors meanings and interpretations (Blaikie & Priest, 2019). The most common strategy in gathering qualitative data is through *unstructured* and/or *semi-structured* interviews and *participative observations*. Such gathering of data is commonly referred to as `field research´ or `ethnography´ - where "ethnography literary means producing a picture of the way of life of some group" (Blaikie & Priest, 2019, p. 202).

This study is founded on a combination of *abductive* logics of inquiry as part of my qualitative research. Blaikie and Priest (2019, p. 90) explain how "a logic of inquiry provides a starting-point and a set of steps by means of which `what´ and `why´ questions can be answered". The purpose of abductive logics is to explore the district with an aim understanding the empirical and social life, including tacit knowledge, and at the end possibly develop a theory about what has been studied (Blaikie & Priest, 2019). However, the purpose of this thesis is not to develop a new theory, but rather to acquire knowledge from the empirical findings collected from the field. Within the field of research that I have explored, medical research has been dominated, and with limited attention specified to the role of health workers and their knowledge.

As already mentioned, I have chosen to be guided by Institutional Ethnography by Dorothy (Smith, 2005). My aim was to investigate South African nurse's everyday work within institutional structures, its power relations, and how such structures shape their practice and ruling relations. The nurses are considered social beings within a social organisation, with both politics and power embedded in their everyday life (McGibbon et al., 2010).

This research is established on ontological assumptions (nature of social reality) that the social word is interpreted by social actors (people) and the interactions between them.

According to the “road map” of Blaikie and Priest (2019, p. 93), abductive logics of inquiry require ontological assumptions of an `idealist´[16] or `subtle realist´[17]. The epistemological assumptions (how one understands reality and knowledge) are based on `constructionism´[18], meaning that objects and social phenomenon have the value that people have assigned it/them over time. Simultaneously, that social facts have been established via discourses. “The constructionist emphasis implies a recognition that discourse entails a selection from many viable renditions and that in the process a particular depiction of reality is built up” (Bryman, 2016, p. 531). More accurately, constructionism and discourses are interconnected.

5.1.2.1 Interpretivism

Bryman (2016, p. 694) describe a paradigm as “a cluster of beliefs and dictates that for scientists in a particular discipline influence what should be studied, how research should be done, and how results should be interpreted”. My epistemological assumptions are guided by an interpretivist paradigm, where it is essential to see human beings as actors in the social world and from a holistic perspective (Blaikie & Priest, 2019). *Hermeneutics* is an umbrella term for interpretation within art, theory, methodology, social science and so on – seeking a holistic interpretation of reality. More accurately, hermeneutics is a general approach and a neutral tool in order to gain a deeper understanding, and at the same time open up for more than one explanation to a phenomenon (Alvesson & Sköldberg, 2018). Through hermeneutical interpretivism the researcher seeks to grasp and understand individual’s subjective values, which cannot be systematically measured in numbers nor statistics [through quantitative data] (Alvesson & Sköldberg, 2018). Social scientists intend to “gain access to peoples `common-sense thinking´ and hence to interpret their actions and their social world from their point of view” (Bryman, 2016, p. 27). A cornerstone in ethnography [in anthropological thinking as well as development studies] is “that human behaviour needs to be understood in the context of their particular society or culture” (O'reilly, 2012, p. 53).

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[16] An *idealist* is “social reality is made up of shared interpretations that social actors produce and reproduce as they go about their everyday lives” (Blaikie & Priest, 2019, p. 102).

[17] A *subtle idealist* is “a knowable reality exists independently of social scientists; cultural assumptions prevent direct access to this works” (Blaikie & Priest, 2019, p. 103).

[18] *Constructionism* “asserts that social phenomena and their meanings are continually being accomplished by social actors. It implies that social phenomena are not only produced though social interaction but are in constant state of revision” (Bryman, 2016, p. 29) because people are unpredictable and can change their subjective understandings of the world due to personal experiences and feelings.

Hermeneutical interpretivism, as well as the logics Institutional Ethnography, is why I wanted to talk, observe and interview informants in their given context, in which they constitute their daily work [in the local health facilities in the Ugu district, South Africa]. Another epistemological considerations in interpretivism is when the researcher “raise questions about the issue of how the social world should be studied and weather a scientific approach is the right stance to adopt” (Bryman, 2016, p. 4). In such interpretation, the researcher’s stance is critically taken into consideration, as his or her own positioning and understandings might influence the way in which the social research is conducted, hence also interpreted (Alvesson & Sköldberg, 2018). The relationship between researcher and the people being studied must be reflected upon. In the light of cultural relativism, my purpose has been to understand the South African health personnel in *their* own context and on their own terms. It has been important for me to distance myself from *my* own understanding of knowledge and my role as a registered nurse [with training anchored in Norwegian standards and structures]. The goal has been not to uncritically compare my reality with my informant’s reality and behaviour, whom are trained within South African standards and structures. During the fieldwork, I took the perspective as a "master student in social science development studies" rather than a registered nurse, as I wanted to understand more of the connection between attitudes, behaviour and knowledge. I find it essential in order to combat the challenging disease FGS, which primarily affects women in rural areas.

5.2 Study design: a field research

The field study was designed to be conducted in an area which has a significant prevalence of FGS, and the Ugu district of KwaZulu-Natal province, South Africa, was the appropriate study site. The study was conducted in a period between 1st of October and mid-December 2019 because this was most appropriate for personal reasons. I was stationed at a local research centre, named BRIGHT (http://brightresearch.org), approximately 130-kilometre drive south from Durban. I rented my own car, which was needed in order to mobilise, as well as maintain everyday routines. The employees at BRIGHT have Female Genital Schistosomiasis as a main focus within female reproductive tract problems and they aim towards endemic area nearby, as well as towards governmental structures. Employees at BRIGHT functioned as my respected gatekeepers into the local health clinics and assisted me in many important ways. Some showed me around and assisted me in settling down. A few helped me to apply for local permissions needed and establish a solid background for my research through introducing me to relevant informants. Others helped me reach out to local clinics, in schistosomiasis endemic areas, in order for me to collect research data through interviews and direct observations. I was also lucky to interview one of the experts at BRIGHT [Expert Informant 11]. She became an important basis for comparison in meeting the level of knowledge amongst the local health professionals at Clinic 1, 2 and 3. Both gatekeepers and acquaintances helped me "translate culture" when needed, in a sense that they could explain to me how to interpret others expressions and behaviour, and how to act around and talk to different kind of health personnel's as well as people in charge. As an example, I was free to interview professional nurses who worked "at ground level" with patients, but I was not in in a position where I could interview the matron at each clinic [who serves as the leading manager internally at the clinic]. Moreover, I was taught some Zulu phrases which helped me gain understanding and trust amongst people and informants.

In the start-up of my field research, I was lucky to conduct three informal meetings in order to establish a solid background for my research. Two of these meetings were held at the University of KwaZulu-Natal in Durban with lecturers in public health [informal informant 1] and nursing [informal informant 2] and one meeting was with a lecturer at `Department of Biomedical and Clinical Technology´ at Durban University of Technology [informal informant 3].

In the start-up of my field research, I was lucky to conduct three informal meetings in order to establish a solid background for my research. Two of these meetings were held at the University of KwaZulu-Natal in Durban with lecturers in Public Health Medicine [informal informant 1] and the Discipline of Nursing [informal informant 2] and one meeting was with a lecturer at `Department of Biomedical and Clinical Technology´ at Durban University of Technology [informal informant 3].

Primarily, data collection took place in three local clinics, located in a Schistosoma endemic area in the Ugu District. Three clinics were chosen from the six that were made available to me. Choosing only three was to help build a trustful relationship with the informants. These are referred to as `Clinic 1´, `Clinic 2´ and `Clinic 3´, in order to maintain full anonymity according to ethical guidelines.

- Clinic 1 are located in an urban area twenty minutes' drive from BRIGHT. They function as a referral for 9 local clinics [including Clinic 3] and provide health service 24 hours, 7 days a week with full medical coverage for approximately 33 000 people (collected empirical data). Informants were midwives who were chosen because of expertise in female reproductive female health.
- Clinic 2 where chosen for its rural location, with a forty minutes' drive from BRIGHT, and being "Number One" clinic in the district. Their opening hours were between 8 am and 8 pm, meaning they did not work shift, which means that nurses do not work shifts to cover 24-hour health services.
- Clinic 3 was located in a rural area thirty minutes' drive from BRIGHT, in the opposite direction of Clinic 2. They provide health service 24 hours, 7 days a week, and have professional nurses [support groups] specialised within psychiatrics, diabetic and asthmatics.

Considering how institutional bureaucracy, including its written routines, procedures and regulations, influence and shape human behaviour and their discourses internally, I was interested to see health professional's practical behaviour, with their own commitments to what they have learned through professionally training.

Through participatory and objective observation, I have gained insight into the three local health clinics. I got to know how they organize and administer their nursing internally and for their group of patients, as well as what diseases and challenges they primarily face. Through visits and conversations with employed professional nurses, I got to talk to them about Bilharzia, as well as how to diagnosis and treat it. On the one hand, I discovered that there is a shared understanding regarding "commonly known" Bilharzia [when it is detected by observing blood in urine, also called "isichenene" in isiZulu]. On the other hand, I found that there is a narrow understanding of Schistosomiasis as a parasite and its complex way of existence.

5.3 Selection of informants

All informants were currently health workers with the majority being professional nurses stationed at the local governmental health facilities. I will now present an overview of my formal informants in total, including what clinic they are connected to; their currently practise as health professionals; and their awareness [status] concerning Schistosomiasis [commonly known as Bilharzia or Isichenene in isiZulu language].

5.3.1 Overview of informants

When referring to my respected informants, I distinguish between "professional nurses" [for those who work more versatile] and "midwifes" [for those who work exclusively with reproductive health]. Nevertheless, all of which have four years of nursing school covering the blocks of *general nursing, community health, midwifery* and *mental health* - if the midwives as Clinic 1 have extra specialization, I do not know. However, the tables show a different number of informants at each clinic, the reason for this is that I did not know who or how many I would meet before each visit, as it depended on who was at work that current day, the clinical workload that moment, and on whom had the time in their schedule to meet me.

Table 1: an overview of my formal informants in total

Forman informants	**Female**	**Male**	**Total**
Community health worker (CHW) - *lay person*	1		1
Professional nurses (PN) - *includes specialities in midwifery, psychiatry, and public health and general nursing*	15	3	18
Teacher in nursing - *area a PN as basic education*	1		1
Doctor – specialized within infectious diseases	1		1
Total	18	3	**21**

Table 2, Clinic 1: semi-rural area, interview conducted at the labour ward (a 15 minutes' drive from BRIGHT)

Code name	**Gender**	**Practising**	**Status Schistosoma**
1 + 2 (FGD)	Female	Midwifery	Unaware
3	Female	Midwifery	Aware
14	Female	Midwifery	Recalled from childhood, neglected disease today

Table 3, Clinic 2: rural area, 45 minutes' drive (I had to pass through Port Shepstone)

Code name	**Gender**	**Practising**	**Status Schistosoma**
Interviewee 4	Female	Midwifery	Recalled from childhood
Interviewee 5	Female	PF	Only through profession
Interviewee 6	Male	PF – reproductive health	Infected as a child
Interviewee 7	Female	PF	Only through profession
Direct observations	2 Female/ 2 Male	PF	No focus on Schistosoma
Interviewee 12 + 13	Male/Female	Ward nurse (PF) and Community Health Worker	Both was aware, referred it to "isichenene" in isiZulu
Focus group discussion (8 participants in total)	7 Female + 1 Male	Mix	Mix

Table 4, Clinic 3: rural area, 30 minutes' drive (passed through Margate)

Code name	**Gender**	**Practising**	**Status Schistosoma**
Interviewee 8	Female	PF – reproductive health	Through profession
Interviewee 9	Female	PF	Through profession
Interviewee 10	Female	Enrolled nurse + PF	Through profession

Table 5: BRIGHT: a research centre/clinic, Shelly Beach

Code name		**Practising**	**Schistosoma**
Expert Informant 11 (also gatekeeper)	Female	Researcher/doctor	Expert in FGS
15	Female	PF + teacher in training nurses (collage)	FGS infected

5.3.2 Snowball sampling of informants

I sampled my respected informants in accordance to *snowball sampling.* "Snowball sampling is a technique in which the researcher initially samples a small group of people relevant to the research questions, an these sampled participants propose other participants who have had the experience or characteristic relevant to the research" (Bryman, 2016, p. 415). I was, given ethical approvals [please read *5.7 Ethics* and appendixes 1, 2 and 3] allowed to gather data at the relevant health facilities located in Schistosomiasis endemic areas. In order to do so, one of my primary gatekeepers first had to introduce me and my research project to the operational nurse or matron at each clinic. The Operational Nurse/Matron then took the responsibility to guide me to suitable informants, based on the criteria I gave her. I did seek specific variables for the research, my wish was to speak to professional nurses experienced with both lower reproductive health problems [hence only informants from the Maternity Ward at Clinic 1] and Schistosoma infections.

The nurses unpredictable working pressure and shift schedule made it difficult for me to arrange second interviews with the informants, even though I really tried to meet a few of them again. I only managed to meet Interviewee 4 a few times as I was given the permission to shadow her [semi participative observations] three times after our initial interview. I did schedule a second meeting with Interviewee 6 a few times through his Operational Nurse, as he was a very interesting person to talk to. However, I only managed an informal conversation with him on his way to lunch, in addition to his initial interview. I wanted to conduct a formal interview with their Matron/Operational Nurse, but my gatekeeper from BRIGHT told me not to, and taught me how she was high in the institutional hierarchy. Henceforth, I gained a greater understanding of local clinics in South Africa and their institutional hierarchy, as well as my own stance as a researcher. I could also see this in accordance to Institutional Ethnography and the workers ruling relation. However, the Matron did join the Focus Group Discussion as `Participant 6´, and Interviewee 15 emailed me last September. The rest of my informants, I met only one time each.

5.3.3 Considerations and limitations

I did not want to be an obstacle to their patient care, as I know how it is to work in a hectic ward in the shoes of a nurse. Sometimes, the clinic was too busy to welcome me when I paid them a visit, so I had to turn around and come back another time. Even though I wished to see the clinical practise in its usual tempo, as `participative observations´ would be more valid for my own personal research. Another consideration was the current weather, as people seem to stay home when it is raining. Therefore, there would be fewer patients on rainy days, and more capacity for them to welcome my research. Additionally, I was recommended to visit on Wednesdays, because most nurses were on duty those days of the week. But in return, the clinics were full of people seeking medical attentions, well aware that there were most nurses on call at Wednesdays. At least, that became my impression after a few weeks in the research field.

5.4 Data collection approach

In accordance with Institutional Ethnography, like other forms of ethnography, I have relied on interviewing, observations and documents as data. However, “Institutional Ethnography departs from other ethnographic approaches by treating those data not as the topic or objects of interests, but as `entry´ into the social relations of the setting” (Campbell, 1998, p. 57). Smith (2005) looks at how text, such as procedures and regulations can be seen as text in the health care sector, and discourse can be a so-called ruling relation, governing our behaviour. we, among other things, are governed by texts.

5.4.1 Observation methods

Participative observations was desired in the field of research, as I truly wanted to get to know their practice and routines at their clinic. I observed their behaviour and how nurses interact internally [though, their conversations became impossible to follow due to language barriers]. I observed how much time was spent on Schistosomiasis, how they met patients and how they otherwise organized their workday by documentation, procedures and institutional work knowledge. Out in the municipalities, I saw how they organized home visits and what they emphasized in meetings with civilians. My informants often translated their activities and conversations for me, in order for me to understand. There was also openness for me to ask along the way.

Ideally, interpretivism require participative observations in the designated research field/context over a longer period of time, rather than objective observations in addition to interviews through a shorter period of time (Alvesson & Sköldberg, 2018). Although two and a half months are not enough in order to get an appropriate understanding of both the context and FGS, my stay in the area contributed to an understanding I could never have acquired through reading books or articles, nor through watching video/television or listen audios. I gained a deeper understanding of Schistosomiasis in the endemic areas, what neglection of FGS means and how South African health worker's practice health care service at the governmental clinics. I also understood more of South Africa as a multicultural society; how people interact; what apartheid was and how apartheid still lives on today; some of the many challenges that people face regularly [both socially, environmental and governmental] and furthermore.

I managed to visit Clinic 2 five times in addition to the days were personal interviews were conducted. Most of the time I sat with the midwife to see if she was considering Schistosomiasis when she was investigating for reproductive problems in the pregnant women. A couple of times I only met the Operational Nurse who, through informal conversation [thus no audio record was completed] taught me more about how their health clinic works on a structural level and under governmental regulation. One day I joined an "outreach" with the Ward Nurse [Interviewee 12, male in his twenties] together with a lay person referred to as Community Health Worker [Interviewee 13, female in her early thirties][19]. That day we visited four households together with different private concerns, and afterwards I was lucky to conduct an interview with both of them together.

5.4.1.1 Considerations and limitation

I was not allowed to be a participatory observer at the clinics as much as I wanted, and perhaps as I had imagined. First of all, the ethical guidelines from NSD did not include data collection from patients, thus I intended to keep absent from the patients and their sensitive information. Although, interaction with patients could not be totally avoided while observing health care professionals. So, the current patients had to give their approval to the professional nurse in charge before I entered the occasion. Secondly, language barriers made it difficult for me to understand all that was going on [please read more in the chapter below, *5.4.2.3 Language barriers*]. Thirdly, I did not wish to be a hindrance to the health professionals' daily treatment of patients, in a hectic working sphere.

At Clinic 1, 2 and 3, it is more correct to say that direct observation [also referred to shadowing] were held to perceive behaviour and care processes within the setting of health care provision, rather than participatory observation.

