Cervical Screening in Swaziland: An Ethnographic Case Study

by

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Abstract

This thesis examines and contextualizes women's fears about cervical screening in Swaziland. I begin with a critique of the historical and epidemiological trend to blame screening avoidance among African women on cultural fears. Then, drawing on data from semi-structured interviews and participant observation, I find that fear of cervical screening is a product of the clinical, social and political contexts of screening, thus challenging assumptions about culture-based fear. The clinical encounter between women and nurses is laborious; complicated by fears of gossip, the pejorative judgment of women's bodies and hospital politics. The complexities of this encounter collide with politically produced realities of cancer treatment scarcity, therapeutic failure and HIV's dominance of local clinical space to further create and sustain fear. Ultimately, women's fears of cervical screening are logical, and must be understood relative to the complex backdrop of clinical sociality, politics and scarcity that situates cervical cancer in Swaziland.

Key words: cervical screening; fear; decision-making; women's health; culture; Swaziland

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List of Terms

Human Papilloma Virus (HPV)	HPV is the most common viral infection of the reproductive tract (WHO 2015). Persistent HPV infection has been closely linked to the development of invasive cervical cancer (Divine and Huh 2014), though most HPV infections are harmless and clear on their own. Two types of HPV (16 and 18) cause about 70% of cervical cancers and precancerous lesions (WHO 2015).
Cervical cancer	Cervical cancer is by far the most common HPV-related disease (WHO 2015). It is caused by persistent infection with one or more of the high-risk HPV types. It is one of the very few cancers with a pre-cancer stage lasting many years, thus providing ample opportunity for detection and treatment (WHO 2014). Treatment of cervical cancer is based on the stage of the disease, and may include surgery, radiation therapy, chemotherapy or a combination of these modalities (Leaver and Labonte 2010).
Pap smear screening	Pap smear screening is a cytology-based form of screening for cervical pre-cancer. It involves taking a sample of cells from the cervix, which are then sent to a laboratory and are examined under a microscope to detect any abnormalities (WHO 2014).
Visual inspection with acetic acid (VIA)	VIA is a method of cervical screening that involves soaking the cervix with a 3-5% solution of vinegar and using a bright light to detect lesions. Its sensitivity is comparable to Pap smear screening, but it is lower in specificity (Carpenter and Casper 2009).

Prologue

Nosipho[1] *sits nervously outside the breast and cervical cancer clinic at Ndate Government Hospital (NGH). In her hand, she holds a white and green envelope that I have seen so often: it contains biopsy analysis results from a private fee-paying laboratory. When I ask how long she has been waiting at the clinic, she answers with frustration: "I have been here since 7am, waiting for the doctor. And I am still waiting. I just want them to read the lab results for me. The nurse says she cannot do it; the doctor has to do it. Now who knows when this doctor will show up?"*

I nod in understanding. After a few minutes of silence, I gently ask what first brought her to the hospital. She tells me that she had been experiencing pelvic pain and bleeding for some months. The bleeding surprised her because she had stopped having her menstrual periods well over two years ago. She had ignored it at first, assuming it would go away. But it didn't, forcing her to eventually come to the hospital.

When Nosipho came to the hospital and described her symptoms, the nurse told her they needed to do a test for cervical cancer. "I was afraid. The nurse told me there were possible signs of cancer after the test, but they needed to do another test to be sure. She said this one must be done at another lab, they are not able to do it here. So I had to look for money to go to there," Nosipho tells me. "I fear this cancer, you know, my neighbor died from it," she continues.

One of Nosipho's children was able to give her transport money, and she took the three-hour bus journey to the private laboratory. They told her to come back after two weeks to get the biopsy results. "I thought when I went back [to the lab] after the two weeks they would tell me the results, you know. But they just gave me this and told me to bring it back here to the hospital," Nosipho continues as she shows me the envelope. Then, she hands the envelope to me, "Can you read the results for me? Can you tell me? Is it really cancer?"

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[1] All names are pseudonyms

CHAPTER 1: Introduction

1.1 Researching Cervical Screening in Swaziland

When a woman enters the waiting room of the Ndate Government Hospital (NGH) in Swaziland, she finds herself staring at a number of health education posters, plastered all over the walls. One of the more prominent posters begins with the heading, “Did you know?” It then proceeds to ask questions that are meant to scare, inspire, or maybe do a little bit of both: “Did you know that you can feel perfectly healthy, but have cervical cancer? Did you know that any woman can get cervical cancer? Did you know that cervical cancer is now also found in women between the ages of 20 and 30? Did you know that early initiation of sexual activity and having multiple sexual partners puts you at greater risk? Did you know that yearly cervical screening can save your life?” Below these questions, the poster shows pictures of what a healthy cervix looks like, contrasted with one where cervical cancer is developing. It concludes with a seemingly simple message: “Early detection is key! Visit your nearest clinic!” Ultimately, the poster presents cervical screening as the logical and most sensible choice for every woman who cares about her reproductive health.

However, the decision to attend cervical screening is not that simple. I first became interested in cervical screening in Swaziland when I came across an online blog article about the launch of the first rural cervical screening clinic in the country (Dlamini 2013). A partnership between the government of Swaziland and an international NGO, the clinic was heralded as one that would contribute to the fight against cervical cancer in Swaziland. The article further encouraged women to make use of the services, and present themselves for screening. As a woman who had grown up in Swaziland and lived there for over eleven years, I was curious to know how such new cervical screening programs fit into the already existing health infrastructure, and how they were being negotiated, received and responded to. Specifically, I was interested in women’s decision making about cervical screening use or avoidance.

Contemporary global health programming has largely obscured the African face of cancer. The popular image of African health often highlights infectious diseases, primarily HIV/AIDS, malaria, tuberculosis and, more recently, Ebola. In part, the relative invisibility of African cancer is due to historically racialized constructions of cancer, which interpreted it as a disease of civilization that was virtually nonexistent among ‘primitive’ blacks and Africans (Livingston 2012; Hoberman 2012; Wailoo 2011). While cancer still tells a complex racial narrative (Wailoo 2011), the racialized portrait of a ‘primitive’ cancer-free Africa no longer holds. In her poignant ethnography about the management of pain in Botswana’s primary cancer referral ward, anthropologist Julie Livingston paints a rare picture of Africa as a “carcinogenic time and place” (Livingston 2012:51). Other scholars have engaged ethnographic and qualitative studies of cancer in African contexts (Harris, Shao and Sugarman 2003; Mulemi 2008; Mulemi 2010; White et al. 2012). Cancer is indeed a “critical face” of African health after antiretrovirals (Livingston 2012:7). I am interested in this ‘critical face’ as it manifests in Swaziland.

There is very little current scholarship on cervical cancer in Swaziland. A recent study indicates that cervical cancer is the most common cancer among Swazi women, and its incidence continues to rise (Okonda, Wright and Michelow 2009). However, until recently, cervical cancer has largely been neglected within Swazi public health. This relative neglect is more apparent when available screening and treatment options for cervical cancer are compared with those available for diseases such as tuberculosis and HIV/AIDS. In particular, HIV/AIDS dominates the healthcare scene in Swaziland, monopolizing scarce public health resources (Okonda, Wright and Michelow 2009). This takes resources away from other health interventions such as cervical screening.

Cervical screening services are available free of charge at most public hospitals and clinics across the country, where nurses serve as primary providers of these services. Yet, cervical screening use remains suboptimal. Further, treatment options for women diagnosed with cervical cancer are hard to access. While hysterectomies are routinely performed at select public hospitals in the country, women often have to travel to neighboring South Africa for chemotherapy and/or radiation therapy. There is a fund available to provide financial assistance for women needing to travel to South Africa for such treatment. However, the process to obtain funding is long and often backlogged. This raises significant questions explored in this thesis:

1. To what extent do clinical configurations around screening and treatment contribute to fear of cervical cancer and screening in Swaziland?
2. How does nursing practice influence women's choice about cervical screening use?

When I initially started thinking about this thesis research, my objective was to map and understand resistance to cervical screening in Swaziland. Thus, I turned to international social science scholarship, which offers useful insights on possible pathways of resistance. Foucault developed the concept of "technologies of the self," to describe how people come to see themselves as subjects (Foucault 1988, 16-49), with the possibility of resistance. Armstrong builds on Foucault's work on "technologies of the self" to argue that women do not necessarily adopt the subject positions created for them by the official discourse on cervical screening. Rather, they produce alternative discourses, as a means of resistance to the official discourse (Armstrong 2007). Resistance to a medical intervention or technology can be manifested in subtle and nuanced ways (Armstrong and Murphy 2012). For example, people can accept a medical intervention while still resisting the framing of the problem or issue (Potts et al. 2004). Further, constructions of risk in public health discourse can influence decisions to accept or reject an intervention, as shown in the case of prenatal testing use among American women (Markens, Browner, and Press 1999).

Specific to cervical screening, international feminist scholarship often contextualizes resistance relative to the social construction of screening, as well as cultural attitudes about women's bodies. The Pap smear was initially a diagnostic tool that was manipulated into the screening clinic (Kaufert 2000). Despite its limitations, it was socially constructed into the right tool for the job, through a history of "compromise and making do" (Casper and Clarke 1998, 255-290). It often represented the power that doctors had over women's bodies (Löwy 2011). American feminist scholars have argued that women often struggle with the vulnerability, invasion and discomfort inherent in the public exposure of Pap smear screening (Armstrong, James, and Dixon-Woods 2012; Bush 2000; McKie 1995; Reagan 1997; Kapsalis 1997). Discomfort with screening is often set in the context of discourses and practices that tend to marginalize female genitalia (Labuski 2013), as well as cultural attitudes about women and their bodies that filter into the hospital space (Kapsalis 1997).