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[19] The Ward Nurse leads up to 29 lay people working in the community as well as to visit private homes in the community. As part of his work he might initiate interdisciplinary collaboration to solve specific problems or lift up health related issues and guide those in need to medical attention. The lay people are referred to as Community Health Workers (CHW). This CHW is responsible for visiting 79 households per month, although she said she did not reach more than 50 households per month. In addition to report health related problems to the Ward Nurse, she guides people in the community to seek medical attention when needed and conduct basic health education in poor private homes with little or no education. Some people that we met do not have a birth certificate and are therefore not entitled to either education or health care. Another woman was suspected of kidnapping the child she was taking care of.

5.4.2 Interviews and Focus Group Discussions

Different interview techniques were applied, considering current recourses, time and space. The interviews were a platform for the respondents to express their thoughts and experiences regarding the research topic. The intention was to allow flow, flexibility and listen to what the respondent had to say. All communication was conducted in English, as all informants had had good English skills.

The interviews took place at the health facilities, as this was most convenient considering practical reasons and planning, access to relevant informants, as well as time and space. Semi- and unistructural interviews were conducted as part of exploratory research and inspired by Institutional Ethnography as an inquiry. The sim was to identify South African health professionals' perceptions and experiences [regardless of gender and the colour of their skin] concerning Schistosomiasis [Bilharzia] and lower reproductive health issues in female patients.

Three Focus Group Discussions (FGD) complimented findings of the personal interviews, although only two participants were available for the two first FGDs. It was not until the end of my collaboration at Clinic 2, that the Operational Nurse managed to gather 8 participants [including Interviewee 4 and 7 and plus a few observers] for FGD – as a final recap after my "stay" there. I will now present each approach in the following section.

Two interview guides were developed as a preparation, required by NSD (*Norsk Senter for Forskningsdata/The Norwegian Centre for Research Data*); one guide for personal interviews for nurses, another for focus group discussion [see appendixes 5 and 6]. These guides were considered necessary to ensure that the topic would be covered during the field research, and they were developed in accordance to the research questions which were guiding the whole master research process. NSD also had to approve that I was allowed to use a tape recorder during the interviews, with requirements for confidentiality and correct storage of the information that the informants gave me. I want to point out that I did not record any sensitive information given by patients during the fieldwork, everything that was said was said by health personnel whom were anonymised. However, I had one informant [professional nurse and teacher in nursing at collage] who chose to share information about her own medical condition, concerning infertility and newly detected FGS. The reason she shared this was because she wanted to use her condition as a motivator to further develop the field of knowledge related to lower reproductive health and Female Genital Schistosomiasis in nursing education.

5.4.2.1 The use of an audio recorder

In accordance to NSDs ethical approval, all personal interviews and focus group discussions were conducted with the help of an audio recorder, converting our dialogue into digital data, following transcription in English. This way, I could focus on the individual(s) in the moment, and benefit from the digital data later in the process. Importantly, this recorder was not present during observations, for ethical reasons as this is a sensitive area, and especially as it was in close contact with patients. However, the issue of tape recordings was mentioned in the consent form, and that all interviews would be anonymised, and tapes deleted after transcription. Using a tape recorder was of great help while collecting data in the field. Tape recordings were listened to privately at the workplace and the most essential relevant messages were written down, to ensure a thick description of the conducted interview. It was important to remember the time before and after the interview and additional notes taken; noting context and body language and add the time of certain gestures like nodding, facial expressions or other disturbances. As such "fresh" notes would help my holistic interpretation at a later stage.

5.4.2.2 Transcription of interviews

In addition to taking notes during and after the interview, while listening to the recordings later that same day, I transcribed all conversations recorded with as much detail as possible. This was to help remember the details at a later stage and ensure a thick description for myself. Although, a `thick description´ is not the aim in Institutional Ethnography: "rather, the aim is to expose the articulation of the activities of everyday life with institutional power relations" in addition to see the importance of texts as a way to organize the social word (McGibbon et al., 2010, p. 1356). Therefore, my thick description from the interviews does not appear in this thesis text itself. However, verbatim transcription is very time consuming, but was done in order to ensure minimal of misinterpretation in my own process. Whilst listening to the recordings several times, and writing it all down, I continuously learned and discovered new assumptions uttered by the interviewees. Quotations and excerpts obtained from the interviews have been referred to in both the chapters of empirical findings and the data analysis. While referring to the informants anonymously in the text, an approximate age of the informants has been included because I think age is an important indicator for experience.

5.4.2.3 Language barriers

Higher education in South Africa is commonly conducted in English, thus local nurses are known to speak English well – even if they are of Zulu or another South African origin. Equally, as I have English as my second language after Norwegian, hence it was acceptable to conduct all interviews in English as were able to communicate. However, language barriers brought me into difficult and frustrating situations occasionally, as neither my informants nor myself have English as first language. We got through this by reformulating until we understood each other, even though we sometimes had to realize that we were "lost in transition" and move on. The reason we did not understand each other was more that we spoke past each other [since I was searching for an unknown disease, which befell confusing for most of my informants], rather than that we did not understand each other's English - thus, both of us did communicate with a broken accent.

While I conducted the observational method, most people around me communicated in isiZulu [both interaction between the nurses and between nurse and patient]. Thus, I did not understand the local dialogue other than what I could guess given the circumstances. Some chose to explain to me in English afterwards, what they had been talking about. Due to language barriers during my observations, it would have been beneficial to have a professional interpreter present, but I considered this both as economically expensive and difficult to plan in terms of time [I had to be very flexible myself, to a degree that was only possible as I was unaccompanied]. At the same time, I found it disrespectful to drag an extra person into the professional nurse’s hectic workday, and especially where patients were in immediate vicinity. It is possible that the choice to exclude a translator has affected my data, but mostly because a translator would have helped me understand the internal conversations. The communication in English during the interviews went well as long as the topic of conversation was clear - it was not until the conversation was about FGS that language barriers began to arise, but this in itself is an important finding indicating that the disease is unknown.

5.4.2.4 Considerations and limitations

During the interviews at the clinics, my informants realized that I held important medical knowledge they did not know about [Female Genital Schistosomiasis]. At that point in our conversation, some informants went puzzled and some became eager to learn more. This was sometimes uncomfortable for me personally, as I did not have any intention on entering the field with a superiority, based on my degree of knowledge regarding their state of Schistosomiasis/Bilharzia. This felt like an ethical issue for me, as I also became very aware of my white colour of skin in a country scarred by the apartheid regime, and me being from the outside entering their sphere.

I could not use the interview guide as much as I wanted, because it asked about Female Genital Schistosomiasis, whom 13 out of 15 respected informants did not know about. Thus, I had to put away the guide and interview them via alternative questions in accordance with `unstructured interview´. Bryman (2016, p. 679) describes unstructured interviews as "an interview in which the interviewer typically has only a list of topics or issues, often called *interview guide*, that are typically covered. The style of questioning is usually very informal. The phrasing and sequencing of questions will vary from interview to interview". Practically, these kinds of interviews are more similar to conversations. Still, many informants were confused by my topic concerning the unfamiliar kind of Bilharzia. In order to maintain a transparent dialogue with them, I chose to explain that there are few experts on FGS in the world today. I told them that some are located nearby [at BRIGHT Research], and that these experts want to reach out to the local clinics as they see a need for increased competence among local health professionals.

At the same time, I pointed out that their current low level of knowledge about FGS is completely natural as FGS is known to be a neglected tropical disease. Therefore, that they should not feel foolish about not knowing. I explained to them that I was there to help BRIGHT in their desire to develop a higher level of competence at the local clinics. My task was to map their surroundings and general level of knowledge, based on assumptions that there is a low level of knowledge regarding FGS [which also was according to my agreement with BRIGHT, as specified in the acknowledgements]. In order to ensure sustainable development in competence among health facilities, I wanted to get to know the people working at a health facility, listen to their needs, and to understand their preferences in how this new medical information can be implemented in their daily quality of care. This approach

/ message seemed to be well received amongst my informants, and some came with very good suggestions for further development of knowledge.

5.5 Data analysis

This study has been analysed in an *iterative inductive* approach, in accordance to O'reilly (2012), which is an approach of `read-*then*-do-*then*-write´. A process where gathering data, analysing and writing is inextricably linked, forcing the researcher to maintain fluidly and flexible during the research with constant evaluation of the process. Whereas weaving together all the secondary data used in the literature review, all the gathered data from the field research and the chosen methodology, ensuring both validity and reliability as well as trustworthiness. I would then discuss it against certain concepts and theories introduced in the theoretical framework. Moreover, inspired by institutional ethnography, I was not guided by one theory when collecting data, but rather trying to extract from people's work knowledge (Smith 2005) how their work was interconnected with other people's work, as well as texts and discourses. According to O'reilly (2012), "ethnographic analysis can look very similar to grounded theory approaches, but ethnographic analysis is less perspective and is happier to adopt and adapt existing theories" (p. 181). I will not explain `grounded theory´ in further detail as it is closely related to both `interpretivism´ and `thematic analysis, which I have rather chosen to emphasise in the following text [please read more in *5.1.2.1 Interpretivism*].

All forms and original audio recordings have been stored at the *OneDrive* of University of Agder, and fully transcribed into a word-document, whereas all information is treated confidentially. The data have been qualitatively analysed according to both Bryman (2016) and O'reilly (2012), with *thematic analysis* and *coding*, which means that the data has been broken down into different overheads or themes, whereas those units have been given labels. After manually sorting all data into categories by hand [thematically and descriptive], I ended up with 13 different categories, each with its own colour code as a way to make sense of it all. This way, I could see patterns emerge and see which categories were more relevant than others, hence which theme to emphasise more. For example, "water activity" were one category [brown colour code] and "patient care" another category [blue colour code]. Both of which were highly emphasised, and much because it was easy to talk about. The category "FGS as a neglected disease" [yellow colour code] on the other hand, where difficult to talk about because few knew what it meant. This is however a very interesting finding, as this category is the cornerstone of my master thesis and illustrate that there is a gap between established medical research and local work-knowledge.

5.6 Trustworthiness in qualitative research

This section reflects on why this study holds *trustworthiness* and *authenticity*, which according to Bryman (2016, p. 384) are the two main criteria for assessing a qualitative study. I hope this study has contemplated authenticity as a main ingredient. Furthermore, to ensure trustworthiness, Bryman (2016, pp. 384-386) suggest four criteria's to be followed, being *credibility, transferability, dependability* and *confirmability*. In the following I present what these four criteria have meant for this research:

- *Credibility*: all data were gathered face-to-face which allowed holistic interpretation of body language, mimic and non-verbal communication, time and space, as well as verbal communication - ensuring a manner of transparency. Such a human-to-human relation seemed also to benefit the establishment of trust, following trustworthiness, authenticity and reflexivity.
- *Transferability*: meaning if the research is transferable to other setting, like Norway, due to a thick description of the findings. In a way, it can be transferred, since health systems around the world comply with fairly general features, and FGS as a disease is globally neglected [and we have women from Schistosomiasis endemic areas in Norway as well]. On the other hand, there are many things that speak against such transferability, as the area in South Africa is tropical and endemic, and the country have a very different history from Norway. Also, the role of the nurse, their ruling relations and their institutional hierarchy are performed very different than in Norway. Despite of my work effort and the time spent in the field, I will never fully understand the complexity of local's realities nor their experience with FGS and lower reproductive problems. Nor how it is to work as a health professional in South Africa, primarily due to my ethnocentric interpretation shaped by my Norwegian background.
- *Dependability*: Stability around the data have been ensured over time. Several hours of interviews and observations have been collected, which did require planning for more than six months in advance as well as good collaboration with established professionals. Records of all phases throughout the research process have been stored, complied with confidentiality of all respected informants, such as ethical approvals;

formulation of topic and research questions; consent forms; interviewee guides; all audios recordings and field notes (dairy); transcribed interviews; considerations regarding analysis and so on. Moreover, I have reread the data multiple times and obtained other people's second opinion in order to ensure a deeper understanding of what the data says.

- *Confirmability*: Informants have on several occasions repeated each other. This type of confirmation of the work process has served as a control mechanism for the information to be reliable. As this study addresses a sociocultural phenomenon, it will change over time due to dynamic social actors [the informants can be considered as unstable factors]. On the other hand, it does not have to weaken the study's reliability, because repetition in the study does not mean repetition of the same result, but rather comparable findings. Furthermore, my supervisor has been of great help by reading and ensuring good interpretation of the collection of data, and I have received help from Expert Interviewee 11. She happens to be an expert on FGS and thus a source to compare gathered data with. I did not allow my personal values and theoretical inclinations influence the conducted research, nor the collected findings. It became a clear ambition for me to keep myself objective and observant of what the social actors contributed with, also during the process of interpretation.

I will also mention *triangulation* as an important measure to ensure *validity*. Which means that the study has been approached by using a variety of methods in the study of social phenomena. Whereas different perspectives/angles have been complementing each other, such as multiple observers, theoretical perspectives, sources of data and methodologies, hence different ways to investigate the social phenomenon (Bryman, 2016, p. 386). Such triangulation has been used to cross-check findings; if what the informants say is related to what they are doing, and whether what they are saying and doing is related to what established research already says.

5.7 Ethics

The core ethical principles are crucial to consider when a researcher involves with subjects. It includes to show respect towards the authors and researchers behind the secondary data by maintaining good referencing, and to show respect towards the involved participants; *voluntary participation; informed consent; freedom to withdraw; right to privacy; protection* *from harm and risk; avoidance of deception; and avoidance of covert research* (Blaikie & Priest, 2019, p. 50). This research was conducted with respect and accordance to Norwegian and South African ethical guidelines, and to the principals of BRIGHT in guidance of my local gatekeepers. To conduct a field research in social science, I have three different ethical permissions, from the Norwegian Centre for Research Data (NSD), from the Biomedical Research Ethics Committee (BREC) of South Africa, and from the Department of Health, Ugu district (the Ministry of Health) [see all the appendixes 1; 2; 3]. Subsequently, in order to actually gather data, I had to ask permission by every clinical leader [Operational Nurse or the Matron]. Given their approval, I was allowed to visit their clinic and conduct my field research, including collect data. Last but not least, I had to gather permission from each individual health personnel's whom I was in contact with, in order to collect data from them. To be sure of their blessing, I brought an informative `Consent form´ for them to read and sign [see appendix 4]. All this before I started to collect the information needed. Altogether, these ethical measures had to be in place before I could complete any field research – though the process was a very time-consuming, and the waiting sometimes frustrating.

5.8 Subjective biases

According to O'reilly (2012, p. 99) "participant observation is an embodied activity; and a reflexive practice that must acknowledge our own role in the practice and unfolding of daily life". Blaikie and Priest (2019) suggest different traditions of `researchers' stance´, whereas to be a *reflective partner* is the one I find most relevant. This stance accept that "premise of social and cultural reality is already pre-interpreted by the participants" and that the people studied have their own interpretations and meanings which can change over time (p. 45). The subjective truth will always be coloured by one's own embodied knowledge developed through a lifetime of experience. Hence, the people being studied will have their own subjective truth, which the researcher will meet objectively. The researcher stance is therefore in a subject-to-object relation, meaning that the researcher will have one's own understanding of the truth – but aim to come closer to the objectives studied by being in dialogue with them. Therefore, it is important to reflect on weather objectivity, and therefore, `true´ knowledge are indeed possible (Blaikie & Priest, 2019).

O'reilly (2012, p. 100) supports this by stating “we cannot undertake ethnography without acknowledging the role of our own embodied, sensual, thinking, critical and positioned self.” Reflexivity is a crucial factor, meaning that the researcher should involve critical self-scrutiny by examine own role and presumptions. By reflecting how own biases have affected choices made in relation to the field and people being researched. And how the biases have influenced the interactions with the respondents researched.

With my background as a Norwegian registered nurse in the South African clinical field, I would not let my professional role colour the sociological study in an undesirable direction. Meanwhile, if I did not have this interest as part of my foundation, I would never have managed to gain an understanding like I have now. As this interest in nursing science has driven the entire research process. With my background from Norway, I will naturally have a different focus in `nursing´ than the local nurses registered in South Africa. This is because our education and training have different needs, thus focuses.

However, I might have an advantage by being familiar with the medical and technological language as well as procedures conducted in the field. And it may allow the interviews to flow freely and unconstrained which is the intended outcome. Nevertheless, some informants seemed affected by my presence and related to me as a nurse and not a student in social science - which did facilitate both trust and respect in our relation. In that case, it was difficult to maintain the focus on the social science. Otherwise, it might have caused the respondents to hold back information because they want to prove or hide certain attitudes, in a way to show their best to me as a health professional myself. Therefore, I was very clear about my role in this research, and I tried to avoid both confusion and to raise doubt.

For future research projects, I ought to be more interested in my informants age, private and professional background and years in their profession, as this can give me more nuance around their knowledge and understanding concerning the objectives. I would also include political, economic and environmental dimensions to a higher extent as this is important in order to achieve a comprehensive understanding.

6 Empirical findings

In the following chapter empirical findings collected from my fieldwork in South Africa, Ugu District will be presented. I collected most of my data at Clinic 1, 2 and 3. Interviewee 15 [female in her late thirties, teacher for professional nursing at College] explained to me how these clinics have a regional responsibility in recording statistics and developing in addition to care for the health of the community. Her statement is important as it refers to the ruling relation between nurses and the state:

> *The local clinics are Government clinics and they function according to government policies and protocols. Nurses do play a part in development of such policies, so they are also involved, and the statistics is sent so that they can tract how cases of any type of a problem was seen in a particular clinic. When this data is analysed it also assist to see of the government needs more staff in a particular clinic or not. And what are the common diseases prevalent in a particular clinic.*

Furthermore, Interviewee 15 described the nurse's role and responsibility at the governmental clinic:

> *At the clinics the nurses function independently. They see sick acute and chronic patients, conduct deliveries on pregnant women unless there are complications, they if there is no advanced midwife in that clinic they refer to hospital where there is a Doctor, otherwise nurses here are trained to everything, including dispensing medication according to the patients problem. If a patient has flue, depending on the signs and symptoms of the patient, the nurse can give antibiotics for the productive and other medication like analgesia and antihistamines if there is a need.*

In a way, they become the state's extended arm by being obliged to report statistics, so that the state know how to facilitate and distribute resources as needed through the numbers received from the clinics. The clinics do this by reporting *what* and *how many* cases they have each day [for example pregnancies, miscarriage, bilharzia, HIV, and I would presume also dimensions such as gender, violence and drug abuse], and I would assume that this will result in an annual report. There is no need for further education in order to be the state's extended arm, as long as the nurse tick off statistics and report well, maintaining an anonymised transparency to the state whom holds the decision-making and defining power. For it to run smoothly, the state and the workplace must have confidence in the nurses; in that they comply with their duties and that they know their routines around reporting and good documentation.

6.1 Local awareness of Bilharzia ("Isichenene" in isiZulu)

As already mentioned in the introduction, there is limited knowledge about Bilharzia and in the following I give an overview of who [of my informants] knows about the *Bilharzia* and to what extent. The majority of informants claimed that, nowadays, Bilharzia is a rare disease and few of my informants could make the link to FGS. As communicated earlier in the thesis, this is part of the problem and may be a reason why so many suffer from the infection today, following social consequences.

The midwives in the `Labour ward´ in Clinic 1 had certainly not seen Bilharzia in their female patients and told me that they did not really understand why I would ask about it in a labour ward. The midwifes reacted surprisingly when I asked about Bilharzia. This reaction may have come from a common knowledge saying that Bilharzia is prevalent amongst young boys swimming in the rivers and dams, and that their symptom is blood in the urine. A research conducted by Andrea Lothe and colleagues (Lothe, Zulu, Øyhus, Kjetland, & Taylor, 2018) in the Ugu District, KwaZulu Natal [same study site as my research], also found that there is high local association between Bilharzia and young boys swimming in the rivers and dams. Interviewee 1 [female midwife in her thirties, Clinic 1] said she was introduced to [urinary] Bilharzia in nursing college. While Interviewee 2 [female midwife in her fifties, Clinic 1] knew about "isichenene" [Bilharzia translated into isiXhosa and isiZulu languages], and that it is common amongst young boys in rural areas. She further pointed out that they have tap water now [locally] and so people are not exposed to Bilharzia anymore, because tap water does not transmit the infection. If she meant that boys have stopped doing recreational water activity, such as swimming in the rivers and dams, due to installed tap water in their household, I do not know.

Interviewees 3, 4, 6, 14, 15 and Expert Informant 11 seemed very familiar with Bilharzia, and said it was a very common disease when they were young. Bilharzia seemed currently more common in Clinic 2 compared to in Clinic 1. Whereas Clinic 1 is located in an urban area, and Clinic 2 in a rural area. It was about one and a half hours drive between these two clinics.

Interviewee 14 [female midwife in her forties, Clinic 1] said she had “never heard of any one with Bilharzia these days.” She explained to me that, if I was lucky, I might find kids with Bilharzia in “outpatient department” [a department where patients come for treatment, but do not require a bed]. Interviewee 4 on the other hand [female midwife in her thirties, Clinic 2], said I will find Bilharzia patients in Primary Health Care (PHC). These two informants give different tips for where to go in order to find patients with Bilharzia. I interpret this as a lack of established routines [text, according to Institutional Ethnography] around Bilharzia because it is not something local health professionals consult on an everyday basis, but I might interpret it wrong.

However, Interviewee 4 said there was a lot of Bilharzia while she was growing up, even though they did not know much about it back then. It was not until nursing college that she understood that Bilharzia is a disease that needs medical attention. When she said this, it became clear that she meant Schistosomiasis manifested in the urinary tract, as she did not know that it could manifest in the reproductive tracts until I informed her after the interview.

Interviewee 6 [male professional nurse, in his twenties] also said he knew about Bilharzia when he was a child, and it was very common although it did not require medical attention. He said that everybody knew about the condition back then, and that red urine and even reddish eyes was a sign that you had been swimming in the fresh water. As for the current situation, Interviewee 6 explained further:

> *It’s not very common nowadays. Even though it comes, it comes very rare. It´s something that’s, hm, that’s really, really, really… I mean, you should see, even the treatment for Bilharzia that we have stays very long ... I mean, the package, the one we have, it is not very quick to run out. I mean, one pack stay the whole year to get finished.*

When I passed this information [this finding] on to Expert Informant 11 [doctor in infectious diseases, female in her fifties][20], she comments “gosh, this is quite a shocking statement, knowing what we know”. When I googled the medication, a package contains 4-6 tablets

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[20] Expert Informant 11 was one of my main gatekeepers at BRIGHT, a current respected researcher regarding Female Genital Schistosomiasis, and a doctor in infectious diseases. I wished to interview her as she has diagnosed multiple patients with FGS through visual examinations, and because she is one of the few people aware of the social, economic, political, environmental and medical complexity behind the schistosomiasis parasite, including the following disease. I have also included a few research articles as secondary data for this research, where she is listed as an author

only. Although I cannot be sure how many tablets they have in each package at the clinic, but the fact that it takes up to a year before such a small package of anti-schistosomiasis medication (Praziquantel/Biltricide) is finished, show me that the focus on Bilharzia is extremely limited at Clinic 2.

Interviewee 8 [female in her forties, professional nurse Clinic 3] said that they sometimes find blood in urine these days, although it is very rare to find it in female patients. She informed me that she gave Praziquantel three months ago and 2-3 years back. Also, she told me that everyone still uses the river nowadays. This indicate that there is lack of knowledge about the connection between water contact and bilharzia, as there are few cases of Bilharzia even though everyone uses the water.

All in all, there were severe assumptions regarding Bilharzia amongst my informants. Some had not heard about it before college, others knew about it as children but was not aware of its need for medical attention. The fact that there are so many assumptions instead of a common understanding, constitutes gaps in the knowledge amongst health professionals. I will discuss this further in chapter 7 “Discussion and Analysis”.

6.1.1 Cause of Bilharzia

Every informant associated water contact with Bilharzia and was fully aware that the disease is spread through contaminated water. The most common cause of infection mentioned was recreational water contact, such as to play and swim in the rivers and dams. In that case, one has to be naked so the parasite can swim through the urinary tract opening. Others assumed that drinking the water could irritate the bladder. Only Expert Informant 11 and “informal informant 1” knew that the disease is transmitted as easily as by skin contact to infected water, meaning that one can be infected just by washing hands in infected water.

6.1.1.1 Water contact

Few informants mentioned water activities other than recreation in open water as a cause of Bilharzia. When I asked about household chores in the rivers and dams, most informants answered that people have tap water installed in their houses nowadays, so “no”. In an attempt to research more in depth, I asked how the community handled its need for water during a water shortage periods. A shortage of water is common in the Ugu District, and this affects most socioeconomic classes because when tap water is not available, people have to collect water from other sources. It was even a problem while I was there. Although I did not have to collect water myself [because the house where I rented has cisterns], many of my acquaintances had to manage periods with water shortage.

Interviewee 12 [male professional nurse in his early twenties, Clinic 2] was clear on this matter: people need fresh water during times of water shortages. At such times they boil the water or add a teaspoon of chlorine before using it because most people are fully aware that their local river water is contaminated. I asked if one could receive Bilharzia just by touching the water, for example when you fetch water for daily chores or do laundry by the river. He answered confidently that Bilharzia is not contagious unless one is fully naked under water. Nevertheless, Interviewee 12 stated that he did not know how the parasite enters the inside of the [naked] body.

Almost all informants (except Expert Informant 11, Interviewee 15 and "informal informant 1") shared the same understanding as Interviewee 12. As an example, I will present a short excerpt from the transcribed interview with Interviewee 8 [female professional nurse in her forties, Clinic 3].

> ***Researcher:*** *Who will be using the river, here in this community?*
> ***Interviewee 8:*** *Especially the ... everyone is using the river.*
> ***Researcher:*** *Why do you think only the boys who are 12 -14 years old will only have Bilharzia, and not the other ones who are using the river?*
> ***Interviewee 8:*** *Most of them swimming. There is a big river that side.*
> ***Researcher:*** *So, you won't be affected if you just use water to wash hands and things?*
> ***Interviewee 8:*** *No, you won't be affected.*
> ***Researcher:*** *How do you think ... how will the Bilharzia enter your body while swimming?*
> ***Interviewee 8:*** *When you are swimming you are naked, right? They can enter through the penis, or the vagina if you are female.*

This excerpt demonstrates what might be a common understanding of how mainly boys becomes infected with S. haematobium through recreational water contact. Simultaneously, it demonstrates the lack understanding and knowledge concerning transmission, including risk behaviour such as varied kinds of water contact.

6.1.2 Symptoms

All of my informants knew that bloody urine [or the medically detected blood in urine, *haematuria*] is a common symptom of Bilharzia. Nevertheless, the development of symptoms is more complex than that [see chapter "3 Literature Review"]. Expert Informant 11 [doctor in infectious diseases, female in her fifties] exemplify this by explaining how bloody urine eventually disappears by itself, because the worms inside the body move to other organs. Please note, that Expert Informant 11 is not representative for the knowledge level [not work-knowledge] at the local clinics and their lever of knowledge. She works partly for herself and is one of the few experts in this field on a world-wide basis. I have been fortunate to use her as an informant to balance my findings, also illustrating that there is a gap in the level of knowledge that needs to be filled. I will refer to an excerpt from the transcribed interview:

> ***Researcher:*** *In this region, the worms would go to the urinary or genital tracts – because the worms favour those part of the body, right? But would the worms, after some time, spread to other organs as well?*
> ***Expert Informant 11:*** *Yes! You know, the worms are one centimetre big, and they can move. So, maybe you noticed that you had red bloody urine when you were child but when you are an adult, you don't notice that anymore. And there is a lot of reasons behind that, I won't dive into that but then they* [the worms] *might move to another place. They might get stuck in the kidney region, blocking off the drainage. And if they are here, they are silent; you don't feel them.*
> ***Researcher:*** *So, when they* [the worms] *are finished in one place, they move to another place?*
> ***Expert Informant 11:*** *That could be a way, or they could go and block Fallopian tubes [the female reproductive organs that connects the ovaries to the womb/uterus]to make you infertile. Or if they are sitting on the surface* [of the vaginal tract], *they can create a bloody surface for the women. In men, they can go into the prostate. You know, they can go anywhere. It's kind of complicated to explain what happens in the whole cycle but we don't really know why the egg excretion in the urine decreases with age. So, you might have had eggs in the urine while you were a little child, and when you're an adult it decreases. So, it's a typical age dependent curve.*
> ***Researcher:*** *But the worms will still be there?*
> ***Expert Informant 11:*** *The worms will still be there (...)*

The explanation by Expert Informant 11 above, contradicts how Bilharzia is viewed by the majority in this study, who consider bloody urine as the only visible symptom of the disease.

A finding from my research is that a few of my informants remember having Bilharzia during childhood. Interviewees 4, 6 and 3 said explicit that it was a widespread issue while growing up, although they did not receive medical treatment. Interviewee 15 [female in her late thirties, teacher for professional nursing at Collage] said she remembered being sick as a child, although she did not get medical treatment. At the same time, she was recently diagnosed with Female Genital Schistosomiasis due to infertility. She makes an example of why the information given by Expert Informant 11 is relevant. There is reason to believe that many people now go undetected due to transitory and nonvisible symptoms.

Interviewee 15 demonstrates how FGS is a neglected disease, explaining how her understanding of Bilharzia and FGS changed only because her own medical condition changed:

> *Yeah, we know about Bilharzia but not necessarily learned about it in depth. It´s like "oh, there is Bilharzia where you just urinate with blood". It was just so superficial, you know. Until I was diagnosed with it myself, currently. Then I went on to deck* [became engaged]*, got a bit more information related to it. As a professional registered nurse, and a lecturer currently, and I am clueless. I do have information, but it was so limited, until I went into depth researching about it, for my own personal use. Other than that, it is not there in the curriculum. I can actually clearly say it is not a lot of it that is* [information regarding FGS that is acknowledged] *... if it is, it is so superficial.*

Finally, regarding `symptoms´, I will present a finding that was mentioned by several informants, that "Syndromic Management" (SM) is used as a strategy to diagnose Sexually Transmitted Infections (STIs). SM is an algorithm recommended by the World Health Organization that guides the health professionals to provide correct treatment in accordance to the patient's signs and symptoms (WHO, 2007). SM is used by professional nurses in tropical areas to effectively diagnose and treat a large number of patients. This in itself seems to be very important and respectable, but it does not include treatment for FGS. Despite the fact that it mentions several symptoms that might be FGS, such as abnormal discharge and ulcers in the abdomen. However, as described in chapter 3 "Literature Review", the symptoms can easily be misinterpreted as FGS and STIs have similar signs and symptoms. Expert Informant 11 who has handled many women with both FGS and STIs issues, both as a clinical practitioner and as a researcher in the field, explained how it can be difficult to draw a conclusion based on signs and symptoms:

> *Well, I don't know if she has FGS. She will come to me and she has stinking discharge, which could be sexually transmitted diseases or cancer; a burning sensation in the genitals; bloody discharge, which could be cancer; pain during sex, which could be psychological, you know; problem with husband, endometriosis. It could be STIs, it could be cancer, it could be schisto…there are a whole range of different diagnosis.*

That WHO does not include FGS in such an important and widespread diagnosis and treatment guide for genital problems, show me that lack of knowledge and neglection of FGS not only is a local problem. It is indeed a global problem, to which I will return in my final chapter.

6.1.2.1 Misinterpret symptoms such as `contact bleeding´

Expert Informant 11, who knows the complexity of FGS, says "contact bleeding" is an issue related to FGS; "sometimes it bleeds as I open the speculum. And I am very gentle when I work, so it is gentler than a sexual intercourse. And these women have to bleed after every sex [sexual intercourse], some of them are *so* damaged." Interviewee 4 confirmed this as she said she is not comfortable with using a speculum on pregnant women, due to "contact bleeding". Though she seemed to consider "contact bleeding" in pregnant women to be normal. Therefore, she did not seem to do anything about it, other than to avoid such examination as it can lead to anxiety for the patient and herself. Otherwise, I got the impression that her threshold is low for referring complicated patients to the hospitals in the specialist health service. Still, she did show signs of wonder, of why pregnant women are bleeding when they are not supposed to have menstrual bleeding. She said "sometimes you think maybe, you were not gentle enough. Yes. Sometimes I do have that feeling". This comment made me wonder. So, after I came home from the fieldwork in South Africa, I contacted two experienced obstetricians (gynaecologists) – both with long work experience from different low resourced hospitals in Africa. I asked about their experience with using speculum in pregnant women compared to non-pregnant women. The first obstetrician told me he did not share the same experience, though rubbing the opening of the cervix may trigger bleeding as the tissue is under influence of pregnancy and growth. Further, he said "that can lead to patient anxiety, but little else." He told me that the vaginal walls function as normal, even in the pregnant state. The second obstetrician said the statement of interviewee 4 was incorrect, further he said “but I have heard that as an excuse many times, especially from South Africa. There is absolutely no reason not to do an indicated speculum examination and the fear of women can easily diffused if the health worker takes the time to explain. Furthermore, there is not much bleeding and if there is [much] bleeding it is either because there is an infection or even a tumour, both situations you would want to know and not to hide by not looking”.

The first obstetrician mentioned that there can be several considerations behind Interviewee 4s decision to avoid gynaecological examinations on pregnant women due to “contact bleeding”. He suggested that a few bad experiences might have shaped her in avoiding such practice. Simultaneously, one cannot preclude that pregnant women with FGS have an increased tendency for “contact bleeding”, although this might not have been explored. However, it may be natural for Interviewee 4 to find pregnant women bleed more easily because there are a high prevalence of FGS in the area her clinic covers, which makes the bleeding rather normal than abnormal [and it might be rationalised by the fact that the pregnant body is in a unique state of hormones and growth] – and as a nurse, it is not normal to rapport normalities, only abnormalities. If it had been abnormal for her, she would most likely refer such findings to hospital.

An example, if the patient is having problems following the speculum examination, it may give the health professional who performed the examination, very bad feelings. Expert Informant 11 strengthen this speculation by saying “you hesitate to investigate pregnant women because you are afraid if an abortion happens afterwards (…) that can be detrimental to any clinic, if you get blamed for being the cause of an abortion. So, you hold back on investigating in pregnant women.” At the same time, it might be good for the pregnant woman and her family, who are in shock, to blame someone for the bad outcome of the unborn baby.

The understanding of Interviewee 4 might have reflected the level of general work-knowledge. However, my understand of Interviewee 4 after getting to know her a little bit, was that she respects the society and the community’s beliefs very much [please read *6.1.3.1* below] and that she wants to protect her patients from harm, rumours and difficult social, as well as family related, situations.

6.1.3 Diagnostics

Expert Informant 11 explain how Schistosomiasis infections might be confused with other diseases, as the damages created by S. haematobium might not be visible from the outside:

> *I think it's a chronic disease that doesn't kill you, obviously. They don't see that it kills you. And you're working in a scenario where… we have had very poor diagnostic tools. For example, the few cases of Bilharzia that do die, they die from kidney failure…and kidney failure is not a disease that you will see. We have no way to measure it, in rural Africa. We have just seen that people become oedematous* [puffy or swollen]*, and you know… we don't have any tools to manage it. We don't have any dialysis machines; we don't measure creatinine, which is what we measure of kidney failure. So, you wouldn't know what your patient has when he or she dies from Bilharzia.*

The quote above shows that S. haematobium is a difficult infection to detect and therefor difficult to diagnose. Furthermore, adequate training and good medical equipment are necessary.