Beyond the discomfort of exposure, the Pap test also filters into women's lived experiences of self. Pap smear screening can alter a woman's sense of body and self (Löwy 2010). This is because an abnormal Pap smear represents embodied or corporeal risk: it is simultaneously a current illness and a signifier of possible future disease (Kavanagh and Broom 1998). An abnormal pap smear may thus create disorder for a woman (Forss et al. 2004), throwing her into a state of uncertainty and ambiguity (Howson 2001).

With these feminist and anthropological critiques in mind, I initially set out to understand and map narratives of resistance to Pap smear screening in Swaziland. However, rather than active resistance to cervical screening, what I encountered in interviews and participant observation was fear: a very practical and logical fear of cervical cancer and screening. Women were not necessarily actively resisting public health framings of cervical cancer and risk, nor were they resistant to screening technology. Rather, they talked a lot about the clinical aspects of cervical cancer – everything from the behavior of nurses to treatment scarcity – as triggers of fear.

Previous scholarship has considered different aspects of fear, though not always in the clinical context. Barker argues that fear can be both social and relational, as the initial stimulus for a feeling of fear may come from one's involvement in a social field, and the expression of fear often involves others. Discourse – which makes it possible to name certain forms of otherness as objects of one's fear – is one of the social means though which people seek to address fear (Barker 2009). Wilce's work on madness and psychiatry in Bangladesh illustrates how fear can arise in situations that raise unanswered questions and signify a loss of control (Wilce 2004). In a recent critique, Humphrey argues that fear does not always need to be paralyzing or dispiriting. Rather, fear can be positively valued, calling up new relations, entitlements and an impulse to action (Humphrey 2013).

For the purposes of this thesis, I use the term fear as women used it in everyday language – to describe feelings of fear, apprehension and in some cases, anxiety. Fear is often distinguished from other negative affects such as anger, sadness, contempt (Watson 1992) and anxiety or worry (Keogh and Reidy 2000). When I interviewed women about cervical screening, they most often used the SiSwati word "*kusaba,*" which literally translates into fear. There are a few instances where women used words that could be more accurately translated into anxiety. However, even in those cases, women often came back to the word "*kusaba*," which thus permeated many of my conversations. Further, panic attacks, post-traumatic stress disorder and anxiety can be considered as "fear-related ailments," (Barker 2009: 269). As such, rather than parse out fear from anxiety in interview data, I chose to use the general term fear throughout this thesis to describe women's feelings of apprehension, fear and anxiety.

I conceptualize fear of cervical screening as a product of clinical, social and political contexts, and examine how it impacts women's decisions and actions. Women manage fear by either avoiding cervical screening, or drawing from social networks to navigate less fearful pathways to screening. Yet, even less fearful pathways to screening are confronted with politically produced realities of cancer treatment scarcity and expense. Thus, I ultimately argue that women's fears are logical, to be understood relative to entanglements of clinical sociality, politics and scarcity, which I will discuss in detail in chapters two through four.

My argument is a critique of the tendency within global public health to make assumptions about fear in the cultural 'other,' and to judge some populations more harshly than others. In the field of women's health in particular, women in resource-poor settings are often defined differently – and more pejoratively – than women in the global north (Carpenter and Casper 2009). Within the epidemiological literature on cervical cancer in Africa, cultural and traditional beliefs are often cited as reasons why women avoid cervical screening (Hoque et al. 2014; Kivuti-Bitok et al. 2013). As such, African women are judged more pejoratively than women in the global north because of their cultural 'otherness.' Yet, for the women interviewed in this study, fear relative to cervical screening is nuanced, multi-faceted and not reducible to culture alone.

Thus, I intend to examine the local complexity of fear and of women's experiences of cervical screening. This contributes to a body of work inspired by Lock and Kaufert's conceptualization of local biologies. They use this construct to show how culture and biology are in a continual feedback relationship where both are subject to variation, thus arguing against assuming or predicting a universality of bodily experience (Lock and Kaufert 2001). My thesis argues against assuming a universal experience of culture-based fear relative to cervical screening. In the sections that follow in this introductory chapter, I discuss the sexualization and culturalization of cervical cancer. I also provide a brief background to the healthcare scene in Swaziland. I then follow with a description of my methodology, and conclude with a brief outline of my thesis, through chapters two to five.

1.2 Cervical Cancer, Race and Culture

Cervical cancer in Swaziland occurs in a mutually constitutive conflation of race, culture and disease. The spaces within which global health acts are socially constructed (Brada 2011). Within these socially negotiated spaces exist generic subjects, who are often made the targets of global public health interventions (Brada 2011; Pigg 1992). In the same way that it constructs spaces and subjects, global public health can also make up diseases. This triple construction – of space, subject and disease – situates cervical cancer in Swaziland. It is informed, in part, by the collision of assumptions about fear with colonial constructs of Africa, the African body, and the African woman.

Informed by long standing stereotypes of the African body, the epidemiological narrative is rewriting cervical cancer in Africa as a sexually transmitted disease (Livingston 2012). Even the poster I saw in the waiting room at NGH is suggestive of this sexualization when it asks, “Did you know that early initiation of sexual activity and having multiple sexual partners puts you at greater risk for cervical cancer?” Devoid of contextual explanation, this poster simply presents ‘risky’ sexual behavior as a potential cause of cervical cancer. This sexualization ignores any mediating co-factors in the progression from HPV infection to cervical cancer. It also obscures the fact that many women infected with HPV never develop invasive cervical cancer. Sexually transmitted cervical cancer is thus a medical half-truth. It is made to “fit” the African scene (Livingston 2012) because of the enduring colonial caricature of the African body. Colonial constructions of the African body depicted it as one possessed by base, uninhibited sexual passions (Jochelson 2001; Vaughan 1991). It was a body defined by disease and degeneration (Comaroff 1993), and inherently contaminated.

This construction of the African body mirrored the construction of the African continent as a diseased space. Colonialism and contemporary global health alike have made up Africa as the *polluted genitalia* of the world. The continent has long been described as a "hothouse of fever and affliction" (Comaroff 1993:306). Contemporary media representations of Africa still portray it as the feminized, diseased 'dark' continent (Brijnath 2007). Such portraits of Africa focus almost exclusively on sexually transmitted diseases. It was sexual contagion that defined Africa in the era of colonial biomedicine (Vaughan 1991). It is sexual contagion that still underwrites the epidemiological narrative of African public health (Livingston 2012).

In contemporary Swaziland, the body is a convergence of the pathological identities imposed upon Africa and Swaziland. Anthropologist Hilda Kuper has argued that in Swaziland, a person is a "meeting point of identities – the identity of siblings, the identity of lineage, the identity of the age group" (Kuper 1986 [1963]: 59). Relative to cervical cancer, this convergence of identities brings together pre-existing constructs of Africa with contemporary constructs of Swaziland. For Swaziland, the country with the world's highest antenatal HIV prevalence rate (Root 2010), the label of women's sexual contagion is particularly persistent. Swaziland is defined by its status as Africa's last absolute monarchy, and as the place where the world's worst HIV/AIDS epidemic resides (Root 2014). Classifications and labels can "make up" people (Hacking 2006, 23-26). The interpretation of Swaziland as an AIDS-ridden space thus facilitates the making up of a sexually contaminated body.

In such a context, the narrative of cervical cancer can very easily be sexualized, creating a negative feedback loop. In a broad sense, the "making up" of sexually transmitted cervical cancer echoes the "making up" of Africa as a sexually diseased continent, and the making up of the "African." The sexualized interpretation of cervical cancer, in turn, only serves to strengthen the existing popular image of an Africa and Africans ridden with sexual contagion. Thus, the disease, space and subject are mutually constitutive: they make each other up. It is a racialized negative feedback loop. This loop has potent implications in Swaziland, *the* ultimate AIDS-ridden country.

Further, this racialized feedback loop continues to be manifested through the implication of culture. In a world obsessed with political correctness, culture has become a covert euphemism for race (Briggs and Mantini-Briggs 2003; Bridges 2011; Saethre and Stadler 2009; Briggs 2005). Unsurprisingly, “African” culture has been constructed as a pathological influence on health (Saethre and Stadler 2009). It has been exploited, both by medical professionals and public health researchers, in their attempts to explain the rapid spread of HIV/AIDS in Africa (Saethre and Stadler 2009; Fassin 2007).

Interpretations of Swazi culture argue that it not only explains HIV/AIDS, but also enables it. For example, a joint report from the UN and the Swazi government stated categorically that cultural practices among the Swazis were “encouraging” HIV/AIDS (IRIN April 2009). Especially in the early days of the epidemic, “ingrained traditions and customs” were seen as a great challenge to HIV/AIDS prevention efforts (Daly 2001:24). It has been argued that in Swaziland, HIV risk is the product of social, cultural, economic and interpersonal forces (Buseh, Glass, and McElmurry 2002). More recently, Sibbald maintains that there is still an issue of cultural beliefs and myths surrounding HIV/AIDS in Swaziland (Sibbald 2013). While these descriptions of culture-blame have happened in the context of HIV/AIDS and not cervical cancer, they do demonstrate the pathological construction of Swazi culture. Further, Hickel is critical of the behavior-change paradigm of Swazi public health, which has constructed pathological sexual behavior as the root cause of the HIV/AIDS epidemic. This over-emphasis on sexuality as root cause ignores and obliterates the larger socio-political and economic forces that may constrain people’s choices (Hickel 2012).