The professional nurses that I talked to at the three clinics associate Bilharzia with bloody urine. In order to diagnose the Bilharzia, they will use a "dip stick" urinary dipstick, which is a tool to check for abnormalities presented in the urine. If abnormalities are found, such as haematuria (blood in urine), the next step is to send a specimen jar filled with fresh urine for laboratory testing. If the test proves positive for schistosomiasis, the patient will receive Praziquantel medication. The treatment dosage is given in accordance with the weight of the patient.

If S. haematobium is manifested in the urinary tract, then this is a correct way to diagnose. However, as described in chapter 3, one can be infected and show other symptoms (such as abnormal discharge), or the bloody urine might disappear with age. Thus, there could be many unrecorded cases of infection, if urine dip stick is the only diagnostic method used at Clinics 1, 2 and 3.

Expert Informant 11 describe how difficult it might be to diagnose [measure the worms] S. haematobium, due to lack of technical recourses:

> *The worms will still be there; we can measure the worms now as we have more fancy techniques, but it's not done in the rural clinics. In the rural clinics they are still measuring just the urine. So, the clinical tool in rural Africa is very primitive – there are no other ways to diagnose Bilharzia, other than through urine analysis. Which is also kind of high-tech, because you need a microscope and a trained laboratory technician. Which they have here, but not everywhere.*

What Expert Informant 11 describes above complicates the health professionals process of consulting and diagnosing patients, as well as to hinder them from doing the job optimally and develop their knowledge regarding FGS. Expert Informant 11 also mention "training" of laboratory technicians, which I will come back to in chapter "7 Discussion and analysis".

During the Focus Group Discussion (FGD), my informants recognized some issues they had seen in real life, after inspecting pictures in the "World Health Organisation (WHO) Pocket Atlas for Female Genital Schistosomiasis" (2015). This pocket-book portrays images of different types of morbidity caused by S. haematobium in the genitals (World Health Organisation, 2015). Participant 6 said the pictures in the pocket atlas shows eroded cervixes and that it resembles a prolapse (a condition when the organ is out of shape or sunken). Two participants said they would be suspect and report of cancer, and further refer them to the hospital. Another participant said she recognized the picture on page 25, which looks like "menstrual blood". Their answers indicate that it is easy to draw other conclusions than FGS when one is not trained regarding S. haematobium. However, it shows me that professional nurses do care and are able to draw a conclusion based on what they observe. But it entails a risk of misdiagnosis and further mistreatment when they have not received adequate training regarding Female Genital Schistosomiases [as they live in a S. haematobium endemic area].

6.1.3.1 Diagnosing genital problems in young girls and cultural consequences

Research has shown that FGS may cause morbidity in the lower reproductive tracts (and other organs) at an early age (E. F. Kjetland, P. D. C. Leutscher, & P. D. Ndhlovu, 2012; Magaisa et al., 2015). Hence young girls may experience problems similar to sexually transmitted diseases, even before they are sexually active. To diagnose them is a problem because one cannot easily perform an intravaginal examination, using ordinary adult-size speculums (Hegertun et al., 2013). According to Expert Informant 11, this is because young girls will have a narrower vagina, and to insert a speculum will hurt the child. Interviewee 4 informed how such practice would be very expensive for her, as she would have to pay a cow for every hymen, she breaks. She told me what she would do if her patient were minor presenting sign and symptoms of STIs, telling me how it would not be a comfortable experience for her personally:

> *We just refer her to hospital, because it is beyond us. Because cannot pass a Cusco* [speculum]. *If we do that, we have to pay the cow (laughing). It will be like, deflowering, breaking the hymen, and traditionally that is done by the husband, when the girl is married, and he paid a cow for her... I can't pay a cow…how many cows am I going to pay? (laughing) So we mostly send them to hospital. And mostly, their parents don't consent the Cusco being passed, until the girl is no longer virgin.*

Several informants told me that they have received young female patients who claim that they are virgins, still complaining of symptoms similar to STIs. In such cases it might be appropriate to consider FGS as a cause behind the complains [as explained in chapter 3 "Literature Review"]. Nevertheless, when I asked clinical nurses about their assumptions regarding such cases, there were several who found it difficult to understand as well provide adequate health care - as it is not necessarily logical that a young child without sexual debut should experience such problems. Others answered that some girls would lie to them about being virgins; Interviewee 14 [midwife at Clinic 1 in her forties] were experienced with "virginity testing" as a ritual to reveal if young girls are "pure" or not concerning sex before marriage. She explained to me that girls often lie about having sex because they do not what to lose their value and honour due to a broken hymen. Traditionally, the girl's purity constitutes a value, which is important for the entire family, their reputation as well as for her own well-being. Although medical research suggests that hymen is a false myth[21] (Brochmann et al., 2018), Interviewee 14 was clearly convinced that the hymen is a sincere pointer to a woman's sexual status, although she seemed undoubtedly experienced regarding the hymens' individual differences in appearance.

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[21] In cultures all over the world, women's virginity is a sign of purity and pride, thus a woman's sexuality has been controlled in contrast to men. It is a false myth that virgin testing can confirm and deny a woman's sexuality, as the hymen do not necessarily rapture during sex. The hymen looks different in all women and changes with puberty. Although the hymen is the narrowest point in the vagina, it is very elastic (as a fetus can penetrate through it). Two studies show that there is a 56% and 40% chance of bleeding during the first intercourse, but it is important to point out that bleeding can come of menstrual bleeding or small tears in the vaginal walls (Brochmann, Dahl, & Tegnehanne, 2018).

One day at Clinic 2, Interviewee 6 [male in his twenties, professional nurse] started to discuss one patient with me, because he was sure I would be able to help. He knew that I am registered nurse and he remembered from our interview earlier, that I study reproductive health problems in female. He said he had a young female patient with problems in her genitals although she is not yet sexually active. He told me that he did not know what to do with her, because he cannot do a vaginal examination on her without her parents' permission, and he assumed they would refuse in fear of losing their daughters value due to lost virginity.

Interviewee 14 can confirm the value and pride of the hymen:

> ***Interviewee 14:*** *Firstly, it is a pride of the family. Having a hymen is a pride. It is something precious. So, losing it, it must be known. "How did you lose it? You have to explain to the parents."*
> ***Researcher:*** *Ah, what's it called ... like a bride price ... what do you call it?*
> ***Interviewee 14:*** *The "Mqhoyiso" (chuckle laugh).*
> ***Researcher:*** *Ok, so it* [she] *will lose value?*
> ***Interviewee 14:*** *Exactly. You lose the value. The bridal price has to be reduced.*
> ***Researcher:*** *Would such lead to stigma, you think?*
> ***Interviewee 14:*** *Sort of, that is why you have to make sure that you keep it very safe.*

This indicates that social and cultural norms and practices leads to guidelines for what healthcare professionals can and cannot do in cases where they suspect illness.

6.1.4 Neglection

Based on the ignorance of "informal informant 2" [teacher in nursing, the University of KZN] and Informant 15 [teacher in nursing at Collage, and recently diagnosed with FGS], FGS is not noticeably included in the curriculum in nursing education. I was wondering who is developing the curriculum, in case this may have an impact on the neglect of FGS. Interviewee 15 informed me about how the curriculum for nursing education is developed and by whom:

> *So, the curriculum is developed by the different nursing education institutions and it is approved by the South African Nursing council. I would like to believe that they just forgot to include FGS in the curriculum maybe because majority of the curriculum development team*

> *are not affected by it or they are from the big cities, so they are not so sure that it has affected a lot of people.*

When I introduced FGS to Interviewee 6 [male professional nurse in his twenties, Clinic 2], he said it must be neglected by the government, because he had not heard of it before. He said that [urinary tract] Bilharzia was given some attention in the curriculum during his nursing education. On the other hand, he did not know that Bilharzia could manifest in the reproductive tracts.

> ***Interviewee 6:*** *It was not a specific chapter* [during nursing education] *we should deal with Bilharzia. It seems like something that is very minor, we don't really treat it* [don't really prioritize Bilharzia]. *I'm not sure, but maybe in your country, it is something serious, but this side it is not something that serious. Even though we do have treatment for it (...)*
> ***Researcher:*** *Do you ever relate it* [Bilharzia] *to reproductive health?*
> ***Interviewee 6:*** *Yes ... (he changed his mind suddenly). No reproductive health? (surprised) No, no, no ... me personally, I never heard of any relation with that. Besides that, the causative organ is probably a ... I mean, it´s what? Is it a bacterium? I don't know.*

As he said, Bilharzia is part of the urinary tract as they learned it during their nursing education [which is also true, yet a narrow understanding of `Schistosomiasis´]. His lack of understanding of the disease indicates that Schistosomiasis is not clearly described in the curriculum, nor received much focus from the government. On the other hand, he has not studied medicine to become a doctor, therefore one cannot expect him to know Schistosomiasis at a detailed level.

"Informal informant 1"[22] [doctor and teacher in Public Health, thus "medical school" at University of KZN] said that FGS is neglected because the country has such a big burden of other diseases, such as TB and HIV and malaria (in the northern parts of the country). She expressed doubts about how extensive FGS really is compared to the other burdens in the country and she told me that more research is needed, i.e. more texts are needed for people to understand the importance of FGS. She also told me that FGS might be presented at first year of medical school, thus, FGS should be known among some doctors in South Africa. On the

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[22] Informal informant 1: a woman in her forties, doctor and teacher in Public Health at University of KZN, who also has a good knowledge of FGS through a collaboration with BRIGHT.

other hand, Interviewee 15 informed me that there are very few or no physicians at the governmental clinics, which is why the professional nurse's function as the locals' first-line service when consulting health problems. Furthermore, currently we have the situation of Covid-19 pandemic that seems to attract the world's attention as an extraordinary priority. Interviewee 15 emailed me in September 2020 and informed me that she will put forward proposals to include FGS in nursing education as soon as the unease around the pandemic has settled, hence there is neither time nor space to put FGS on the agenda currently because no one will find it important compared to Covis-19 and so FGS might continue to be downgraded.

6.2 Gender

From a gender perspective, I wanted to know whether male and female nurses have the same amount of influence. Interviewee 15 [female in her late thirties, teacher for professional nursing at Collage] told me how the opportunities are the same regardless of gender, although the health sector continues to be female dominated service:

> *Opportunities are the same here for both genders but nursing being a female dominated profession, you find more females in senior positions and depending on how many nurses from the different genders further their studies and climb the ladder. Otherwise the opportunities are available to all but it's just that females are a majority here as compared to males.*

6.2.1 Assumptions about gender differences in FGS

The informants gave their assumptions regarding age group and gender which they associated with Bilharzia. As one can see in the *Table 6* underneath, most of my informants associated young adolescent boys to Bilharzia. Their answers seemed to be based on their idea of who most frequently swims and play in open water [my interpretation]. Expert Informant 11 [by referring to Mazibuko, Flack, and Kvalsvig (2019)] said that it is often the popular sporty children who like to go swimming, whereas the "bookworms" tend to stay at home. I find this interesting because it points to cultural practices as well as gender roles in the community, furthermore *how* such discourses affect people's idea of "who they think is infected". I will discuss this further in chapter 7 "Discussion and analysis".

Table 6: How interviewees associated age group and gender with contracting Bilharzia

Interviewee number	**Age group (years old)**	**Gender**
5	12 – 18	Mostly boys
6	3 – 5	Mostly boys
7, 8	10 – 14	Mostly boys
9	10 – 12	Mostly boys
10	7 – 15	Mostly boys
(12), 13	11 – 15	Mostly boys
2		Mostly boys
14		**Mostly girls**
3, 4, 11, 15		Everyone

There is also reason to believe that boys are associated to Bilharzia because boys can see their own urine while urinating, whereas this is not necessarily the case with girls. Which brings us to the biological gender differences. However, since this was not a finding obtained from my informants, but rather an understanding acquired by reflecting together with my gatekeepers at BRIGHT, and because this is a research in `social science´, I choose not to go further into these biological gender differences.

The mainstream answers [“mostly boys”] are based on a common understanding in community, thus discourses, but few assumptions stood out from the average: Interviewee 6 mentioned [mostly] boys between 3-5 years of age. This is a younger group of age than everyone else mentioned (except Expert Informant 11); Interviewee 14 [midwife in her forties from the labour ward, Clinic 1] was the only person who associated Bilharzia with girls. Although she did not mention damages to female reproductive tracts, in fact she asked me if I had come to the wrong place for my research. She said to me: “you know that this is a labour ward, right? There is no bilharzia here.” My anticipation regarding her answer [“mostly girls”] is either that she remembered the disease from childhood, or she might have realized what I was asking about by reading the “information and consent form”- and therefore answered me what she thought I wanted to hear. In any case, she could not elaborate much on why her answer was "girls", which might indicate a low level of knowledge on this exact topic. However, Expert Informant 11, Interviewee 3, 4 and 15 answered was the only ones saying that “everyone” can receive Bilharzia. Why these answers stand out from the mainstream understanding of “who contracts Bilharzia”, might be their personal experience of Bilharzia from their own childhood.

I will now present a small excerpt from my conversation with the Ward Nurse [male in his twenties, professional nurse at Clinic 2] and the Community Health Worker [Interviewee 13, female, early twenties]. They told me their assumption on why girls suffer less from Bilharzia compared to boys:

> ***Researcher:*** *Have you ever seen girls with Bilharzia?*
> ***Interviewee 12:*** *I have seen girls with Bilharzia, but I mean, it is rare because they are not allowed to go out and play. Because the mothers use this thing of protection, they protect their children.*
> ***Researcher:*** *Why would they protect the girls more than the boys?*
> ***Interviewee 13:*** *Because, there is crime.*
> ***Interviewee 12:*** *Especially here in South Africa, there is that thing of rape. It is common. So, you have to protect your* [female] *child.*

Interviewee 12 and 13 saw a connection between Bilharzia and gender differences in a social context, explained by the fact that girls are not as socially free as boys. Their answer was different from the other professional nurses. There is reason to believe that these to people work in closest contact with poverty in rural community, therefore witness most crime and social injustice during their everyday workdays. Their answers also told me that they have access to a reality that is far more dire than what the other nurses working at the clinics [whom gave me an even more "stereotypical" picture of the sexes]. Moreover, it told me that they have different positions in society and that those who are higher up in rank are more shielded from the harsh realities of life (e.g. rape).

The professional nurses at the Focus Group Discussion gave me different assumptions to why boys swim more compared to girls. It was said that boys “disappear” from the house, whilst the girls are more loyal to their mother and their household chores. All of which may be recognized as social and cultural norms. It might as well reflect traditional gender discourses. Accordingly, it may provide girls and boys with different opportunities and roles in societies everyday life.

After a while in the field, it gradually became clearer how girls and boys are raised differently with very different expectations and assumptions. One factor might be that the boys have fewer household chores and are freer to do what they want. Interviewee 12 said boys live under less strict circumstances because they can run and hit back, whilst girls cannot. Therefore, a mother would not worry much if her son run away for some time to play, because she would trust he would be fine. Unlike if her daughter was gone for some time, the mother would mediately start to worry. Another woman I talked to [in her thirties, informal informant 3], said she was worried about how boys and girls are raised differently. She gave me a general example where she always had to watch the clock and never stay out after dark. If she was only 5 minutes late, she would be punished by her caregiver. In contrast, the brother could come and go whenever he wanted, with no negative consequences from the caregiver. She announced, it is no wonder why there are major gender differences in this country. Furthermore, she told me that one can blame such gender discrimination for gender-based violence such as rape. Interviewee 14 [female midwife in her forties, Clinic 1] and I talked about why the rate of rape is so high in South Africa. She said:

> *I think, just because women were oppressed hard* [much] *here. Because, during the time of oppression, there was `African people oppression´. And then there was `women oppression´. So, if you are a woman, you are oppressed times two. So that kind of oppression makes the white look superior. And then the men also look superior. You should obey everything that was said by men. It was all about men. So, now there is this thing of `we need to be equal´* (…) *and it is stressing men* [so they force back their power that is no longer there, by rape and criminal actions].

This section reveals how the informants experience gender inequality in their society. They mention how girls are raised more strictly than boys, and in a sense more “tied to the household”. This may be due to cultural practices, and/or it may be because girls are more vulnerable to external dangers such as sexual violation, hence they are in need for protection. On the one hand, girls may live with a limited radius compared to boys which may also explain how girls are less known for recreations water contact. On the other hand, gender-based violence does seem to increase the risk of reproductive female morbidity [as elaborated *4.3 Gender Inequality*]. Nevertheless, there seems to be little focus on helping *the men* to prevent violent actions and attitudes. This in turn points to gender discrimination, when there is a strong focus on protecting the girls compared to their boy peers who are released "free" instead of taught to understand the seriousness about this. Here I will refer back to Cornwall and White (2000) and Chant and Gutmann (2002) who argue that men should not be overlooked and left to themselves in the process of equality, as this may lead to more violence against women. Furthermore, these violent tendencies exemplify what can happen to person when power is deprived, and the feeling of injustice becomes overwhelming.