Throughout this thesis, I challenge the mutually constitutive conflation of race, culture and disease relative to cervical cancer in Swaziland. I do this by focusing my research on understanding the clinical context as an influence on women’s fears and choices about cervical screening use, rather than assuming fear is culture-based. This uncovers a complex web of clinical, political and economic factors that constrain women’s choices.

1.3 Background about Healthcare in Swaziland

The Ministry of Health and Social Welfare (MOHSW), provides executive and administrative management for the public health system across Swaziland. The system is decentralized through four regional health offices, which implement national health policies and plans (AHWO 2009). Most public hospitals are highly subsidized, and most patients pay only minimal user fees per visit. Private clinics across the country charge higher fees, and mostly cater for those who can afford to pay.

The healthcare scene in Swaziland is fraught with contradictions created in part by an awkward international presence. Swaziland has the highest antenatal prevalence rate of HIV in the world. This fact alone has attracted a large volume of international attention and funds. Burgess writes that this has raised questions about the influence of global partners on national government planning relative to HIV/AIDS. Further, local communities have not been engaged in the process of program planning, a failure which has led to services at “odds with community needs” (Burgess 2014, 467-480). Hence the painstaking paradox: an international apparatus attempting to resolve a “local” problem, yet often operating “at odds with community needs.” Admittedly, this critique does not imply that all international donor programming in Swaziland conflicts with local community needs, but it does offer an important insight into prevailing tensions.

In addition to the dichotomy between community needs and international donor programming, there is a tension between “traditional” and “modern” systems of healing in Swaziland (Green and Makhubu 1984). The terms “traditional” and “modern” are in themselves problematic, because they virtually assume a clear distinction between two opposing systems of healing. The situation in Swaziland is, however, much more complex. Among “traditional” healers, there are differences both in terms of practice and in attitude towards Western medicine (Knox 2010). Further, what has typically been labeled as “traditional” medicine in Swaziland has been transformed by exposure to the global system, as well as changing local perceptions and needs (Gort 1989). This makes the work of characterizing “traditional” medicine in Swaziland a difficult one.

More importantly, Swazi “traditional” medicine is not perceived as necessarily problematic, neither is Western medicine always accepted on blind faith. This creates a duality negotiated by individual healthcare providers and women alike. Local practitioners of Western medicine maintain mixed attitudes towards “traditional” medicine. For example, Swazi nurses’ attitudes towards collaboration between indigenous and cosmopolitan health care systems have been mixed, with some nurses favoring collaboration while others are ambivalent (Upvall 1992). This means that while some nurses have been in favor of traditional healers working alongside practitioners of Western medicine, others have not. Further, some nurses are aware of specific indigenous healing practices, and have themselves visited traditional healers (Upvall 1994).

Similarly, both traditional and modern systems of healing remain a salient presence in Swazi women's health seeking behavior. Twala et al argue that in some rural parts of Swaziland, women hold a dual health belief system, incorporating aspects of both traditional and modern medicine. They give traditional medicine to their babies and perform specific rituals post-partum. At the same time, they use self-prescribed pharmacy medicines and rely on both traditional and modern contraceptives (Twala, Holroyd, and Jones 2012). Women thus move easily between the two systems of healing, without necessarily considering one wrong and the other right. This duality makes healthcare in Swaziland a space ridden by tensions and contradictions, not only between "traditional" and "modern," healthcare providers, but for individual women as well.

Further, women's healthcare in Swaziland is precariously positioned in a society that has taken decisive measures to control female sexuality, in a bid to curb the HIV/AIDS epidemic. Prominent on this list of measures is a ban on sex with young women, which was imposed by His Majesty King Mswati III in 2002. The ban was a nostalgic attempt to resurrect a tradition of virginity that was perceived as lost (Leclerc-Madlala 2003). On the one hand, this ban can be seen as positively protective of young women. On the other hand, a discourse that describes the tradition of female virginity as "lost" inherently blames women for the crisis at hand. It assumes that Swazi women are no longer as virtuous as they used to be, without giving due consideration to the totality of factors that have led to the "loss" of virginity as a value. It puts Swazi female sexuality under public scrutiny.

Cervical screening thus enters a complex set of discourses and subject positions in Swaziland. It interacts with a history of HIV/AIDS, the public scrutiny of female sexuality and ongoing tensions between "traditional" and "modern" medicine. Further, cervical screening itself adds another layer to the public scrutiny of female sexuality in

Swaziland. This scrutiny happens in the cervical screening clinic, where women are examined by doctors, but more often by nurses. It also happens in the media, and in publications about cervical cancer and sexuality. It is in this context that Swazi women negotiate and experience cervical screening. My goal in this thesis is to understand and situate their experiences within this local complexity.

1.4 Methodology

Over the course of three months of fieldwork, I conducted participant observation, and semi-structured interviews with women and with health workers. I chose to do ethnography because it would allow me to "sit," without necessarily assuming intervention as a moral imperative (Pigg 2013). Ethnographic sitting involves active listening, at the site of women's lived experiences and in the method of preventive public health itself. Sitting is a method of "slow research." Adams et al define slow research as research which is opposed to the "new normal" in global health, and which recognizes that "global mandates can impede local effectiveness (Adams, Burke, and Whitmarsh 2014, 179-197).

As a researcher investigating cervical screening in Swaziland, I assumed the methodological perspective of slow research. By this I mean that I was willing to consider global mandates as a possible impediment to local effectiveness. This perspective allowed me to scrutinize the cervical screening intervention at work, and to problematize clinical contexts rather than women or their cultures. I wanted to challenge the culture-blame narrative, and ethnographic sitting gave me both the freedom and the time to do that. Because I was not bounded by the typical moral imperative to action that often pervades global health (Pigg 2013), I could take my time to thoroughly observe cervical screening at work in the Swazi context, and to ask the hard questions.

1.4.1 Interviews with Women

I conducted twenty (20) semi-structured, in-depth ethnographic interviews with women. I recruited women for the study through several different ways. I made presentations about the research at the Ndate Government Hospital (NGH), community centers, and markets where women tend to gather. My recruitment presentation was brief. I explained my university affiliation, the purpose of the research, confidentiality protocols, and the participants' ability to withdraw from the research at any time. I distributed study information sheets (see Appendix 3) in SiSwati or English to all in attendance at recruitment presentations. The study information sheet had my address and phone number, where I could be contacted later to schedule an interview if so desired.

These recruitment procedures resulted in interpersonal relationships that led to other research participants around town. Participants were selected based on whether they had prior knowledge of cervical cancer and screening, were above the age of 18, were resident in Swaziland and wished to be included in my study. I developed an interview guide (see Appendix 1) that helped guide conversations with participants. Most of the interviews occurred in a private room at the hospital, at participants' homes, at shops around town and other private locations that were conducive to participants. Before each interview, I explained confidentiality protocols and asked participants to affirm their consent by signing a written consent form, either in English or SiSwati per their linguistic preference. I then began each interview by asking women to complete an intake questionnaire (see Appendix 4). This brief questionnaire helped ascertain that study participation criteria had been met, and was often a good conversation starter. Most interviews occurred in SiSwati, and a few in English.

1.4.2 Interviews with Health Workers

In addition to interviewing women, I conducted seven (7) semi-structured interviews with health workers at the Ndate Government Hospital and an affiliated clinic. I identified pertinent participants when I saw them interacting with patients in the waiting areas or consultation rooms. I developed informal relationships with many of them as I often saw them on a daily basis at the hospital, and I volunteered to help them with minor tasks as often as I could. I took the opportunity to request interviews with them during lunchtime or in the afternoons, after most patients had been attended to. The chief medical officer of NGH was among the seven health workers I interviewed. I had met him on my first day at the hospital, as I needed to see him to request hospital permission to conduct the research. He agreed to an interview when I later approached him about it.

I used the same confidentiality and consent protocols for interviews with health workers as I did for women, with a modified intake questionnaire (see Appendix 5). I asked the nurses and the chief medical officer a range of questions about cervical cancer screening and treatment protocols at the hospital (see Appendix 2). They provided a professional and medical perspective, which allowed me to contextualize women's experiences and map the transmission of various understandings about cervical cancer screening and treatment.

Further, the health workers helped me understand some of the gaps, inequalities and political challenges within the public healthcare system in Swaziland. Their perspective was critical in helping examine the complex biomedical arrangements around HIV/AIDS and cervical cancer that figured prominently in my interviews with women. Further, because women talked a lot about the kind of care and attention they received from nurses, it was important for me to hear and understand the nurses' own perspectives and explanations. Hearing from nurses augmented my understanding of the complex local clinical environment in which cervical screening occurs. It also made me appreciate the tensions and contradictions of nursing practice.

1.4.3 Analysis of Interviews and Field Notes

SiSwati is the lingua franca of Swaziland. I speak SiSwati fluently, as I lived in Swaziland for a little over eleven years. In interviews, I gave all participants the option of conversing in the either SiSwati or English, as they felt comfortable. Most participants chose to converse in SiSwati. Even among those who spoke in English, the conversation often switched to SiSwati. Thus, most interviews had to be translated from SiSwati to English, and then transcribed.

A research assistant, who had been thoroughly briefed on the study ethical and confidentiality protocols, helped complete most of the translation and transcription work while I was still in Swaziland. I then transcribed and translated the remaining few interviews upon my return from Swaziland. Lastly, I listened to all the audio recordings again, and reviewed the transcriptions that had been done by my research assistant.

Inevitably, something is always lost in the process of translation. When I was reviewing the translated transcripts, I felt that there were instances when English was inadequate to capture the full meaning of a SiSwati word or phrase. For example, take the relatively common SiSwati phrase "*uphatsana kahle*" which women used to talk about some nurses. In SiSwati, the phrase implies kindness, impartiality, care and genuine concern for people. We found it hard to succinctly translate this phrase into English, and we rendered it as "treats people well" or "takes good care of people" in most transcripts. That captures the essence of what women meant, but does miss some of the nuance and depth behind the original phrase. Ultimately, we did the very best we could with the translation.

The transcribed interviews and accounts from field notes were then systematically organized and analytically coded. I used a standard word-processing program to sort the data by creating files, highlighting and entering code categories. I began with analytic open coding, which encompasses a line-by-line analysis (Emerson et al 2011). I then followed with focused coding, also through line-by-line analysis, but based on a subset of key themes. I then looked at the key themes and systematically analyzed them to identify patterns and variations (Emerson et al 2011). Based on the patterns and variations, I chose three of the most prominent themes to write about. These were themes reoccurring in most of the transcribed interviews. I then went back to the full data set, re-read and re-coded around those three central themes to further understand the contexts in which women discussed them. I kept code memos to keep track of my observations.

1.4.4 Limitations and Reflexivity: Situating the Researcher in the Field

I grew up in Swaziland and speak SiSwati fluently. Thus, I was able to relate easily with participants. I realized as my fieldwork progressed that my participants saw me as a quasi-authoritative figure. I am well educated, I am fairly knowledgeable about cervical cancer, and I live overseas. Therefore, participants might have thought I was looking for a specific kind of response. Interviewer-interviewee relationships inherently involve a power dynamic that is hard to ignore. I tried my best to mediate that power imbalance: I assumed a neutral tone, I tried to make participants feel comfortable and relaxed during the interview, and I was open about my own childhood growing up in Swaziland. For most women, that created a friendly, relaxed atmosphere where we could talk in confidence.

In my interviews with medical and health professionals, the power dynamic was often reversed and I felt less like an expert and more like a student learning from them. I had, however, built informal relationships with most of them over time before I interviewed them. That relationship facilitated a cordial, less stressful interview atmosphere. It was a challenging but rewarding experience for me to sit down with them. Further, it seemed my status as someone who had come from outside Swaziland gave me an enduring authoritative label, even with health professionals. I found that they often asked me for advice either during or after our interviews. While I was happy to share my opinions, I often did so after the interviews, or informally as we chatted while I helped them around the hospital.

While I was able to collect sufficient data during the three months I spent in the field, the relatively short period of fieldwork was a limitation on my work. Specifically, it made it difficult to pursue additional emergent leads. There are several other themes that emerged in the course of my conversations with women, such as fear of diabetes, which I would have wanted to investigate further. However, due to the shortness of time, I had to stay focused on tracking themes directly related to fear and cervical screening.

Further, my fieldwork was conducted in a semi-rural town. Thus, most of the women and health workers I interviewed were mostly working class, while some came from disadvantaged socio-economic backgrounds. This sample may not be representative of the entire population of Swazi women, especially women from more affluent backgrounds. However, the data effectively represents local patterns of effect that can be tracked and further studied.

1.5 Scope of the Research and Thesis Outline

Few ethnographic studies have examined fear in the context of cervical cancer screening and treatment protocols in contemporary Africa. As of the time of writing, I do not know of any such study conducted in Swaziland. In this thesis, I turn away from racialized critiques of Swazi women or their cultures, to examine fear arising out of local configurations around cervical cancer screening and treatment. Each chapter examines a specific element of fear relative to cervical screening, and the ways in which women express, manage or respond to their fears.

Chapter two of this thesis begins the examination of fear, exploring why it arises out of the clinical encounter between women and nurses. The focus of this chapter is on women's perceptions of nursing care, and the ways in which nurses' behavior or attitude towards patients may contribute to fear of cervical screening. Findings from interviews with women describe the clinical encounter as fearful and unsafe, because of the possibility of verbal abuse, negligence and the pejorative judgment of women's bodies. The chapter also includes an analysis of interviews with nurses, not to excuse nurses' behavior, but to contextualize the entanglements of bureaucracy, politics and emotion that complicate nursing practice. The chapter thus conceptualizes the nurse-patient encounter as a laborious one, impacted by socio-structural factors that influence both women and nurses.

Chapter three maps fear, by examining how women navigate less fearful and less laborious pathways to cervical screening. Interview findings indicate that women manage fear of clinical gossip by expressing a preference to be examined by nurses they do not know or nurses they will never see again. Women pursue social distance in order to achieve freedom and anonymity, thus avoiding negative judgments of their bodies and possible pathways of clinical gossip. The findings in this chapter illustrate the social safety of distance. This contributes an alternative construct of social distance within biomedical care to the literature.

Chapter four politicizes fear, by considering the clinical positionality of HIV and cervical cancer in Swaziland. The focus of this chapter is on unequal place and space making for the two diseases within the public health system, the unequal creation of a form of therapeutic citizenship, and the fear arising out of this inequality. Women and health workers alike describe cancer as worse than HIV, because of the vast differences in treatment availability and access. This creates and sustains a very practical fear of cervical screening. This chapter discusses the ways in which political and human choices can render diseases unequal, and how this inequality filters into women's lived experiences.

Finally, chapter five briefly summarizes the clinical, economic, political and social contexts in which choices about cervical screening use are made in Swaziland. Ultimately, women respond to the fear triggers outlined in chapters two and three in one of two ways: either avoiding cervical screening altogether, or mapping out less fearful pathways to screening, in biomedical sites where they may feel assured of nursing practice marked by respect, confidentiality and kindness. Yet and still, the realities of cancer treatment scarcity, therapeutic failure and disease inequity outlined in chapter four remain a challenge. As such, addressing cervical cancer in Swaziland necessitates dealing with the political, economic, social and clinical entanglements that complicate women's choices and nursing practice.

Though specific to cervical cancer, this thesis contributes to an anthropology *of* global public health interventions in Africa. It has wide application to health and social science studies of power, culture and disease. Specifically, this thesis effectively shows how fear of cervical screening in Swaziland is complicated, multi-faceted and – contrary to the epidemiological bias – not reducible to culture alone. A culture-blame narrative is sadly typical in discourses about African public health, because of prevailing pathological constructs of African cultures. The findings in this thesis challenge this culture-blame narrative relative to cervical screening in an African context. As such, the thesis increases our understanding of ongoing tensions within global public health interventions in contemporary Africa.

CHAPTER 2: Complicating Fear: Laborious Clinical Encounters

2.1 Introduction: When Nurses Scold

> The nurses who scold, ah! They shout, "Raise your legs!" Oh my! Speak properly to me, [don't start] shouting. If you speak normally I will hear, [there is no need] to scold. That is the problem I have, being scolded is something I do not like.

Andile and I were sitting in a quiet corner of an empty school library when she exasperatedly began to talk about her recent experiences with nurses at local hospitals. She described nurses as prone to scolding patients, something that often discourages her from going to the hospital for cervical screening. Two months ago, she went to a nearby government clinic afraid that she had chicken pox. When Andile went in to the consultation room, the nurse asked her to remove her shirt so she could examine the spots on her back. As she began to remove her shirt, the nurse took a quick look and immediately exploded, in a voice loud enough to be heard in the waiting area outside: "Sister, who told you that you have chicken pox? Because these are just your own spots! This is not chicken pox! Wasting my time." Andile tried to respond, "But nurse, I…" The nurse would have none of it. Embarrassed, Andile quickly pulled her shirt back on and left the room. Other patients stared at her as she walked quickly towards the main clinic exit:

> She [the nurse] did not treat me well at all… I don't go to that clinic even when I am sick. Why did she not just explain calmly and properly to me that I did not have chicken pox? The spots were itchy. When I looked at it, I thought it was chicken pox. She could have just explained properly to me… Because when you are sick, even if whatever you have, when you think of going to the hospital, [you] think, "Oh but I must go and meet with those people who scold!"

For Andile, the hospital has become a space that inspires fear, rather than hope and healing. This is not because the hospital is inherently fearful, but it is a difficult space to navigate for women and nurses alike, the dynamics of which I will explore this chapter. In Andile's case, her construct of the hospital is a direct result of her previous experiences, and it negatively impacts her willingness to attend cervical screening. She does not want to attend cervical screening with "those people who scold." Maya, who had recently gone for cervical screening at the Ndate Government Hospital (NGH), shared a different experience with me:

> I was well taken care of, it also encouraged me to come again, because sometimes you really do come to the hospital and you are not well taken care of at all. Then you find yourself just staying away with the disease killing you.

Maya decided to visit the gynecological clinic at NGH after a few weeks of experiencing unexplained pelvic pain and bleeding. Upon hearing her symptoms, the attending nurse recommended a cervical screening exam, to which Maya consented. The nurse was kind enough to explain the screening procedure to Maya, and to answer any questions she had. Maya referenced this kindness several times throughout my conversation with her.

Yet, embedded within Maya's response is an acknowledgement that the quality of hospital care is differential. There are times when it is preferable to stay at home "with the disease killing you," rather than to face the prospect of mistreatment at the hospital. Nursing practice is variable, sometimes kind and other times unkind. I will examine the complexities of nursing practice from the perspectives of both women and nurses.