6.2.2 Water contact during traditional rituals

Through several interviews, it was mentioned that the open water is used in various rituals, such as baptising, cleansing of bad spirit, celebrating the girls first menstruation and female virginity testing. During the Focus Group Discussion at Clinic 2, Interviewee 4 [female midwife in her thirties] explained to me how traditional healers and priests would use the river:

> *They take the people to the river, to cleanse them of bad spirits …* (people are laughing, including interviewee 4, who then say something in isiZulu) *and in churches, for baptizing the people. They take them to the river. You put your whole body in then.*

Interviewee 14 mentioned rituals that is only for girls:

> *Yes, when there is someone with that ritual. Like the teenage girls, when they are still virgin. Checking their hymen, and then they go bath in the river. Not really into the river but dripping water … It is just a ritual, that very early in the morning, before sun comes out. Usually it is done in rural areas. All of you as virgins go to the river, and you go without anything – without dresses, without.*

Based on what they say, I consider that my informants have not learned the risk of simply being in skin contact with water. Although they seemed informed that bathing in contaminated water leads to a risk of infection, which is also right but a narrow understanding of Schistosomiasis. This in turn is about them not having access to adequate information about the disease, which results in a lower level of knowledge although it is not their fault.

6.2.3 Embarrassment, taboo and stigma

Some informants said it would not be embarrassing for patients to report their state of [urinary] Bilharzia because it is common. Interviewee 6 [male in his twenties, male professional nurse, Clinic 2] said he had urinary Bilharzia as a child, and that it was not embarrassing. He said it was normal back then, thus he did not see any need for medical attention. Simultaneously, he did not want his mother to know he had been swimming in the open water, because she did not allow it as she knew that the contaminated water would make him sick. So, he kept it a secret. He could not remember many girls with Bilharzia back then but said he probably did not know about the infected girls because they kept it a secret from the boys. Today he would give medication, regardless of gender. On the contrary, some women participating in the Focus Group Discussion thought the other way around. They told me that boys were "lying" more often or would withhold information, whereas girls would communicate their complaints to their mother. If their assumptions reflect the local gender discourses, I would argue that their assumptions have reduced reliability as human interactions (and relationships between children and parents) are highly individual.

Expert Informant 11 told me about her assessments when young patients come to report problems in the reproductive tract, which also involves assessing sociocultural conditions that may be vulnerable to the patient. Additionally, she indicates that it is difficult to distinguish between FGS and STI when sexual activity might be a risk factor for female morbidity:

> *So, if I am here in an endemic area, I would also ask them about water contact… Some would say "oh, I haven't started having sex yet", which is an answer I cannot completely trust. Because I know that people would not want to admit it; if you are 15 years old, your mother is going to shout at you, or you think that I am going to shout at you – then you won't say that but say I have a 15-year-old, and she have a stinking discharge and a burning sensation in her genitals, I would inspect; I would ask her…Currently, a clinician in the rural area will almost certainly give her tablets for sexual transmitted diseases, independent on what she answers. They would think she has been sexually abused or had sex, but she doesn't want to admit.*

Several informants said there are taboo, embarrassment and stigma associated with reproductive issues ["the private parts"], and that this was a problem since some would under-report. Which is an obstacle because good "history taking" from the patient is required in order to give best possible health care assistance. They mentioned tensions and unwritten rules and attitudes related to genital health, and that bodily elimination (urine, stool, menstruation or discharge) is often associated with something dirty. Negative emotions may therefore occur in the patient. Interviewee 5 [women in her fifties, professional nurse at Clinic

2] said young girls neglect their health problems because they want to be normal. Also, in the Focus Group Discussion, it was conversed how elder people refuse to seek medical attention until it has developed too far, and it is too late to treat properly. A possible reason for underreporting that emerged from my findings was the high costs connected to medical attention [transport and time away off work], or that they are refused by family/partner to investigate the problem in her genitals [because this area is related to shame and taboo, my understanding]. The latter would reflect a way of "social control" affecting females, as their self-agency are controlled by others.

Participant 6 from the Focus Group Discussion [female in her fifties, professional nurse, Clinic 2] said she sometimes observed menstrual blood on ladies above 60 years, which is abnormal findings:

> *And they are not supposed to be having menstrual blood, and also (...) they don't want to come and report to the clinic that "oh, my private part is ... I am having this kind of discharge". The other… there was a grandmother… three months having the same problem, and but not coming to report that to the clinic ... and they come now as a terrible order ... and then that is, when they decide to come to the clinic. They don´t feel comfortable.*

An issue to be recognized, is women who report late because they might feel too embarrassed and/or ashamed of their own private health condition. Nevertheless, menstrual blood at such an old age could be a symptom of female morbidity.

6.2.4 FGS and social inequality

According to Expert Informant 11, in some areas people perceive schistosomiasis as a sign of poverty. For instance, missing tap water in the house means one has to fetch water from the river. A social consequence of this would be that members of the household signal that they are poor. Hence, poor girls would go to the river to do their laundry, and the rich girls will not. Rich households might have a washing machine or a maid to do their laundry. Consequently, Bilharzia infected patients under medical treatment might neglect their own health situation, in fear of being perceived as poor.

According to "informal informant 2" [a teacher in nursing, KZN University] the nurses' training program includes social anthropology and it is taught in the curriculum due to the need of cultural understanding amongst nurses in South Africa. This is because their nation incorporate diversity in people, resembling the Rainbow Nation. Therefore, nurses must behave professionally and be neutral and understanding in meeting with South Africa's multiple cultures. Nevertheless, some of my informants [members of the middle class] have uttered patronizing attitudes directed to people with traditional conviction. Others were very understanding and embraced the national diversity. There are reasons to believe that some patronizing attitudes might contribute to social divides. At the same time, large class differences affect people's understanding of practice, which may explain why important phenomena are overlooked.

6.2.4. Inequalities in a Post-Apartheid system

Governmental clinics are known to have less recourses than private clinics in South Africa. The cause of these differences probably anchors hundreds of years back, with a society dominated by racial and class segregation (Eriksen & Millstein, 2016). Interviewee 14 explained how public health care was distributed between black and white people and how there were very few clinics for the black majority compared to the white minority living in South Africa. Following, how black people were forced to move further into rural areas in order to give space for white population. She said that the situation has gradually changed since apartheid ended in 1994:

> *We are trying to close that gap now (...) Better than before. Far better than before (...) It is difficult to understand. Not unless you have seen the ... even our children. I think my son cannot believe it. Because now they are mixed, but before, we were not mixed, we were not allowed (...) It was creating hatred before. You know, between people. Now, the African people know that the whites are normal people. And vice versa.*

Expert Informant 11 told me that Apartheid created a structure for how the black majority was treated in the health care system. She said "they used to say 75% of the education funding was given the white schools before, 25 % was given the black population. Whilst the black populations constituted 90 % of the population. So, the funding was distributed unfairly". According to Noah (2016) the education provided to the black population earlier was organized through missionaries who wanted to Christianize and Westernize the native. Such injustice and influence have probably left its mark, and according to my observations it may seem that such inequality is ongoing. On the one hand, several of my informants claimed to have experience significant change; with better infrastructure; more evenly distributed resources; and improvement in many fields. On the other hand, Expert Informant 11 said: "The post-apartheid era has been trying to erase that situation but if you go here and look at any of the local clinics or hospitals, you would hardly see any white people there (…) all the whites would go to a doctor as a first line of treatment, not to a nurse." I recognized myself in what she said, when I experienced being the only white person at Clinic 2 and 3[23]. However, most of my informants said people would contact a professional nurse [from a local clinic] as their first line of treatment, and some of my informant assumed that the majority of the black community tend to have traditional healer as first their line of treatment. Most of the white people, on the other hand, would consult a doctor as a first line of treatment.

It is probably natural that historical conditions continue to characterize the health system and that cultural practices lead the population to seek out various first-line services, such as traditional medicine / healers. However, this topic is not the purpose of this thesis as the matter is too complicated to be included, although it could be a topic for further research. However, challenges must occur when the population is characterized by difficult history and thus conditions, as they live with a distinct heritage. As UNAIDS (2019) points out, black women in rural areas bear the greatest burden, both socio-economically, in terms of health and inequality. Moreover, it is also a question of who designs health policy and educational training for nurses. According to South Africa's history, attempts have been made to change the rural areas as well as the urban areas, but as the interventions are not designed for this population, South Africa gets characterized by strong inequality (Eriksen & Millstein, 2016).

6.3 Development of knowledge about FGS

All the informants I saw their own responsibility to inform others, as well as educate as part of the treatment. It could be by giving advice and guidance to the individual patient. It could also be by asking the patient to bring along (for example, a partner or caregiver) to ensure that the information was disseminated. It was also mentioned to encourage patients to spread the information teach their family and friends at school. One informant mentioned that she experienced that the children actually taught each other about risk factors for infection when they played. In this section, I will first present how to acquire knowledge via and after nursing

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[23] The local patient and health professionals looked at me as I was a foreigner wanting something else than health care. At Clinic 2 especially, I was allowed to go straight to the matron's office, and I was treated with great respect – all of which made me feel very "white" and it gave me position I was not comfortable with.

education. Lastly, I will mention a few recommended and planned measurements in order to increase the level of knowledge regarding Female Genital Schistosomiasis.

6.3.1 South African training of professional nurses

In the beginning of my fieldwork, I had an informal conversation with the "head of nursing education" [informal informant 2] at the university of KwaZulu Natal. He informed about the universities' strategy of "problem-based learning" (PBL) in training professional nurses. With this strategy, the students learn based on the cases they meet, under supervision, in their clinical practices' periods. He said that they conduct interviews in order to understand what the clinical practice community needs thus which cases are relevant for them to focus on, in order to function as nurses in their place of employment/clinical practice. Accordingly, students navigate their own way to find the solution to a common problem at that specific clinic, which for example could be malaria, tuberculosis and/or HIV [South African context]. Interviewee 15 [female in her late thirties, teacher for professional nursing at Collage] said that PBL is primarily used within universities. She said the colleges do not have enough equipment's, such as proper laboratories and computer labs in order to research the given problem. Therefore, collages primarily use an oral teaching strategy, such as lectures in addition to "in service training".

Interviewee 15 further informed me about a new strategy coming up in South Afrika. It is called "Continued Professional Development" (CPD), which is a pilot project expected to be rolled out approximately 2021, to ensure health professionals to stay updated:

> *We recently launched the CPD program, Continued Professional Development, which is a requirement from the South African Nursing Council for every nurse that works in the country. Every year, they need to meet that* [CPD]. *It's like they need to go attend workshops, attend conferences; you get points in order for you to be able to register as a nurse* [renew the authorization] *(...) People will be obliged to keep themselves updated.*

Such "in service training" will ensure the quality of health care in South Africa as the health personnel must compulsorily earn and renew their authorization every year. This shows a responsibility from the government, in that they aim a high level among the health service.

6.3.2 Measures to increase knowledge about FGS

After the interviews, I asked my informants how they prefer to work strategically to develop a higher level of knowledge regarding Schistosomiasis. Interviewee 14 answered [female midwife in her forties, Clinic 1]:

> *Hm, I think, going to the communities but, because, the health professionals do not know about it. That's a first thing; they must help the health professionals know about it and understand. What it is, and the affects is. And if they know… you know, there are community outreach*[24]*, even in rural areas. They can be included. When the community health workers go for outreach in the rural area, we include the diagnoses. Like, when they do BP checking* [blood pressure]*, checking for diabetes. It must be included; checking for Bilharzia.*

Interviewee 15 answered [female in her late thirties, teacher for professional nursing at Collage]:

Well, according to me, I think it should be in the Community Nursing curriculum, which is done in the first year, second year and third year in our collage (…) Like, currently, if it is there [syllabus on FGS], it is not done in depth. That's why, by the time they are professional nurses, they don´t know about it (…) So, if it can be introduced into the curriculum, and it is there; the students are taught extensively, and they can be able to identify it even if they go to the community clinics. And it can actually do us a lot of good, because then there is going to be knowledge about it. About the signs and symptoms, and therefore be able to treat it.

During the Focus Group Discussion at Clinic 2, Interviewee 4 said she wanted to be trained so that she can recognize the disease without having to do a genital examination. By referring to what she described in section *6.1.3.1 Diagnosing genital problems in young girls and cultural consequences*, it is difficult to diagnose young girls who have not yet debuted sexually, in respect of their hymen. Participant 6 enhanced [female in her late thirties, Clinic 2]:

> *Because, I was going to suggest. Because we are professional, as much as we will learn from their service* [BRIGHT - https://brightresearch.org] *but if they can make a pamphlet that can be distributed amongst the facilities. Because there is a lot of facilities, if you can imagine*

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[24] Such as the Community Health Worker [Interviewee 13] and Ward Nurse [Interviewee 12].

> *KZN as a whole. You know, make a pamphlet that can be distributed, and then we can just read about it. It can even assist us to educate the patient.*

Considering “training of health personnel” as a measure to develop a higher level of knowledge regarding FGS in the community health services, I asked Expert Informant 11 if visual [speculum] examination is the cheapest diagnostic method. The answer was following:

> *We want to develop a teaching tool that is cell phone based, where they can look at images; be trained and tested. As many people now have a smartphone… For me, it has taken about 6 weeks to train other doctors. It´s not a quick fix. And here we have to train nurses to do it, because they are in the frontline. They are functioning like general practitioners in Norway. They are doing the full job and they are offering the treatments. So, ideally it should be a simple way (...) and then you should be able to dispense treatment, then and there. Because, you know also that the patient doesn’t have money to come back to the clinic …if you lose them, they are gone… if you don’t give them treatment here and now, you will never see them again.*

Here she says that one must train health professionals both broad-spectrum and effectively. At the same time, the strategy should be operative because if the Clinic provide poor health service, they may end up losing patients. Subsequently, the patients will go untreated and the clinic will gain a bad reputation due to the bad presented on the South African Statistics - as they are obliged report data in terms of statistics (informed by Interviewee 15).

7 Discussion and analysis

In the next part, I will draw inspiration from Smith (2005) and the inquiry of Institutional Ethnography. I will analyse the relationship between text, behaviour and different power relations that arise within an institution. The aim is to bring out possible reasons for the low level of knowledge among the local health professionals I spoke to, as well as reflect on how FGS affects society and how society affects FGS. But first, I will start this chapter by discussing social aspects of `symptom´, `diagnostics´ and measurements around `treatment´ for FGS.

7.1 Female Genital Schistosomiasis (FGS)

The professional nurses that I met seemed to be well-educated within the `cause´ of reproductive health problems, except FGS. However, because none of the professional nurses at Clinic 1, 2 and 3 knew about FGS, I choose not to discuss their assumptions regarding the `cause of FGS´ in further detail, as it appeared to be "unknown". Anyhow, it turned out to be a consensus amongst the professional nurses that contact with contaminated water is the cause of [urinary] Bilharzia, which is consistent with the findings of the biomedical research referred to in this thesis,

7.1.1 Symptoms

As presented in both chapter 3 "Literature Review" and chapter 6 "Empirical findings" one can point to several reasons why FGS goes under the radar, as well as what morbid consequences it provides for the woman. Overall, I will argue that this constitutes a *morbid* marginalization and/or discriminating of the woman: as morbidity in the genitals increases the risk of being exposed to social stigma and negative self-esteem; some young girl might lose value if she presents symptoms of STIs which can be devastating for the whole family, whereupon causes external pressure that threatens women's self-agency; long-term infection in the genitals might destroy the hormone balance and the infection might lead to fatigue as the larvae feed on her blood [among other things]. The latter threatens women's self-agency from *within*. If such a fate applies to the majority of women in a society, it will contribute to socioeconomic gender inequality due to income differences. This in turn, may be detrimental to the development of whole society, and appear on national statistics.

Participants in the focus group discussion mentioned considerable embarrassment amongst the elderly with lower reproductive tract symptoms[25]. Such attitudes prevent the elder from contacting the health care facility for help. As a consequence, the symptoms they have might develop too far, which can result in irreversible or very extensive damages. This is a big problem because the symptoms might be difficult to treat optimally. Besides, if patients seek medical attention without experiencing improvement, it might lead to stress, accusations of having preformed a bad job as well as a bad reputation upon the clinic. Interviewee 4 told me that she refers symptomatically complicated patients to a hospital where a doctor can examine

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[25] I do not know what age people defines as "old" but a dear friend of mine, in her sixties, defined herself as old and said her work here on earth has come to an end and she was ready to meet Jesus.

the patient and provide more advanced health care. In other words, the nurse's judgment call regarding the patient's symptoms is an important part in order for the women in society to get the help they need. Moreover, during the focus group discussion, it was mentioned many women might not have the economy nor the opportunity to pay attention to their own symptoms until the health problems are too severe to live with - although large extensive problems are more difficult, and thus more expensive to treat than minor problems.

In other words, the impact of not focusing on FGS are severe for the women affected and may lead to a further marginalisation of women in society, as well as confusion amongst health professionals who provide medical attention.

7.1.2 Diagnostics

As presented in this thesis, FGS seems difficult to diagnose as it can be challenging to detect the clusters of eggs; as adequate equipment is expensive; and as sufficient training of health professionals is required (according to Expert Informant 11, she spends 6 weeks to train one personnel). In other words, it requires a lot from the clinic to be well prepared for FGS, if the goal is to consult the patients with professional competence. There is reason to believe that the training of health professionals may meet barriers. In the following text, I will discuss a few possible barriers in light of IE.

7.1.2.1 Barriers in training of health professionals

Firstly, there are many clinics in the endemic areas and each clinic should probably train more than one nurse. Secondly, adequate equipment's are expensive, such as the instrument called "colposcope"[26] which is used to examine the cervix and vagina with light and magnifying glass. Thirdly, training is time consuming and expensive [and should training take place during or outside normal working hours, and who should pay for it?]. Fourthly, it may challenge normal staffing at the clinic if the training takes place during working hours as it might ruin normal operations of health facility or become expensive if they have to hire replacement/assistant with a certain level of competence. Another dimension is that someone has to decide that `training´ is necessary. It goes back to the question of who has the power to decide which diseases or disorders should be given priority, and it is only when something is

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[26] A tool that would make it possible to visually examine and diagnose FGS without further need for PCR or analysis of other body fluids.

defined as necessary that it can also trigger funds. It is the discourses and text that govern, which can mean that important dimensions of an under-explored disease are not seen/treated/researched.