I did not go into my interviews with women necessarily expecting to talk about nursing practice. However, whether through accounts of kindness, as well as of neglect or verbal violence, the behavior of nurses loomed large in women's interview responses about fear relative to cervical screening**.** These differential accounts evidence a complex, laborious encounter for both women and nurses. For their part, women often described the hospital environment itself as a space ridden with fear: fear of nurses, fear of being scolded, fear of being judged and fear of being mistreated. This fear was expressed by women who had experienced cervical screening as well as by women who had not. As for Andile and Maya, prior experiences of nursing care were a major influence in women's decision-making. Whether or not they would consider going to the hospital for cervical screening, or returning for further screenings, was dependent on *how* nurses had treated them in the past.

In order to further understand the importance of nursing practice and the clinical context of cervical screening, I asked: In what ways does the hospital environment contribute to fear of cervical screening? What factors influence the nurse-patient interaction? What social or structural factors within the hospital environment affect nurses' behavior or attitude towards patients? In order to explore these questions in this chapter, I will examine the viewpoints of women and nurses about cervical screening and its immediate hospital context. I will combine an analysis of participant responses – from both women and nurses – with previous social science scholarship to conceptualize cervical screening in Swaziland as a laborious encounter, rather than a pure clinical encounter between women and nurses. Examining the labors of both women and nurses, I will situate the nurse-patient encounter in the context of wider socio-structural factors that affect women and nurses.

2.2 Judging Female Bodies

Within the Swazi publicly funded health care system, nurses provide basic primary care and are usually responsible for referring patients to doctors for further review when necessary. Nurses are thus the first point of contact for the majority of women attending government hospitals. This means that nurse-patient interactions have the potential to shape women's experiences of the health care system, and their expectations of cervical screening.

Amzat and Razum have defined the practitioner-patient relationship as a domain of power relations (Amzat and Razum 2014). Within this domain, the imbalance of power can impact the dynamics of what is said or unsaid, who gets to speak and for how long, and who makes decisions (Carpenter-Song 2011). This power dynamic is navigated differentially as clients and practitioners interact in any given hospital setting. To a large extent, people's experiences of the health system are shaped by the nature of their interactions with health workers (Govender and Penn-Kekana 2008). Most importantly, the nature of client-practitioner relations can affect use of health care facilities, as well as the quality and outcomes of care (Amzat and Razum 2014). Specific to cervical screening, Armstrong et al argue that health professionals may minimize or ignore women's emotional responses, by constructing cervical screening as a routine, everyday occurrence. This may contribute to feelings of discomfort and violation among women (Armstrong, James, and Dixon-Woods 2012). While some of this scholarship is based on studies in contexts other than Africa, it collectively provides evidence for how women's experiences of healthcare – and of cervical screening – can be affected by the nature of their interactions with individual health practitioners.

My discussion of health practitioners' influence on women's experiences focuses on nurses, because they are they are the primary providers of cervical screening services in Swaziland. Swaziland's nurses work under severe resource constraints, in a country where the nurse and midwifery workforce density is 1.602 per 1000 of the population (WHO 2015). This is far below neighboring South Africa's density of 5.114, and is a far cry from Canada's 9.288. Any study of nursing practice in Swaziland thus has to contextualize it relative to the reality of personnel constraints, and other structural challenges within the public healthcare system.

Scholarly studies on Swazi nursing practice are scarce. One study among patients seeking treatment for tuberculosis at a public health facility in a Swazi town documented complaints about nurse scolding and shouting (Escott and Walley 2005). An older study also suggested that one of the reasons why women in rural areas of Swaziland may avoid seeking prenatal care is the rudeness of staff in the hospitals (Nagawa 1994). This does not necessarily blanket all nurses in Swaziland as intentionally cruel or hard-hearted, but it does show that nursing practice can and does influence local health seeking behavior. I intend to examine this influence relative to cervical screening, as well as situate nursing within the wider socio-structural context in which nurses carry out their work.

Throughout my fieldwork, I often found an informal, negative discourse about nursing practice in Swaziland. Early into my interviews, a lot of women told me about an incident that had recently happened at a major government hospital, where a newborn baby had died. After hearing this story from several women, I decided to look it up in newspaper archives. As reported in the *Times of Swaziland* (Shongwe 2014), a woman in labor had been told by the nurse-midwife on duty to walk outside the maternity ward for a couple of hours, as she was not yet ready to give birth. This instruction was given despite the fact that the woman was already visibly in pain from intense contractions. The poor woman had complied. Shortly thereafter, a startling scream was heard. A few patients and staff rushed to the screaming woman, only to find that her baby had crowned, dropped head first on to the floor, and died on the spot. The newspaper article covering this story provoked a nationwide response. It was widely discussed on social media and in informal circles, with many women commenting about the prevalence of nurse neglect and cruelty across the country. Women who shared this story with me in individual interviews reiterated many of the same comments I had read on social media: “How can they let a baby die just like that? So cruel! This is how nurses behave in this country!”

As this theme continued to emerge in interviews, I became aware of how nursing practice affects women’s decisions about cervical screening use and avoidance. In individual interviews, most women expressed discomfort with the ways in which nurses look at women. They described the nursing gaze as critical, scolding and judgmental. Sipho, who I interviewed while she was waiting for customers in her privately owned hair salon, told me that if it were possible for her to self-collect the cervical sample and take it to the hospital for analysis, she would be the first in line. When I asked why, she explained:

> I think the big problem is that I must go and open my legs there [at the hospital]. I don’t know how this person [nurse] will look at me. Maybe [she] will look [at me] like this, (*frowns and scowls face*). You see this thing? But if you have brought this thing from home you just drop your sample, they do their thing, and tell you the results and you go.

Sipho is uncomfortable with the thought of having her body exposed to the examining eye of a nurse who might frown or scowl at her. Her fear is not of bodily exposure, but of the possibility of her exposed body being disapproved of, even if the disapproval is expressed nonverbally. Thabo, who later joined my conversation with Sipho, added a detail about the verbal expression of bodily judgments:

> Because for others it is really hard to open up their legs, its hard… when the nurse is with you and says, “It serves you right to be sick! You don’t bathe!” You see? Maybe it is hard to bathe, the person first of all is old. Then when you are on the [waiting] bench outside, you hear “How can you not get sick? When you smell like this?”

Thabo had been sitting on a bench at NGH, waiting to be attended to, when she overheard a nurse scolding a woman for not bathing, and having an unpleasant bodily odor. While the scolding happened in a private nurse consultation room, the nurse’s voice was loud enough to be heard in the waiting area. Whether or not it was true that the woman had not bathed, what Thabo stressed to me was that the humiliating scolding was unnecessary. It had made Thabo conscious of her own bodily odor, and created a sense of insecurity. Zodwa, an elementary school teacher, echoed Thabo's fears about scolding and bodily judgment:

> Just here at the hospital… they talk! They say, "Ha, people's private parts! *Sengafa kunukelwa*!" You see, things like that. Then let's say I have heard you, they say they are tired of our smell, then you will be afraid. They even say you must not come in the afternoon, when it has been a long time since you bathed in the morning, it will smell.

Bodily judgments inspire fear among women. Zodwa here uses a SiSwati phrase *sengafa kunukelwa*, which loosely translated means, "I am sick and tired of their smell." However, the English translation is inadequate to capture the deeper meaning of this phrase. The verb *kufa* literally means to die, while *kunukela* connotes a deliberate attempt to make someone smell a scent. Thus, when a nurse says *sengafa kunukelwa*, it means more than just being sick and tired. It means being so sick and so tired of the smell that one could die. It connotes disgust, as though women come to cervical screening exams just to parade their "repulsive" odor in front of the nurse.

There is an inherent vulnerability in the encounter of cervical screening, as discussed in scholarly critiques (Reagan 1997; Kapsalis 1997; Armstrong, James, and Dixon-Woods 2012). This vulnerability is understandable, because the encounter of cervical screening asks women to take off their clothes and allow someone else access to the most intimate parts of their bodies. Further, cervical screening has also been described as an invasion (Armstrong, James, and Dixon-Woods 2012; McKie 1995). By very definition, an invasion involves a violation of personal boundaries: an unwelcome entrance into an otherwise personal space. This heightens the sense of vulnerability. When this vulnerability is met with scolding, frowning and the negative judgment of women's bodies, it makes the cervical screening encounter emotionally unsafe for women, creating fear. This is the fear expressed by Sipho, Thabo and Zodwa above: a sense of vulnerability to judgment and criticism.

There is a distinction to be made here between fear of bodily exposure itself, and fear of bodily judgment in the process of exposure. Fear of or discomfort with bodily exposure is indeed a reason why some women may avoid cervical screening (Kivuti-Bitok et al.

2013). Admittedly, a few women I interviewed did express fear of the act of bodily exposure itself. However, like Sipho, Thabo and Zodwa, most women feared the kind of gaze that looked upon their exposure, rather than the act of exposure itself. In other words, women are willing to be exposed in the cervical screening room, but they want that exposure to happen in the presence of a neutral and respectful gaze: one that does not unduly blame, criticize, scold or magnify bodily odor. They want a nursing gaze that will not pass undue judgment on their already vulnerable bodies.

In essence, the type of nursing gaze feared by women eerily mirrors the colonial gaze in its pejorative judgment of African female bodies. Historically, the dominant image of the African woman was one of licentiousness, promiscuity, dirt and sexual contagion (Stoler 2002; Jochelson 2001; Fassin 2007; Vaughan 1991). While colonialism is technically history, the colonial caricature of a foul and sexually diseased African femininity is sadly enduring. So too is the tendency to blame and pejoratively judge African women's bodies, as well as black bodies more generally. There has been little change in how white-dominated mass media represent black women (Hooks 2014). Combined with science and technology, mass media and other modes of popular culture continually collide to create tropes and readings of the black female body that echo historical tropes of illicit sexuality, criminality and deviance (Hobson 2012). Ibhrahim has argued that to fall under the eye of power – the gaze – is to find oneself in a context where the body is already authored, read, fixed, known, and spoken about (Ibrahim 2003). In a sense, when Swazi women come under the nursing gaze in the cervical screening room, they find themselves in a space where their bodies may already be authored, known, fixed and pejoratively judged, irrespective of their individual subjectivities.

Whether consciously or unconsciously, nurses appropriate certain elements of the colonial gaze in the cervical screening room. Women perceive this gaze as judgmental, offensive and a deterrent to cervical screening use, describing it in language that mirrors the early pathologization of African female bodies. I must here note that there are contextual reasons why nurses are sometimes judgmental, and I will return to discuss the local structural and political constraints on nursing practice in section 2.4 of this chapter.

2.3 “We are People”: Selective Refusal of Screening

Soon after I had finished my interview with Sipho and Thabo, I went to a local tailor shop because I needed to have a dress altered. The shop is owned by a group of three female entrepreneurs, and they were all hard at work that day. I initiated a conversation with the head tailor, Mandisa, as she was taking my measurements for the dress alteration. While I waited and she worked on my dress, she and I continued a casual conversation. Mandisa refused to have our conversation audio-recorded, but she allowed me to take notes as we talked. What she shared with me was heart wrenching. She had recently given birth to her lastborn daughter at NGH. She had had a long and difficult labor. She was given maternity underwear immediately after the birth, but she was bleeding profusely, and thus stained her bed sheets.

About three hours after the birth of her daughter, the attending nurse came to check on her. When the nurse realized how badly stained the bed sheets were, she ordered Mandisa to immediately go to the hospital laundry room and wash the sheets. Shocked and not knowing what else to do, Mandisa said she would go. But she asked if she could be given pain medication and more maternity underwear. The nurse threw one piece of maternity underwear at her and curtly replied, “Do you think you are the only one who has given birth in this hospital?”

Weak and exhausted, Mandisa made her way to the laundry room, clutching the underwear and soiled bed sheets. Behind her, and in her hearing, the nurse shouted, “Why can’t you also be like the other good women who do not soil their sheets?” Mandisa was fighting back tears as she hobbled her way to the laundry room. She told me:

> When I think of that experience, it hurts me to this day. When I think of the pain that I was in, the way I was bleeding, it just hurts too much. All I wanted was to rest and hold my daughter. I mean, I did not mind having to wash my sheets, hey. But did she have to talk to me that way? Did she have to make me feel like dirt?

By taunting and scolding her, the nurse had attacked Mandisa’s very sense of self: she had made her feel like dirt. Further, by comparing her to “other good women who do not soil their sheets,” the nurse had effectively labeled Mandisa a bad woman. This is a label that Mandisa refuses to identify with. When I asked her if she would ever consider going for cervical screening at NGH, her answer was a firm no. This refusal to present for cervical screening was a way for her to say, “I am not dirt, I am a good woman.” She summed it up in these words:

> I don’t know if I could put myself through that again. I mean, I know, not all nurses are the same. And if there is another place where I can be treated with respect, I won’t mind going for screening… I just want someone who will make me feel that I am also human, who will listen to me, you know, like the way that you have listened.

Mandisa’s case illustrates a categorical refusal of cervical screening, rather than a refusal of screening in its entirety. I borrow the concept of categorical refusal from Rayna Rapp’s work on amniocentesis, which has shown how a medical technology can either be categorically rejected or accepted as a package with all its values and assumptions (Rapp 2000). Mandisa’s refusal is categorical because she is willing to attend screening at a different hospital, if examined by a more respectful nurse. As such, her categorical refusal is a means for her to challenge what she sees as dehumanizing nursing practice, and construct an alternate identity for herself.

Hacking’s work has shown how classifications and labels can make up people (Hacking 2006). In the context of cervical screening in Swaziland, nurses make up women, while simultaneously making themselves up. Verbal violence from nurses can work to construct women as stupid, bad, responsible for their own predicaments, and/or somehow subhuman. These constructions of women circulate as an informal dialogue between nurses, patients and their social networks. Further, by making up women negatively, nurses simultaneously make themselves up. Labeling women as stupid, bad or irresponsible effectively asserts nurses as the exact opposite: intelligent, good and responsible, setting up an identity in opposition to the one they assign to women. In part, nurses are able to do this because of the kind of labor they engage in.

For women, refusal to attend cervical screening within the circle of a nursing dialogue that negatively constructs them is a means to challenge those constructions, and make up alternate identities for themselves. This allows women to move themselves from positions of objectification to ones of empowerment. In addition to verbal violence, women spoke about negligence or neglect as another discomfiting aspect of current nursing practice. In most cases, women described acts of nurse negligence or neglect as objectifying and dehumanizing. Andile, whose story I introduced at the beginning of this chapter, described a rather humorous incident of nurse negligence:

> The last time I went to the hospital, I entered through the door. I found her [the nurse] busy, texting on what's app… And she says, "Sister what have you come for?" She takes her paper and writes, [but] she's also busy on the phone. "What is your name?" She even wrote a wrong name for me *(laughter).* She even wrote the wrong name! She was still on the phone texting, and asking me, "What have you come to do?" Ha!

I appreciated that Andile could at least laugh about this incident! But behind her laughter was a strained disappointment. She felt as though the nurse had treated her as less than human. She went on to tell me:

> Her, how would she feel if she came to school to register her child and found the deputy. "What is the child's name?" *(demonstrates writing while texting on the phone)* You see that she can feel bad? We are people.

"We are people." Andile's words are poignant. They reveal a perception of nurse negligence or neglect as dehumanizing, and a stubborn refusal to be thus dehumanized. Sipho, whose thoughts about the critical nursing gaze I introduced earlier in the chapter, echoed this sentiment:

> Ok something else that frightened me, at the hospital, someone died while in the queue… They came to pick the body. The nurses do not have the way of approaching us… I have a headache, but I can wait with my headache until I get seen around 3 or 4pm. Yes I woke up early, but I can be able to wait with my headache, you see? But the person who is looking down, shaking… You may find that in my heart I wish they could take him ahead of the queue and attend to him, but they just said, "You should wake up early when you come to the hospital. Don't just sleep if you feel sick, wake up early!" He died. He entered to see the nurse, when they were transferring him to the doctor, I saw them coming [for the body]… the story was over.

It was evident in her tone of voice and posture when she spoke about it that Sipho still felt incredibly sad about that man's death. She kept reiterating to me that the nurses should have noticed his urgent need for emergency medical attention, and taken him ahead of the queue. Instead, they had scolded him and told him to wait his turn in the queue. He died not long after his turn came to actually see a nurse in the consultation room. Admittedly, there is no way to know whether or not emergency medical care would have saved this man's life. However, the point remains: from an observer's perspective, the failure to give emergency medical attention to a man who could barely stand upright in a queue was negligent.

Women yearn for a clinical encounter that affirms, rather than attacks their humanity. Selective refusal of cervical screening is thus empowering; it moves women out of the plane of objectification. Eunice was the most direct in how she expressed this: "Treat me like a person. Treat me like a human being, [do not] treat me like I am stupid, like I am a child." Eunice refuses to be seen by any nurse who will not show her basic human respect. She does not expect to be treated like a queen, but she will not tolerate being treated like a stupid person or a child either. In light of historically racist and colonial tropes dehumanizing black and African bodies (Wailoo 2011; Bridges 2011; Fassin 2007), this selective refusal is telling. Feminist author Hooks argues that black women have revolutionarily challenged the status quo, moving themselves from manipulatable objects to self-empowered subjects (Hooks 2014). Whether or not they are conscious of racist historical portraits, most of the women I interviewed women use selective refusal of cervical screening to move themselves from "manipulatable objects" to self-empowerment. By refusing to be examined by negligent or verbally violent nurses, women effectively assert that they are deserving of better, more humane care. As such, selective refusal of cervical screening is a means for women to challenge dehumanizing practice and reassert their sense of humanity.

I must here acknowledge that the quality of nursing care in Swaziland is differential. While several women shared stories of negligence, verbal violence or the pejorative judgment of bodies as described above, a few women shared stories about kind, patient, understanding and compassionate nurses. This is to be expected, because nurses are individuals, and it would be unfair to label them all as unnecessarily cruel, rude or abusive. I turn now to a discussion of the local complexities of nursing practice.

2.4 Entanglements of Politics and Nursing

The more I listened to accounts of verbal violence and pejorative judgment from women, the more tempted I was to criticize nurses, as is often the case when one assumes a patient-advocacy stance (Long, Hunter, and van der Geest 2008). However, the more time I spent with nurses, the more I came to appreciate the difficulty of their work. In this section, I argue that accounts of verbal violence or the pejorative judgment of women's bodies illustrate the complexity of nursing practice in the context of an impure clinical encounter, where entanglements of politics, medicine and emotion complicate nurses' daily work. I use the term "impure clinical encounter" based on Kruger and Schoombee's discussion of a pure medical encounter as one that is precisely ordered, meticulously controlled, organized, functional, clean and not marked by violent encounters. When faced with the impossibility of the pure medical encounter, both nurses and patients can become furious and desperate (Kruger and Schoombee 2010,).

In Swaziland, nursing practice is complicated by structural constraints. The consideration of structural constraints is not a way to excuse the behavior of nurses, but it challenges the exclusivity of blame. Andersen notes that complaints about poor behavior of health workers in African health systems have been reported from all corners of the continent. While some have been quick to blame this on an attitude problem inherent to nurses, doing so often obscures other important factors within the hospital setting that may influence patient-staff interactions (Andersen 2004). Rather than demonize nurses, Jewkes et al have shown that structural factors, such as salaries and conditions of service, may contribute to patient abuse (Jewkes, Abrahams, and Mvo 1998). Differential treatment of patients can sometimes provide nurses with a form of agency, and a means of managing the contradictions within hospital practice (Andersen 2004).