Lastly, I will discuss barriers with the alternative diagnostic solution mentioned by both Expert Informal 11 and UNAIDS (2019) which are `telemedicine´ and the use of smartphones. On the one hand, I understand that this is a good idea because, in theory it requires only a healthcare professional with a smartphone. On the other hand, it would require good and probably expensive smartphones [with good storage capacity and well-developed camera, my opinion]. Furthermore, there ought to be extra requirements for privacy - if the smartphone is private and used during a confidential patient meeting. There ought to be extra requirements for hygienic conditions as mobile phones are known to be unhygienic [and this can be a problem in meeting with medical sterile procedures]. Because a suitable smartphone will be expensive, unhygienic and because it will require the nurse to cross the private and professional sphere and the use of a smartphone as a tool should be voluntary. Hence, one cannot ensure that everyone chooses to follow up the `telemedicine´. Alternatively, the government must purchase suitable and work specific smartphones, as it is a question of finances as well as maintenance in the event of an accident [my professional opinions].

Multilateral institutions and government are in a position of having the power to delegate priorities, thus, they have an enormous power of whether `telemedicine´ becomes a national priority. It would still dependent on the competence to guide and treat, as well as the resources to cover financial costs. If they opt out of this investment, it could in practice mean that local health professionals are deprived of an opportunity to develop work-knowledge regarding FGS. Simultaneously, if the field is unexplored, knowledge will not emerge, and consequently it will not be prioritized either. This can be linked to women's lower status in the field, hence women's diseases versus other diseases. However, FGS is s marginal disease, and if there ought to develop a sustainable change around it, it cannot just be about *the treatment* of FGS [as with MDA]. Possibly the status on FGS must increase too, by spreading knowledge about FGS [cause, symptoms, diagnostics and the treatment] before it can be sustainably implemented. This way, the vulnerable people are not seen as the "problem" but rather the *solution*; when they learn and recognize the issue in their own life, they may get motivated to solve the problem on their own initiative thus create an interest and self-driven movement. This in turn may resemble the Health Belief Model. On the contrary, lack of emphasis may cause work-knowledge, habits and routines to freeze [thus patterns might deepen] and become “institutionally captured” which may lead to blindness that in turn may overshadow the patients' well-being.

7.1.2.2 Cultural barriers

Interviewee 4 [female midwife in her thirties, Clinic 2] found it is difficult to examine with a speculum in pregnant women. This might be difficult to understand as an outsider, but there are often a lot of emotion around the lower reproductive tract, which is evident in the empirical findings, as several informants linked *sensitivity* to reproductive health problems. As interviewee 4 herself uttered, health problems in private organs would lead people to under-report because they are ashamed or embarrassed. Furthermore, in a context where women’s virginity is carefully considered. Health professionals might choose to respect by not interfering too much. Unless the health personnel have gained good confidence and trust amongst the family and the patient beforehand – and the gynaecological examination can be conducted with great trust (Expert Informant 11). Here, the power position of the health personnel is challenged by cultural practices in the community. At the same time, the nurse is challenged by the patient’s private sphere, as the “emotional patient” and family have certain expectations to the nurse's supportive role. If the health service provided by the nurse does not meet expectations, the nurse will be accused of having done a bad job and get a bad reputation, which can also be destructive for the clinic as a whole. This is as an example in accordance to Smith's Institutional Ethnography, as the nurse's behaviour (based on written procedures) and decision-making power are threatened by external power factors. It is also an example of how rationalization cannot compare with the actualities, hence rationalities of power.

7.1.3 Schistosomiasis Control Program

As presented by Magaisa et al. (2015), the Department of Health has developed texts [“The Primary Health Care Package for South Africa – A set of norms and standards”] in order to incorporate Schistosomiasis control programs in Primary Health Care, and to assist health planners to bring services up to a national standard. After researching this document, I discovered only *one page* dedicated to Bilharzia on a general level, next to other central public health issues in South Africa [see Appendix 8] (SADoH, 2000). The text works as a good overall standard with relatively simple guidelines to adhere to. Although the text encourages staying away from Schistosomiasis infected water, as well as attracting community's attention with posters and warning signs, in addition to provide health education. However, it says nothing about Female Genital Schistosomiasis, how the disease can degenerate and what consequences it can develop (both individually and on a social level). In other words, when the guidelines are relatively simple, it might not increase interest because they do not appeal to anyone's emotions. During my fieldwork, I got a good impression that my informants conduct health education about Bilharzia [e.g. by avoiding contaminated water] to their patients when needed. However, my impression is that the encouragement was about avoiding swimming specifically, and not water contact in general. I also did not see any posters about Bilharzia [instead, I saw posters concerning TB and HIV]. This constitutes of an example where *texts* might not "speak" to people and thus create limited attention (even when the text is meant to network), as my findings from the field indicated narrow attention to Bilharzia. It is also an example that this is not considered important enough to be given much attention, and thus it is not allowed to govern in a positive way (which constitutes ruling relations) and it prevents health workers from developing knowledge.

According to Stothard et al. (2020) and Magaisa et al. (2015), improved water and sanitation should reduce risk factors for Schistosomiasis transmission. This is also a specified in the UN Sustainability Goals (6th SDGs, 2015) which seems to have worked positively, both when I have talked to my informants and read up on the current water and sanitary status in Kwa-Zulu Natal (Eriksen & Millstein, 2016; SA, 2020b). Another requirement for successful control program where adequate access to drugs against Schistosomiasis (Praziquantel) at local and regional health facilities. According to my empirical findings, it did not seem problematic to maintain enough medication in the clinics which was a requirement in order to succeed the Schistosomiasis control programs, as Interviewee 6 said that the one package of medicine could last up to a year. On the other hand, they have not administered considerably medication because Bilharzia has not been given much attention, hence there has not been a perceived need for medication. This shows me insofar as there is also little focus on Bilharzia in general, as it seems that there are few who are treated all together, despite the implementation of interventions. However, it will be exciting to see how UNAIDS (2019)' new recommendations goes, which is to implemented FGS in already established HIV programs - as HIV and FGS is closely linked.

When it comes to MDA, it does not necessarily require full understanding from the healthcare professionals administrating it, as the point is to "just give out" medication to anyone who may need it. If the healthcare professionals do not fully understand what the medicine is intended for [what the point is], there may lead to misunderstandings or lack of interests. When there are no “real need” to increase professional work knowledge regarding FGS, one would not fully understand, and it can be more difficult to create ownership of the competence as well as increase gender inequality. Hence, development may stagnate. I will refer here to why the Health Belief Model would be a good tool, as the goal is to create personal motivators for health development [read *4.1.1 The theory of the Health Belief Model*]

7.2 Neglection of FGS

I interpret the term "neglect" in that there is an awareness around a current phenomenon, but the phenomenon is forgotten and/or not included in assessments. As UNAIDS (2019) presents, Female Genital Schistosomiasis is still a neglected tropical disease (NTD) although the WHO decided to recognize FGS as a disease to prioritize already in 1997 through “The Gender Task Force of the Tropical Disease Research Programme” (TDR) (Christinet et al., 2016, p. 396). The research centre BRIGHT is an example of how there has been activity to promote focus and reduce the scope of FGS in South Africa since 2009. Besides, even though the WHO decided to redo the terminology from *urinary schistosomiasis* to *urogenital schistosomiasis* in October 2009 (Stothard et al., 2020, p. 410), it does not seem that the understanding of Schistosomiasis has yet changed in practice. Through the data I collected during my fieldwork in South Africa, I found that there are publications on FGS compared to other burdens of diseases, and both the curriculum in the nursing education and the professional nurses whom I interviewed, still recognize Schistosomiasis/Bilharzia exclusively as a `urinary problem´. I accordance to Expert Informant 11, a possible explanation for this might be because, when a child urinates blood it is a cause for concern, and one will contemplate a bladder disease. Another possible explanation might lie in that it is the boys who make the disease visible, as they detect blood in the urine when they urinate standing up, compared to girls while sitting down. However, seen in the light of Institutional Ethnography, I would argue that the discourses around Bilharzia are old, as the first uranological schistosomiasis was first reported in South Africa in the year of 1863 (Magaisa et al., 2015). Hence, the discourses regarding schistosomiasis, “mostly boys” and as a “urinary problem” are have become well established in both society and among health professionals since then. I experienced clear agreement in the discourses around Bilharzia among my informants as it is young boys who like to swim that are associated with Bilharzia, and that they come complaining of blood in their urine. The extra focus on boys I also experienced is based on strong gender discourses, as it emerged from the data collected that it is the boys who are active and bathe while the girls are calmer and more protected in their home. The discourses that shape the roles of boys and girls in society thus indicate that boys are more exposed to infection than girls, while information provided by my informants and the literature and research on Female Genital Schistosomiasis indicate otherwise [e.g. household chores, crossing rivers, rituals involving river water].

The knowledge around FGS are there but it is not included in the texts of which the professional nurses can learn from. The exclusion of FGS in the curriculum leads to `neglection´, but it also deprives local health professionals of their power to provide adequate health care when the knowledge does not reach them. I would therefore argue that FGS is neglected at a structural/organizational level, and hence *not* neglected by the nurses themselves, as they are not given the opportunity to learn [there must be some form of knowledge around the phenomenon in order for it to be called "neglected", and in this case FGS does "not exist" for the health personnel, hence it is not neglected to them]. However, *Syndromic Management* (SM), the diagnostic algorithm used by professional nurses in South Africa in order to diagnose Sexual Transmitted Infections (STIs) are a good example of FGS remaining neglected at an organizational and rhetorical level, as it is not included in the text; this global strategy does not include FGS as a possible reproductive problem in the diagnostic algorithm, in line with other STIs, even though SM is developed by WHO whom are aware of FGS[27].

Via collected data, I have gained a strong impression that there is a need for more research, media coverage, attention, i.e. more texts so that people can learn about the importance of FGS. This way of increasing knowledge will be a strategy that develops from a "top down" perspective, as the texts are "given to the people", but is this approach alone sustainable? The Health Belief Model refers to an opposite development strategy that works from a "bottom up" perspective, although it practically approaches "top-down" like models often do when the

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[27] "Female Genital schistosomiasis: a pocket atlas for clinical health-care professionals" developed by WHO is an example of this well-established awareness on a global level (World Health Organisation, 2015) and are developed in order to make the diagnosis of FGS manageable for local health professionals.

goal is to embrace as well as develop a group of people. HBM's goal is for the people who are exposed to the disease to understand why it is threatening, hence the locals must be emotionally involved in the health problem in order for them to wish for a change. In other words, when the motivation comes from within, the development will also take place more sustainably. Interviewee 15 is a good example of someone who is driven by personal motivation, as when she was diagnosed with FGS herself, decided to promote proposals in order to include FGS in nursing education. Nevertheless, I see Interviewee 15 as a unique woman; she has a position of power by being a nursing teacher, thus she has voice in the education system that is very important in order to highlight female reproductive health.

7.3 Gender inequality and empowerment of women

South Africa is a country characterized by large differences between the two gender roles. Women (especially with black skin colour) from lower social classes have fewer opportunities compared to men, thus women have not been given much attention (UNAIDS, 2019). This is probably also an important background for why FGS is not a priority in research, as this disease affects those of the lowest status. However, these gender differences have emerged through my empirical findings as well. My informants told me that girls have less Bilharzia compared to their boy peers because they swim less due to more protected lives. The UN's sustainability goal 5, "gender equality and empowerment of women" aims to strengthen these girls and women who live under stricter social control with the goal of a more equal world (SDGs, 2015). Accordingly, I would argue that the term "empowerment" should be used cautiously in the field of development, as no one but oneself can mature "self-agency" and empower. The guidance within development ought rather to be about providing sense of space so that self-agency can be strengthened by oneself, so that females can make their own choices and have their own opinions - also in meetings with people in power, such as the health professionals. Anyway, I want to highlight the professional nurses whom I interviewed during my fieldwork. These are women with a long and difficult history by growing up under Apartheid, whom I assume have fought hard to for their current rights and social position today despite of living in a high criminal post-apartheid (Eriksen & Millstein, 2016). Interviewee 14 told me how women recently and historically have been oppressed "times two", by both white people and men, and how not even her son can understand the struggle they have been through. Hence, as this is a relatively new feminist phenomenon in the South

African history of apartheid and [current] post-apartheid, female professional nurses are examples of women who have increased their self-agency and empowered. Still, I wonder if they are understood and perceived equally to male health professionals, as the status and role of women and men seems to be very different in South Africa still [this remains an important reflection, as this opens up to a broad issue that cannot be answered in this current thesis].

7.3.1 Gender and skewed power relations

Moreover, it has traditionally been men who have managed the political agenda, media as well as priorities in research. According to Austveg and Christensen (2010), black women are to be found at the bottom of the social hierarchy, as they do not pose a threat. In other words, it is not dangerous for higher decision-making powers to neglect or await them, and thus they do not acquire power. When black women are affected by tropical diseases and neglected, it might be challenging for black female health professionals as well to bring about change. As Female Genital Schistosomiasis affects most black women, the fight for FGS might be no exception when it comes to low priority in development. Skewed power structures, ruling relations and discourses are formed both due and with an aim to control gender, race [as a social construction] and knowledge systems, in order to prevent people from challenging existing structures. Since the health sector is a hierarchical scheme, such a power structure can become extra clear in the medical field. Moreover hospital systems and healthcare professionals may be at extra risk of being institutionally captured (Austveg & Christensen, 2010; Smith, 2005). In the next section, the term “hierarchy” will be further deliberated.

As a new employee, one will have to learn the language in the workplace, as discourses contribute to form "the occupational frame". Understanding the language in the workplace (how we talk together and with patients) is fundamental to feeling that you belong, do a good job and understand what is happening and make yourself understood in collaboration with others effectively (Smith). Another clear empirical finding was that the nurses talked about girl and boy patients differently. Female nurses said that girls did not have problems reporting problems in their “private parts” to them, compared to the boys who were embarrassed and withheld information. On the other hand, Interviewee 6 [male nurse] said boys had no problem talking about problems in their “private parts”, whilst girls kept such problems a secret. This constitutes a gendered power relationship where the nurse should adapt to the procedure according to which gender the patient is, to ensure a good history taking of the patient. At the same time, this is very individual, and it is about personal suitability regarding building trustful relations to their patients. As some female informants said, girls also underreported because the genitals are taboo, or they do not want to stand out as "the sick person" amongst their peers.

7.4 Professional nurses' position of power

Professional nurses work in a formal system, an organization/institution that is built on several layers of power relations. The directives from above require that nurses follow their duty, whereas a standardized system contains of rules, regulations, guidelines, officially authorized definitions, forms, protocols and directives. Involving different power relations with asymmetry; some call this "a hierarchy", and it is necessary for the health facility to function effectively (Smith, 2005). According to Interviewee 15, nurses contribute to develop policies by sending in statistics in order to map what type of health problems the community struggle with, in addition to analyse the need for health professional at each clinic. This also goes back to the guidelines for health planners, where the aim is to meet the needs of their population and bring the services up to national standards (Magaisa et al., 2015). More accurate, my findings show a democratic solution which creates space for the health professionals to develop and increase knowledge, i.e. they have been given a form of power by reporting statistics to the South African government. It would have been exciting to see if FGS had gained significant status if it became part of the South African statistics. However, based on my observations in the field, confidence was experienced over the fixed framework given the role of a nurse, based on duty, procedures and protocols. On the other hand, there was an uncertainty about practice outside the everyday activities and work-knowledge. In other words, the texts govern, and it increase assurance, but when the texts fail to govern, uncertainty emerges. One may wonder if there is enough room for the nurses to reflect on their own practice as well as the use of judgment in the face of various patient cases. It is difficult to say how much genuine power they have, taken into account all the needs to be covered across the variables in ruling relations. Such a distribution of power requires people to do what they are obliged to do [written in an oath or contract], as well as maintaining own integrity and confidence in their own decision. Power relations provide with ethical dilemmas as part of everyday work life; professional nurses must comply both with the standardized system, but also with the patient's best interests [patients' needs and wishes]. If one "works on the floor" as a nurse, and has no decision-making power, only a duty to perform, then the standardized system is constant and difficult to change/develop. Patients, on the other hand, are dynamic to the highest degree as each patient is an individual with his or her own swinging dynamics. Health professionals must deal with all of this, which in practice provides limited power.

On top of all this, there are requirements for supply and demand on behalf of health personnel. If the health service does not adhere to a good standard that stimulates trust among the community, they will receive a bad reputation and it can affect status at work, reputation, finances and further job opportunities [my interpretation is based on fieldnotes]. In the clinics I visited, the patients came in a continuous queuing system. According to my observation, this puts nurses in an unpredictable position. The length of the queue determines how effective or thorough the professional nurse can be with each patient. My impression is that long queues occasionally can lead to a bad conscience and stress. Furthermore, affect the quality of the health services. Especially when time is short, and the patient group is demanding. In some cases, stress [read about "occupational stress" in *3.2.1 An example of Institutional Ethnography*].

7.4.1 Educating Professional Nurses

Professional nurses in South African have four different specialisations in four years, that is *general nursing, midwifery, community* [public health] and *psychiatry*. Moreover, they manage the health facilities themselves and have the authority to diagnose patients and prescribe medication. In Norway, this would be the doctor's responsibility. Norwegian nursing education lasts for three years to become authorized as a *general nurse*. With my Norwegian gaze, I see South African first four years of nursing education as one that entails much "quantity rather than quality" as they receive less in-depth education and far more responsibility compared to Norwegian nurses. In Norway, we say that the nursing education is only preparatory, and that you truly learn when you first start to work. My impression of the nurses educated in South Africa is that they are very skilled with a much broader and in-depth education than in Norway [more focus on microbiology among other things]. However, I see it as understandable as the areas contain of many people spread over a relatively small health system and low doctor coverage, it is only natural and necessary that nurses are trained to handle a greater responsibility.

Nurses are guided by written procedures and routines that must be adhered to in order for the health facility to comply with continuity and predictability in meetings with patients, colleagues and those with decision-making power (the government and ruling organisations). As Interviewer 15 and “informal informant 2” mention, Problem Based Learning (PBL) is used during the education of nurses at the university. My understanding of this is an important and good way to meet necessary needs where one works/train, it is also a way to keep the curriculum up to date on what appears to be the current need locally. At the same time, such an approach could lead to a reproduction of "work knowledge", in that a new employee will work to fit into already established routines and ways of handling situations. New employees will learn patterns that are typical of the workplace and colleagues and make this a repetitive routine that is recognizable to others around - so that others can learn again and collaborate easily. These routines are often governed by text, because text is constant and is thus easy for several to relate to at the same time. For example, it is absolutely necessary that the health system is recognizable via a set system, so that it will be safe for substitutes or new employees to “jump in” when necessary. Texts can be seen as a glue between human actions because it binds people's actions together in a kind of "intertextuality" (Smith, 2005). On the other hand, this may limit a developing learning curve at the clinic, or the possibility of renewal, in that there is little [time and] space for new and updated knowledge. FGS is an example of this as it is not included in their texts, and therefore does not constitute a change. According to my observations, I am unsure of how much room they have to reflect on their own, even though PBL requires thinking and reflective actors. Nevertheless, I experienced that the nurses were very good at established work-knowledge and less reflective on rarer phenomena. At the same time, I can understand frequent experiences "freezes" and constitutes *a fact*. For example, when it is "normal" for pregnant women to bleed at gynaecological examinations [contact bleeding] as Interviewee 4 claims. In other words, recurring events are accepted and constitute a normality, which makes one forget to think of *cause* and *reason*.

Nurses in training are given space to reflect on their own practice via PBL, even though they themselves must discover the locally governing work-knowledge. At the same time, it is known that the field of medicine is built on a strong hierarchy in order for the system to work properly [roles in different ranks and positions must complement each other and constitute a holistic institution]. Thus, it may be that there is no room for thinking outside the given framework, because it can mess with the system. There is a paradox in the fact that PBL demands that "the state of things" should govern the training, but the training and the given frameworks still governs "the state of things". That said, a hierarchy can also cultivate arrogance among those who have more status than others, and when one sits with a certain amount of power, it can be difficult to accept other people's fresh news - which leads to less development in work-knowledge compared to if arrogance had not been present in the hierarchy.

According to my informants, a clinic with many patients, critical needs and so few resources, one must take responsibility for what "cries the loudest". Then there will be no time to pursue preventive health development. Treating FGS will be to prevent other problems such as STIs or HIV prevalence, but since FGS is invisible to the naked eye, the disease is not prioritized by those who lay the guidelines. I would assume that nurses do not have time nor space to update their knowledge of other things that are not absolutely necessary. Interviewer 15 told me that there are programs to update the knowledge, but that this is not done in practice because it is voluntary. She says that it is downgraded because the topic does not interest them or because there is a lack of time to prioritize it. In any case, when there is no room for prevention, I would argue that in practice it is like "putting out fires" of what is visible to the naked eye, which can slow down the sustainable development of the health system. Yet, nurses have a duty to keep themselves updated on important professional knowledge that is relevant where one works. Interviewer 15 mentions the new strategy to be introduced in 2021, Continuity Professional Development and that it will become mandatory [Read *6.2.1 South African training of professional nurses*].

8 Concluding Remarks

The problem statement in this thesis has been:

"How does local health professionals in South Africa relate to the neglected *Female Genital Schistosomiasis* and why does the work-knowledge seem to be stagnating?"

Through observations and interviews conducted with health professionals in the Ugu district, South Africa, this master's thesis has sought to answer local nurses' relationships to female reproductive problems in Schistosomiasis areas. Inspired by Institutional Ethnography, the role of nurses has been emphasised, as well as what possible reasons to rationalise the gap between biomedical research and nurses' work knowledge. The thesis has also shed light on what FGS does with society and what society does with FGS, and what it has to say for social development.

The overall conclusion on what the reasons are for why there are a gap between the local professional nurse's work-knowledge and the biomedical research has proven to be complex. Several of the reasons, such as insufficient information, skewed power relations, South African history, women's historically low status [within health] and the impact of established systemic texts and discourses are reasons that are in line with the theoretical framework used in this thesis (Austveg & Christensen, 2010; Bruun & Aagaard-Hansen, 2008; Smith, 2005; Sundby, 2019; UNAIDS, 2019). Although these are causes that may characterize similar research elsewhere, this research is slightly different as it has emerged between two separate research fields, namely *(bio)medicine* and *social science*. Therefore, it has been relevant to see how a neglected tropical disease can affect a society, and why it is perceived as challenging to implement knowledge about FGS in the South African governmental health care structures.

I have found a clear gap between the established biomedical research presented chapter `4 Literature Review´ and the locals work knowledge presented chapter `6 Empirical findings´. On the one hand there are experts who have established and developed biomedical researched and literature regarding FGS [the S. haematobium parasites, cause, symptoms, diagnostics and prognosis of the following disease] at an impressive level of detail [far more detailed than what I have chosen to present in this thesis]. On the other hand, FGS seemed to be "non-existent" among the health professionals that I talked to at the local clinics in the Ugu District, South Africa, although Bilharzia/Isichenene is a well-known urinal disease amongst young boys, which also rise from the parasite S. haematobium.

Global guidelines, such as the UN Sustainability Goals, have been considered in this thesis as collective rules [rules of the "global game"] that entail a form of international agreement. Nevertheless, following these rules rises the risk of "pitfalls" one must try to avoid, as the rules help us remember who is weaker, and as a result acquire the weaker people less status because they are less successful compared to strong and rich people [thus, teach us to categorize people]. It boils down to being about social and economic power relations, thus; who and what has more or less status, such as female reproductive health is left with marginalised status and become neglected as a result of several complex causes. Moreover, nurses' room for ruling is governed in many ways by these global guidelines, while at the same time it is observed that there is no room for exploring FGS as a neglected disease - even though the diseases are well-known to the global institutions. One may wonder if they *exclude themselves* because they do not have enough confidence in themselves and their own competence, or if they are not *given* room to develop their knowledge because their role is too preoccupied with everything else that needs to be done. Neglection may occur when greater power structures need to prioritize what "screams the loudest" [such as in the current situation with the Covid-19 pandemic], all in all contributing to skewed power relations.

Women affected by this FGS are the same who often fall between the cracks, those who are forgotten by the majority because their voice is lower and self-agency restricted. Either their voice is overheard by the majority in the political game (included in "democracy"), or they exclude themselves because they have been taught that "my voice is less important in this context, so I keep my head low". Marginalised societies full of smart and talented people, working hard and innovating, caring for themselves and others around, just like in any other rich community. However, they do not have the same privileges, hence individuals from the smaller groups are quickly neglected, especially when they pose a minor threat to society and/or do not affect individuals from the majority on a personal level – hence, when there is a lack of understanding from people who belong to the majority. Accordingly, all groups in society are "socially constructed" by us humans, and our discourses are stronger than we can imagine. Following, the diversity in society is not adequately taken care of [despite many attempts, including the idea of the Rainbow Nation by Mandela and Tutu], which simultaneously depresses self-agency and decision-making power amongst people. Consequently, the health professionals who care for them work under high intersectional pressure.

In light of `ruling relations´, the nurses act as an intermediary between `medical science´ and the local community, as they must educate in addition to treat. In line with the education sector, they have a responsibility when it comes to society's level of knowledge when it comes to health. At the same time, they have a responsibility to prevent morbidity. Based on my empirical data, I find that local health personnel should not be blamed for a low level of knowledge. Rather the overall structures for education of medical personnel need to be scrutinized, as well as the seemingly lack of interest to explore what seems to be an under-researched disease with severe impacts for affected women, women who represent a group already marginalised health wise, thus rural woman. The overall neglection the disease deprives local health professionals' opportunities for knowledge. Especially when South Africa has known about this disease since the 1863 and had FGS committed actors working hard to increase the focus (as from Bright)**.**

8.1 A possible next step

For further research, I could study Schistosomiasis in a mobilization perspective, where migration health is essential. After several months where I have worked on this thesis here in Norway, people have asked me about my master thesis. I have experienced very little knowledge amongst the people I meet regarding Schistosomiasis. Hence, I fear the consequences following the neglection of Schistosomiasis at a global level. I find it important to inform about this disease amongst migrants and backpackers who have exposed themselves to Schistosomiasis infected water in tropical areas also in Norway [at this is where I am stationed]. For further work, it would be interesting to elaborate the combination of the Health Belief Model and Institutional Ethnography.

Measures in order to increase awareness around FGS

With the intention of uniting two fields (social sciences and nursing), it is a special experience to sit on the side-line, knowing about a complexity associated with a disease that people do not understand due to little widespread knowledge. As a nurse, my duty is to continuously evaluate and implement measures when needed, and it is therefore natural to think in those paths now as well. Based on secondary data and people I have talked to during the fieldwork, I will address a few measures regarding FGS and information flow. However, it is important to point out that the following text is not part of the main thesis, but an attachment.

According to my informants, portable water should be provided in the communities to improve water and sanitation, and bridges or steppingstones may be constructed at sites where people need to cross rivers. Furthermore, educational programs should prevent contact with diverse contaminated water and likewise encourage prophylactic treatment, thus include all levels in society. In order to increase the level of knowledge, priorities such as gender rights approach and dynamic gender analysis concerning risk behaviour should be emphasised. Including variables of poverty, skewed power relations/inequality, stigma, discrimination and poor access to education. Simultaneously, MDA campaigns should not leave anyone, but rather make a further attempt to include children both in and out of school. Healthcare and facilities should be accessible, acceptable, remain good quality and tolerance, as well as being free from stigma and discrimination (Galappaththi-Arachchige et al., 2018; Hotez et al., 2019; UNAIDS, 2019).

With the aim of enlightening and increasing understanding and awareness of FGS, UNAIDS (2019) recommends using already established programs related to reproductive health and right (such as HIV/AIDS preventing programs). If the problem is not recognized by public actors, government health personnel nor community, FGS will continue to be a public health and human rights issue. Currently, epidemics such as FGS (and HIV) does reflect social inequality in health. Therefore, one could use a holistic approach to seize the layers of intersectional health, by engaging networks of people and health personnel throughout the community. UNAIDS recommend mobilizing in order to increase the level of knowledge around the neglected disease and reproductive health. Sacolo-Gwebu, Kabuyaya, and Chimbari (2019) recommend teach caregivers (parents and guardians) as they have a crucial role in raising the young population in South Africa. Research show that caregivers predispose preschool children to Schistosomiasis due to a lack of understanding. Consequently, caregivers tend to mislead others in the community and/or engage in risky water-related practice. Therefore, excluding them will result in negative impact on the effectiveness and sustainability. Hence, they should be included in developing and mobilizing the community's knowledge, attitudes and practices (Sacolo-Gwebu et al., 2019, p. 2).

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Appendix 1

NSD's (Norwegian Centre for Research Data) personal data assessment of project: "Nurses perspectives on lower reproductive health problems in a schistosomiasis endemic area"

Our assessment is that the processing of personal data in this project will comply with data protection legislation, so long as it is carried out in accordance with what is documented in the Notification Form and attachments, dated 20.09.2019, as well as in correspondence with NSD. Everything is in place for the processing to begin.

NOTIFY CHANGES
If you intend to make changes to the processing of personal data in this project it may be necessary to notify NSD. This is done by updating the information registered in the Notification Form. On our website we explain which changes must be notified. Wait until you receive an answer from us before you carry out the changes.

TYPE OF DATA AND DURATION
The project will be processing general categories of personal data until 31.12.2020.

LEGAL BASIS
The project will gain consent from data subjects to process their personal data. We find that consent will meet the necessary requirements under art. 4 (11) and 7, in that it will be a freely given, specific, informed and unambiguous statement or action, which will be documented and can be withdrawn. The legal basis for processing personal data is therefore consent given by the data subject, cf. the General Data Protection Regulation art. 6.1 a).

PRINCIPLES RELATING TO PROCESSING PERSONAL DATA
NSD finds that the planned processing of personal data will be in accordance with the

principles under the General Data Protection Regulation regarding:

- \- lawfulness, fairness and transparency (art. 5.1 a), in that data subjects will receive sufficient information about the processing and will give their consent
- \- purpose limitation (art. 5.1 b), in that personal data will be collected for specified, explicit and legitimate purposes, and will not be processed for new, incompatible purposes
- \- data minimisation (art. 5.1 c), in that only personal data which are adequate, relevant and necessary for the purpose of the project will be processed
- \- storage limitation (art. 5.1 e), in that personal data will not be stored for longer than is necessary to fulfil the project's purpose

THE RIGHTS OF DATA SUBJECTS
Data subjects will have the following rights in this project: transparency (art. 12), information

(art. 13), access (art. 15), rectification (art. 16), erasure (art. 17), restriction of processing (art. 18), notification (art. 19), data portability (art. 20). These rights apply so long as the data subject can be identified in the collected data.

NSD finds that the information that will be given to data subjects about the processing of their personal data will meet the legal requirements for form and content, cf. art. 12.1 and art. 13.

We remind you that if a data subject contacts you about their rights, the data controller has a duty to reply within a month.

FOLLOW YOUR INSTITUTION’S GUIDELINES
NSD presupposes that the project will meet the requirements of accuracy (art. 5.1 d), integrity and confidentiality (art. 5.1 f) and security (art. 32) when processing personal data.

As private devices will be used to process personal data, we presuppose that this is in line with the institutions guidelines for use of private devices in processing personal data.

To ensure that these requirements are met you must follow your institution’s internal guidelines and/or consult with your institution (i.e. the institution responsible for the project).

FOLLOW-UP OF THE PROJECT
NSD will follow up the progress of the project underway (every other year) and at the planned end date in order to determine whether the processing of personal data has been concluded/is being carried out in accordance with what is documented.

Good luck with the project!

Contact person at NSD: Jørgen Wincentsen
Data Protection Services for Research: +47 55 58 21 17 (press 1)

Appendix 2

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI
RESEARCH OFFICE
Biomedical Research Ethics Administration
Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

14 October 2019

Prof M Taylor
Discipline of Public Health
School of Nursing and Public Health Medicine
taylor@ukzn.ac.za

Dear Prof Taylor

Protocol: Applying Social Science to understand the contextual factors for the transmission of female genital schistosomiasis. The promotion of preventive measures and improving the current management of the disease at the district, community and national levels in South Africa.
Degree: Non-degree
BREC reference number: BE064/17

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 29 June 2019
Expiration of Ethical Approval: 28 June 2020

I wish to advise you that your application for Recertification received on 08 October 2019 for the above protocol has been **noted and approved** by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

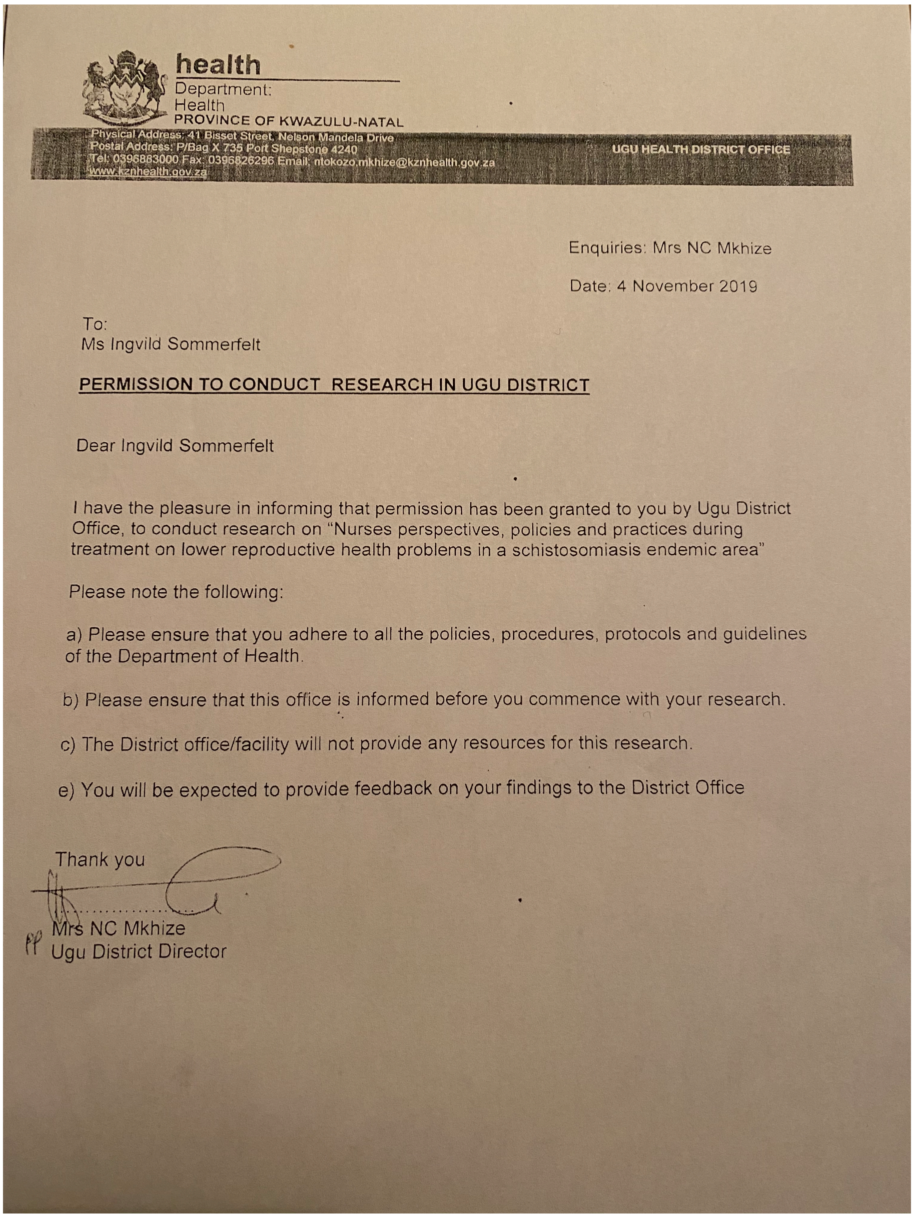
If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

The committee will be notified of the above approval at its next meeting to be held on 12 November 2019.