In addition to structural constraints, there is an emotional labor inherent in nursing work. Livingston describes nursing as a dangerous endeavor, balanced as it is between the vulnerabilities of the ill and the pettiness of bureaucracies (Livingston 2012). Nurses walk this precarious emotional tightrope daily, striving to meet patient needs and manage their own emotional burdens. They do this in a space stifled with bureaucracy, contradictions, politics, and structural challenges. Cervical screening in Swaziland is not immune to these tensions, hence my characterization of it as an impure clinical encounter. While this does not excuse nurses' behavior, it helps explain it, to a certain degree.

In order to further understand the complexity of the cervical screening encounter and nursing practice, I spent time observing and interviewing nurses at the Ndate Government Hospital (NGH). At NGH, the cervical screening program is located within the gynecological clinic. Inside, the clinic comprises of the breast cancer clinic, the cervical cancer clinic and the gynecologist's consulting area, all in one small room. There is a bed, a stool next to the bed for the examining nurse or doctor, and a desk with three chairs for consultations. The specific method of screening used in this clinic is visual inspection with acetic acid (VIA). The VIA technique involves soaking the cervix with a 3-5% vinegar solution and using a bright light to detect lesions. While VIA is comparable to Pap smear screening in terms of sensitivity, it is lower in specificity, which may result in more women being treated unnecessarily for non-precancerous lesions (Carpenter and Casper 2009).

The gynecological clinic itself is located at the end of a hallway within the outpatient department (OPD) at NGH. In order to get into the queue for the clinic, women have to first pass through the OPD registration process, where their blood pressure, pulse and body temperature are taken. The registration area is the first thing you see when you enter the OPD. There are benches for patients to sit and wait, and then one desk where a nursing assistant registers patients. On some days, there are two nursing assistants, or a nurse, on duty at patient registration. The registration desk is not shielded from the waiting area, so everyone can hear and see what happens between the registration staff and individual patients. After their blood pressure and vitals are taken, patients are asked why they have come to the hospital. Women who mention any complaints related to the female reproductive organs, or who say they have come for breast or cervical screening, are directed to the gynecological clinic.

Lindy is the nurse currently assigned to the gynecological clinic, and is thus the main point of contact for all women attending the clinic. She diagnoses minor complaints, conducts all the VIA screening tests, and sends any complicated cases to the gynecologist or another attending doctor for further review. My initial observations of Lindy's work in the clinic intrigued me. There were moments of intense care, compassion and dedication, just as there were moments of indifference and rudeness. I had seen Lindy take an old woman by the hand and walk her all the way to the south wing of the hospital where she needed to go after the cervical screening exam. I had seen her sit beside a woman and hug her while she wept after a positive cancer diagnosis. On the other hand, I had also seen her respond curtly to a patient, rush through a consultation, or ignore a patient clamoring for her attention. Her work was a paradox, and it mirrored the narratives of differential treatment I had heard in my interviews with women.

I eventually sat down with Lindy for just over one hour in the gynecological clinic late one afternoon, after she had finished attending to all her patients. It is custom at NGH for management to rotate nurses between different hospital units in order to facilitate staff training and development. Lindy took up her assignment at the gynecological clinic in January 2014, and she worked extremely long hours as the only nurse assigned to the unit. She told me she was eager to be reassigned soon. In the past year, she had seen more pain and suffering than throughout her entire nursing career. Further, she told me there were many changes she wished to make to the screening program; changes she often felt powerless to effect:

> I wish we had a bigger room, you know, for the screening program. It's hard in here because every time the doctor comes to see the more complicated cases, I have to pause my work and allow him to use the room. And you know, the women are not always comfortable when the doctor is in here. Some are ok, but for others it is not ok. I wish we had a bigger room, more staff, more support…

Lindy is, in a sense, stuck in an environment that constantly asks her to do her best work without providing her the best space and resources. This contradiction was evident in the narratives of other nurses I spoke to. Anne, the nursing sister who is responsible for supervising Lindy and the gynecological clinic, expressed many of the same frustrations that Lindy had shared with me. Anne told me that the clinic, and the hospital at large, are not well staffed. She went on to describe how the hospital administration had recently submitted a request for additional nurses, recognizing the urgent need for more staff. The result was not as they had expected:

> Just this morning, we were getting a feedback from the matron, a call from the minister… We had, eh submitted our request for staffing for expansion of some of the units. Ok, it was accepted, but then they have to submit somewhere as well, even them, so we were getting the feedback. Out of the number we requested, it was brought down to almost half, that is for the whole ministry. So we really don't know how many [additional nurses] are we going to get…

In other words, the decision to hire more nursing staff is decidedly political. It is not up to Anne, the matron, or even the chief medical officer of NGH. The best that they can do is to submit reports and requests for more staff. These requests ultimately have to be decided upon at the national level through the Ministry of Health and Social Welfare (MOHSW), which governs all public hospitals in Swaziland. Musa, a male nurse who has often provided palliative care for cervical cancer patients in the gynecological ward, was very open with me regarding his frustrations about the politics of the nurse hiring process:

> In fact each and every health facility has got what is called an establishment register. This register was crafted long time ago, the time immemorial, ages, whereby maybe they were saying at NGH they need 20 nurses. By then, that number was enough, but now, maybe we need triple that number… to actually come to terms with the workload. But the problem is… the protocols, we have to go through the public service, we have to motivate that through the parliament, ah, so!

My intention here is not to demonize the MOHSW or parliament, but to highlight the entanglements of politics, medicine and emotion that complicate the working environment for nurses at NGH. As evidenced in my interviews with NGH nurses, their work is set in the context of overwork and inadequate resources. These realities are politically produced, in so far as decisions about adding staff or expanding nursing units often come from outside NGH, and are made in political circles at the MOHSW and parliament.

Added to these structural pressures, nurses also deal with the emotional stresses of the suffering they witness on a daily basis. During my time at NGH, I saw an intensely personal side to this suffering. It first came up in my conversation with Lindy:

> Especially when you have a colleague who comes in, also you have to tell [her] if there are lesions or suspicion of cancer. Quite sad, because they come, they want to know what is happening. You have to tell them as much as is it your colleague.

Lindy’s eyes were teary as she continued to tell me about Busi, a colleague who had recently died from cervical cancer. At the time of our interview, another staff nurse had just been diagnosed with cervical cancer. Lindy’s pain was raw, and she was not the only nurse grieving. Anne paused in silence for a few minutes when I asked her about nurse Busi’s death. “It is sad,” was all she could manage to say about it. Other nurses I spoke to mentioned the loss with equal sadness. Some further talked about the emotional strain of providing palliative care for cervical cancer patients in the gynecological ward. In her ethnographic analysis of oncology nurses in Botswana, Livingston makes the observation that in addition to balancing the pressures of work and family, nurses are themselves often grieving. They grieve for lost kin as much as for patients (Livingston 2012). This grief was palpable at NGH, where nurses are often overworked, powerless, and emotionally burdened.

Nurse cruelty towards or mistreatment of patients, while not inexcusable, needs to be understood within this complex web of structural, personal and political dynamics in the hospital setting. Some nurses have days when they attend to well over 70 patients. Others skip their lunch break because there are simply too many patients to be attended to. Still others feel that their pleas for additional support and resources have gone unheeded. Thus situated, nurses themselves cannot solely bear the blame for dehumanizing nursing practice. That is not to say this practice is acceptable. Rather, it recognizes that nursing practice does not occur in a vacuum, and is daily complicated by politics, bureaucracy and emotion.

2.5 Conclusion: Laborious Encounters

Cervical screening in Swaziland is not a pure medical encounter. Rather, screening in Swaziland happens in the context of a laborious encounter between patients and nurses. Medical sociologists Potter and McKinlay have argued that the doctor-patient interaction is best conceived of as an encounter, rather than a relationship. They contend that broad socio-structural factors in the organization of medicine may impact how doctors and patients relate. Thus, it is not necessarily the individual patient or doctor who needs to change, but rather the pressures and constraints of the context within which the doctor-patient encounter happens (Potter and McKinlay 2005).

Stacey et al build on this theoretical prompt to conceptualize the doctor-patient encounter as demanding. While individual patient or doctor behavior may play a role in making an encounter demanding, there is a socio-cultural backdrop that often influences interactional realities within the doctor-patient encounter. Although Stacey et al focus on patient consumerism and the internet-informed patient as the socio-cultural factors that may contribute to the demanding encounter (Stacey et al. 2009), their conceptualization is useful for thinking about the provider-patient interaction as a space that can be affected by factors external to individual behavior.

In the context of cervical screening in Swaziland, these factors combine patients' previous experiences of nurse negligence or abuse, the pejorative judgment of women's bodies, nurse overwork, hospital resource constraints, political agendas and organizational power dynamics. These factors may not necessarily be socio-cultural as in the case study by Stacey et al, but they are certainly socio-structural. When women go to the hospital for cervical screening, they enter a space that may evoke memories of verbal violence, negligent care and judged bodies. Consequently, the clinical setting itself generates varying degrees of fear or hesitation. Further, also situated within the clinical context are nurses themselves – overworked, underpaid and often contending with hierarchies and constraints beyond their control.