Yours sincerely

Prof V Rambiritch
Chair: Biomedical Research Ethics Committee

Appendix 3



health
Department:
Health
PROVINCE OF KWAZULU-NATAL
Physical Address: 41 Bisset Street, Nelson Mandela Drive
Postal Address: P/Bag X 735 Port Shepstone 4240
Tel: 0396883000 Fax: 0396826296 Email: ntokozo.mkhize@kznhealth.gov.za
www.kznhealth.gov.za

UGU HEALTH DISTRICT OFFICE

Enquiries: Mrs NC Mkhize

Date: 4 November 2019

To:
Ms Ingvild Sommerfelt

PERMISSION TO CONDUCT RESEARCH IN UGU DISTRICT

Dear Ingvild Sommerfelt

I have the pleasure in informing that permission has been granted to you by Ugu District Office, to conduct research on "Nurses perspectives, policies and practices during treatment on lower reproductive health problems in a schistosomiasis endemic area"

Please note the following:

a) Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health.

b) Please ensure that this office is informed before you commence with your research.

c) The District office/facility will not provide any resources for this research.

e) You will be expected to provide feedback on your findings to the District Office

Thank you

………………
pp Mrs NC Mkhize
Ugu District Director

Appendix 4

Are you interested in taking part in the research project?

"Nurses handling lower reproductive health problems in a schistosomiasis endemic area"?

Information Sheet and Consent to Participate in Research

Date: Greeting:

My name is Ingvild Sommerfelt from the University of Agder, working with Dr Eyrun Kjetland and Myra Taylor from the University of KwaZulu-Natal.

Purpose of the project
This is a research project where the main purpose is to explore nurses' perspectives, policies and practices during treatment for lower reproductive health problems in a schistosomiasis endemic area. Here we give you information about the purpose of the project and what your participation will involve.

Who is responsible for this research project?
The research will be undertaken by Ingvild Sommerfelt, conducting fieldwork as part of a master thesis through the University of Agder, in Norway. This is being done in collaboration with UKZN in Durban, who are working on Female Genital Schistosomiasis with the Bright Research (http://brightresearch.org) (De E. F. Kjetland).

Why I ask you to participate:
I will conduct an ethnographic study of how South African nurses in local clinics handle a so far poorly researched condition, Female Genital Schistosomiasis (FGS), also called *genital bilharzia*. The study is expected to enrol two or three nurses (depending on the size of the clinic) from each of the 6 study sites. It will involve observation and an interview and discussions with the nurses.

What does it mean to participate?
I will be interviewing health professionals in clinics which are located in rural areas with endemic schistosomiasis. The goal is to visit the six clinics, and eventually compare the findings. I will then give back the results to the clinics and will publish an article. This way, the clinics can learn from each other's practice. In the end, this can benefit the patients who come to seek health care at the clinics. I will mainly be interviewing health professionals and observe their practice in health clinics and try to understand how the nurses inform their patients about this disease and its following conditions and observe how nurses practise their assistance to their patients. I will, given consent from each individual, audiotape my interviews and transcribe them. I will carry a recorder throughout the fieldwork for me to focus greatly on the individual(s) and will request permission from each participant to use this. I would also want to observe the nurse's interactions with their patients if this possible. Importantly, this recorder will not be present during participative observations as this is a sensitive field. I would also where possible, hold a focus group discussion in each clinic to listen to nurses' concerns.

The study received permission to work in six local health clinics:

1. Asisi Clinic
2. Dududu Clinic
3. Gamalakhe Clinic
4. Madlala Clinic
5. Geilima Clinic
6. Jiangwini Clinic

It is voluntary to participate

It is a voluntary decision to participate in this project. If you choose to participate, you may withdraw your consent at any time without giving any reason. All information about you will then be anonymized. It will not have any negative consequences for you if you do not want to participate or later choose to withdraw. Although the study will provide no direct benefits to participants, we hope that it will help provide information and improve the care of patients with FGS.

Your privacy - how we store and use your information

We will only use your data for the purposes specified in this information letter. Your name will be replaced with another name. Neither participants nor clinics will be recognizable in any report or article.

What will happen to your personal data at the end of the research project?

At the end of the project, all personal data will be deleted, including any digital recording.
The anonymised transcripts will be kept until the project is completed.

Where can I find out more?

If you have questions about the study, please contact:

- Ingvild Sommerfelt – the researcher
  Email: i_sommerfelt@hotmail.com

- The University of Agder, Norway. Department of global development and planning:

Hanne Haaland - academic supervising the master thesis.
Email: hanne.haaland@uia.no

- NSD - Norwegian Center for Research Data AS
  Email: personvernombudet@nsd.no

- Eyrun Kjetland
  Email: e.f.kjetland@medisin.uio.no

- Myra Taylor
  Email: taylor@ukzn.ac.za

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BEO64/17).
Sincerely,

Ingvild Sommerfelt	Hanne Haaland
Eyrun Kjetland	Myra Taylor

Consent to take part in research

"Nurses handling lower reproductive health problems in a schistosomiasis endemic area"?

I (Name) have been informed about the above study entitled by Ingvild Sommerfelt.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researchers at:

- Ingvild Sommerfelt – the researcher
  Email: i_sommerfelt@hotmail.com

- The University of Agder, Norway. Department of global development and planning:
  Hanne Haaland - academic supervising the master thesis.
  Email: hanne.haaland@uia.no

- NSD - Norwegian Center for Research Data AS
  Email: personvernombudet@nsd.no

- Eyrun Kjetland
  Email: e.f.kjetland@medisin.uio.no

- Myra Taylor
  Email: taylor@ukzn.ac.za

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

I have received and understood information about the project

"Nurses handling lower reproductive health problems in a schistosomiasis endemic area"?

and have been given the opportunity to ask questions. I give consent:

- ☐ to participate in interviews
- ☐ to participate in focus group discussions
- ☐ to be present while the student does her participative observations

I.. voluntarily agree to participate in this research study.

Signature of research participant

--   ---------------------

Consent to use a audio-recorder

- ☐ I agree that a recorder can be used for the study interviews and focus group discussions

______________________________   _________________

Signature of participant   Date

Appendix 5

Interview guide for nurses

Today's date: |_|_|2019| (|DD|MM|YYYY|)

1. In what Clinic do you work at?
2. Where did you train to become a nurse?
3. What position do you have at work?
4. How long have you worked here?
5. Do you have any previous work experience? From where, how long?

6. What is your understanding of lower reproductive health problems and Bilharzia?
   - Is it a disease which is frequently discussed amongst nurses in the clinic?
   - How have you learned about the disease?
   - Have you seen many examples of it? How frequent is it?
   - How do you talk about it with other nurses?
   - How do you talk to patients about it?
7. What kind of information on lower reproductive health problems and bilharzia is important to tell?
   - Do you teach your patients about lower reproductive health problems and bilharzia?
   - What do you focus on if you teach?
   - Is there any information which is not so important to tell? Why? Why not?
   - How do your patients react when you give them treatment information?
   - Do they return to talk to you, what is the follow up procedures?
8. What do you think your community feels about lower reproductive health problems and Bilharzia?
   - Is lower reproductive health problems much talked about in the community? Where, when?
   - Some people might not want to receive treatment for Bilharzia. Why do you think they don't want it?
   - How common are traditional medicines in the treatment of lower reproductive health problems and Bilharzia?
   - Can traditional medicine contribute to the treatment of lower reproductive health problems?
9. Do you find that there are any obstacles to handle while providing information about lower reproductive health problems and bilharzia to patients? What kind of obstacles?
   - Do you need more information on how to handle the disease than what you have already?
   - Why do you think there would there be obstacles as all?
10. How do you do a gynaecological examination of a patient?
    - Are there any practical issues standing in your way, while examining and informing your patients about lower reproductive health problems and bilharzia?
11. Comments or questions?

Appendix 6

Focus group discussion for nurses

Today's date: |_|_|2019| (|DD|MM|YYYY|)
Time:
Length of interview:
Location:
How many are present:

1. What are lower reproductive health problems?
2. What is Bilharzia?
    - What does it do?
    - Who gets Bilharzia?
    - How many thinks that Bilharzia is sexually transmitted?
    - What are common ideas of how Bilharzia is transmitted?
    - Is bilharzia considered to be a difficult disease? How/why?
    - How common are traditional medicines in the treatment of Bilharzia? Which medicines are used?
3. What kind of information on lower reproductive health problems and Bilharzia is important to tell?
    - Do you teach/tell your patients about lower reproductive health problems and Bilharzia?
    - What do you focus on if you teach/tell?
    - Is any information less important than other? Why, why not?
4. How widespread is the treatment?
    - How does your patients react when you give them treatment information?
    - Would you recommend other treatments than tablets?
        - Some people might not want to take the tablets, why do you think that is?
5. What do you think people in your community feels about lower reproductive health problems and Bilharzia?
    - Some people might not want to receive treatment for Bilharzia. Why do you think they don't want it?
    - How common are traditional medicines in the treatment of lower reproductive health problems and Bilharzia?
    - To what extent can traditional medicine help in treating lower reproductive health problems and Bilharzia?
6. Do you find that there are any obstacles in handling information about lower reproductive health problems and bilharzia to patients? Why/why not?
    - Why do you think there would there be obstacles as all?
7. How do you do a gynaecological examination of a patient?
    - Are there any practical issues standing in your way, while examining and informing your patients about lower reproductive health problems and bilharzia?
8. Comments or questions?

Appendix 7

This is the email I have sent to come in contact with meet people who can guide me in the right direction for this research. My aim has been to build a good foundation for my research, before I enter the field. The letter has been adjusted to every person it has been sent to.

Dear XX

My name is Ingvild Sommerfelt. I am master student in Development Management at University of Agder (UoA), Norway. I am currently working with Dr Eyrun Kjetland, Silindile Gagai and Myra Taylor from the University of KwaZulu-Natal, who are working on Female Genital Schistosomiasis (FGS) with the Bright Research.

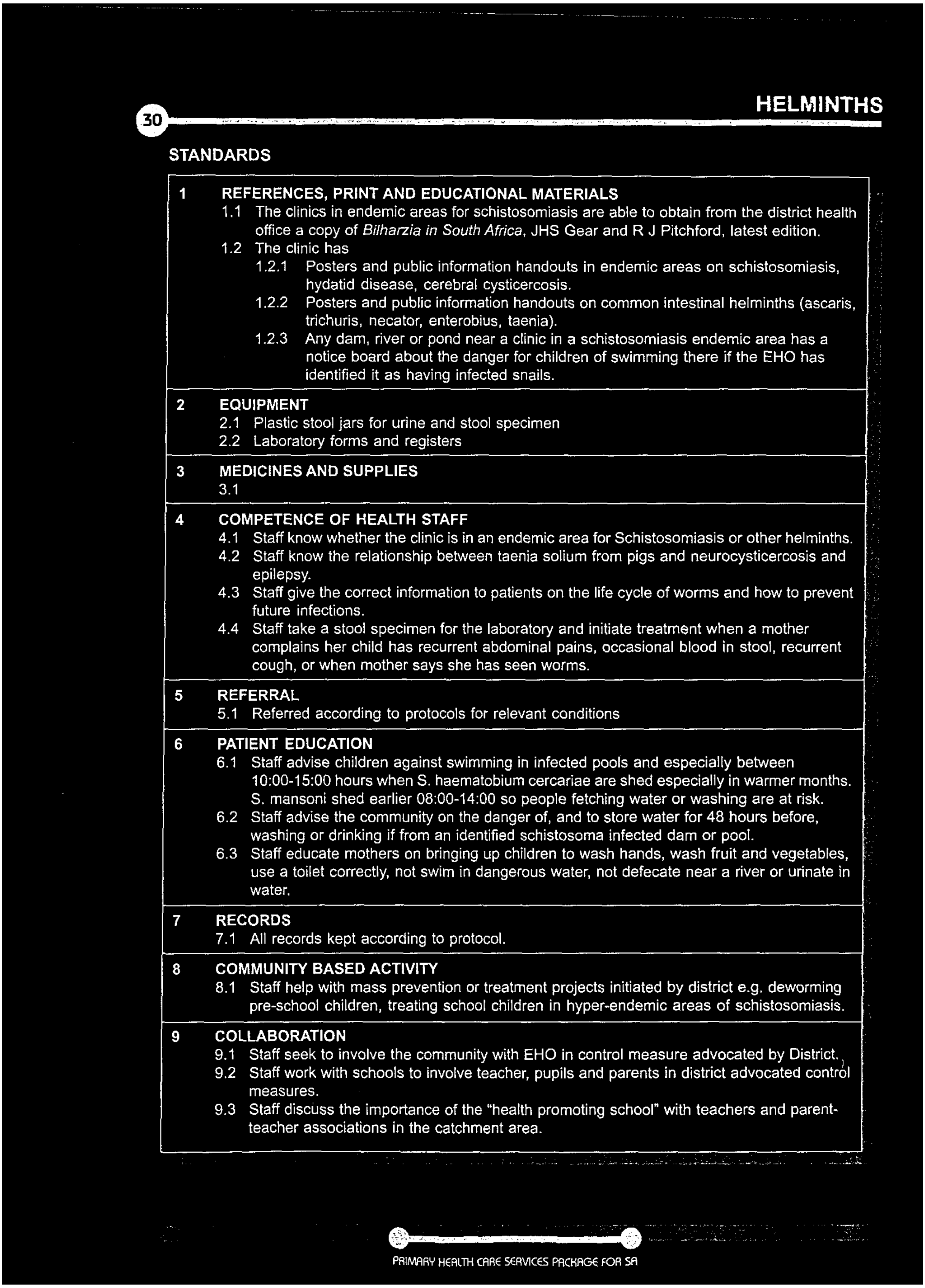
I am conducting fieldwork as a research method in social science for my master at UoA. This is a research project where the main purpose is to explore health professionals' perspectives, policies and practices during treatment for lower reproductive health problems in a schistosomiasis endemic area. In this case, I would love to talk to you in order to gain a better understanding of the health professions education in South Africa, and their understanding of FGS in South Africa.

Silindile and I will be happy to meet you, whenever you have time in your schedule.

Wish you a great week,
Kind regards,

Ingvild Sommerfelt
Master student in Development Management from the University of Agder, Norway.

Appendix 8



HELMINTHS

STANDARDS

1 **REFERENCES, PRINT AND EDUCATIONAL MATERIALS**
- 1.1 The clinics in endemic areas for schistosomiasis are able to obtain from the district health office a copy of *Bilharzia in South Africa*, JHS Gear and R J Pitchford, latest edition.
- 1.2 The clinic has
  - 1.2.1 Posters and public information handouts in endemic areas on schistosomiasis, hydatid disease, cerebral cysticercosis.
  - 1.2.2 Posters and public information handouts on common intestinal helminths (ascaris, trichuris, necator, enterobius, taenia).
  - 1.2.3 Any dam, river or pond near a clinic in a schistosomiasis endemic area has a notice board about the danger for children of swimming there if the EHO has identified it as having infected snails.

2 **EQUIPMENT**
- 2.1 Plastic stool jars for urine and stool specimen
- 2.2 Laboratory forms and registers

3 **MEDICINES AND SUPPLIES**
- 3.1

4 **COMPETENCE OF HEALTH STAFF**
- 4.1 Staff know whether the clinic is in an endemic area for Schistosomiasis or other helminths.
- 4.2 Staff know the relationship between taenia solium from pigs and neurocysticercosis and epilepsy.
- 4.3 Staff give the correct information to patients on the life cycle of worms and how to prevent future infections.
- 4.4 Staff take a stool specimen for the laboratory and initiate treatment when a mother complains her child has recurrent abdominal pains, occasional blood in stool, recurrent cough, or when mother says she has seen worms.

5 **REFERRAL**
- 5.1 Referred according to protocols for relevant conditions

6 **PATIENT EDUCATION**
- 6.1 Staff advise children against swimming in infected pools and especially between 10:00-15:00 hours when S. haematobium cercariae are shed especially in warmer months. S. mansoni shed earlier 08:00-14:00 so people fetching water or washing are at risk.
- 6.2 Staff advise the community on the danger of, and to store water for 48 hours before, washing or drinking if from an identified schistosoma infected dam or pool.
- 6.3 Staff educate mothers on bringing up children to wash hands, wash fruit and vegetables, use a toilet correctly, not swim in dangerous water, not defecate near a river or urinate in water.

7 **RECORDS**
- 7.1 All records kept according to protocol.

8 **COMMUNITY BASED ACTIVITY**
- 8.1 Staff help with mass prevention or treatment projects initiated by district e.g. deworming pre-school children, treating school children in hyper-endemic areas of schistosomiasis.

9 **COLLABORATION**
- 9.1 Staff seek to involve the community with EHO in control measure advocated by District.
- 9.2 Staff work with schools to involve teacher, pupils and parents in district advocated control measures.
- 9.3 Staff discuss the importance of the "health promoting school" with teachers and parent-teacher associations in the catchment area.