Thus, when they meet in the context of cervical screening, both nurses and patients come from complex social positions. The reality of these positions filters into the space within which cervical screening occurs, making it a laborious encounter for both women and nurses. As such, the nature of the encounter itself contributes to fear, impacting the use of cervical screening services. Some women manage this fear by avoiding this encounter altogether, while others find ways to carve out a less laborious encounter for themselves, as I discuss in the next chapter.

CHAPTER 3: Mapping Fear: the Safety of Social Distance and Kindness

3.1 Introduction: “Not Here”

> *Hawu*! Here? *(points at clinic)* We will never go! You know the mistake they made here is that they brought people from home, people that we know to work here. And now they want me to go and do this in front of someone that I know? Ah, never *sisi*! Never!

I had met Paula, and her friends Maureen and Shelly, on my very first day at Uthando clinic, a semi-private health center affiliated to the Ndate Government Hospital (NGH). Uthando runs a cervical screening program, though they use the traditional Pap smear method of screening rather than the VIA used at NGH. Paula, Maureen and Shelly each have a market stall just next to the clinic gate entrance, where they sell fruits, potato chips, sweets and other snacks. Most of their customers are children from the elementary school nearby, as well as the Uthando clinic staff. I made it a habit to sit and talk with them as often as I could whenever I went to Uthando clinic. They had taken to calling me *sisi*, which is SiSwati for sister. I was leaving the clinic one afternoon when Paula pulled me aside, saying she had a question to ask me. She confided, “ You know I no longer get my periods, five years now. But why am I feeling this pain? And this bleeding? I think I need to go for this Pap smear thing that they talk about, you know. But where can I go?”

In answer to her question, I told Paula that she could get a pap smear done right there at Uthando clinic. “Oh no, *sisi*,” Paula exclaimed as she turned to Maureen and Shelly, “We cannot come here for this!” The other women immediately voiced their agreement, at which point I sat down as our conversation continued. All three women told me it wasn’t because they disliked the nurses or Uthando clinic. Rather, as Paula had explained to me, the nurses were “people from home.” And a pap smear was not something to be done with “people from home.” Paula continued by telling me, “We would rather go somewhere far away, to a different hospital, you know, a place where they do not know us. It’s better that way.” In other words, if they were to get a Pap smear exam done, Paula, Maureen and Shelly would want to be examined by a socially distant nurse, at a geographically distant hospital. Their choices about cervical screening use had a sociogeographic specificity. This specificity permeated many of my conversations with women in Swaziland.

Previous anthropological scholarship on Africa has considered the preference for culturally distant healers within traditional systems of healing. Rekdal's work among the Iraqw of Tanzania showed how people often seek out healers from cultures other than their own. Rekdal characterizes this preference for the culturally distant as indicating an openness to the unfamiliar, alien and unknown, which may have played a role in the acceptance of biomedicine (Rekdal 1999). Based on ethnographic research in coastal Tanzania, Kamat contends that the process involved in seeking out culturally distant healers is context dependent, and that people often seek help from distant healers after exhausting locally available resources. He defines distance as geographic, social and cultural – such that a distant healer is one who is removed from a client's immediate social networks (Kamat 2008).

Reasons for pursuing distant healers vary. First, people may pursue a distant rather than a local healer because of the perception that the most powerful healing originates from outside the immediate local culture (Rekdal 1999). Second, distant healers can sometimes acquire an enchanted status just by virtue of them living distantly from patients (Parkin 2014). Third, because a distant healer is unfamiliar with a client's social network, he or she may be less likely to recommend therapy involving the participation of those close social networks (Kamat 2008). Thus, within traditional systems of healing, the preference for distant healers arises from perceptions of power and the need to protect oneself from therapeutic interventions involving the participation of immediate social networks.

In this chapter, I explore a different formulation of distance, as it relates to fear of cervical screening. The distance I examine here happens within biomedicine rather than a traditional system of healing, is driven by a fear of clinical gossip, and ultimately provides social safety. As discussed in this chapter, distance shows a social rationale behind decision-making about cervical screening use, again contesting epidemiological assumptions about culture as a primary source of fear. It also elaborates more reasons why the encounter between women and nurses is laborious, and discusses how some women carve out less laborious encounters for themselves.

In individual interviews and casual conversations, most women I talked to preferred to attend cervical screening with socially distant nurses and at distant hospitals, for two primary reasons. First, women pursued distance in order to achieve anonymity, which shields women from pejorative judgment and provides freedom. Second, women pursued distance in order to prevent clinical gossip – which threatens privacy and confidentiality – from infiltrating their immediate social networks. I use the term clinical gossip here to refer to gossip initiated and circulated by nurses, who are the primary providers of cervical screening services. The clinical gossip women seek to avoid is territorial, marked by a geographic and social specificity. In other words, it matters where and with whom the gossip happens. Thus, in the context of cervical screening, fear is socially and geographically specific, redirecting pathways to cervical screening. In order to understand how and why this happens, I will examine women's viewpoints about distance, as well as fears of gossip and lack of confidentiality.

For the purpose of this chapter, I define distance as primarily geographic and social, where a nurse or hospital is considered distant when removed from a patient's immediate social networks. I argue that fear redirects cervical screening pathways to distant sites, where distance provides a sense of social safety. Such an analysis of distance, in the context of cervical screening, is a unique contribution to the literature on biomedical protocols in Africa.

3.2 *Kukhululeka*: Travel, Freedom and Anonymity

For most of the women I interviewed, pathways to cervical screening often involve travel to biomedical sites far from home, or to nurses who are not "people from home." In the context of cervical screening in Swaziland, travel influences women's experiences in two seemingly opposing ways: it can either create fear or provide a sense of freedom. This duality evidences the multiplicity and complexity of women's experiences. I will return to a discussion of the ways in which travel creates fear in chapter four of this thesis. In this section, I focus on how travel to distant biomedical sites mitigates fear, by providing anonymity within the clinical encounter. Anonymity, in turn, acts as a shield from the pejorative judgment of women's bodies that I discussed in chapter two, and provides women a sense of freedom in the cervical screening room.

Previous social science scholarship has examined individual pathways of healing and travel between biomedical healing sites. Roberts and Scheper-Hughes group travel in pursuit of bio-medical treatment, bodily alteration or biological logics within the broader framework of medical migrations. Medical migrants' origins and destinations are variable, happening within the larger political economy of sickness and health care (Roberts and Scheper-Hughes 2011). Writing about medical travel by citizens of rich countries to countries with cheaper biomedical facilities, Sobo highlights a range of motivations: some people seek world class care at cheaper prices, others hope to cure terminal illnesses, and others may do so for reasons relating to ethnic or national identity (Sobo 2009). Whittaker et al have examined the threat that medical travel and the worldwide exportation of for-profit health care may pose for access, equity and the right to health (Whittaker, Manderson, and Cartwright 2010).

Medical travel is not always international, as some patients shop around for medical care within their own countries (Hudson and Li 2012). Cohen's work on Indians living abroad and Chinese Malays compellingly argues that medical migrations cannot necessarily presume northern exploitation of the global south. He documents internal exploitation based on local economies of body trade (Cohen 2011). Parkin's work on medical travel in East Africa shows how individual therapeutic journeys can change direction as people move through different areas and compare treatments. Thus, pathways to health can map routes to areas known for certain healers or a particular ethic, with possible detours to other therapy sites governed by the same ethic (Parkin 2014).

Within Swazi public health, selective preference for certain nurses, hospitals or healers among patients is not a new concept. Choices about where to go for treatment are pragmatic, often based on personal preferences. A much earlier study showed that women in rural Swaziland seeking prenatal care did not necessarily use the service facility closest to them, but they chose a facility if it offered the services they wanted and liked (Nagawa 1994). There is, at the very least, a suggestion here of selective use of available health services, based on personal preferences about the services offered at a particular hospital.

For most women interviewed in this study, selective preference for particular hospitals as ideal sites for cervical screening was based on their social distance from the nurses conducting the cervical screening exams. More often than not, women found socially distant nurses in geographically distant hospitals. As Mercy told me:

> You see if you go to the hospital you need one that is far, where you are not known. Even if I go, there is freedom because I don't know this person, I am seeing them for the first time and last time, and I will leave the person here. Maybe next time I will find someone else.

A greater distance between a woman's social and clinical networks allows for a greater sense of freedom. In other words, travel to biomedical sites away from home allows a woman to experience freedom rather than fear in the cervical screening room. Travel is thus an important means through which women carve out less fearful and less laborious clinical encounters for themselves. In my introductory chapter, I discussed the difficulties inherent in translating interview transcripts from SiSwati into English. Mercy and I spoke in SiSwati through most of the interview. When she refers to freedom here, she uses the SiSwati phrase *kukhululeka*. While it does mean freedom, the phrase is also used to describe a sense of being oneself, without inhibitions, holding nothing back. Travel to a distant biomedical site makes it possible for a woman to be examined by a nurse who does not know her and may never see her again: a person who is not from home. In such a situation, inhibitions crumble, and a woman is free to be herself. Thus, travel transforms an otherwise fearful clinical encounter into a less intimidating one.

The flexibility within the public hospital system in Swaziland facilitates this kind of medical migration. Women are not obligated to visit the same hospital each time, or even to be attended to by the same nurse or doctor. Further, hospitals themselves tend to rotate nurses between different departments as a means of training them and expanding their professional experiences. While a nurse may be assigned to the cervical screening program this year, she could be reassigned to a different department, such as pediatrics, the following year. Thus, if Mercy decides to return to the same hospital for her second cervical screening exam one or two years from now, a different nurse will probably examine her. Moreover, she could also just choose to go to a different hospital. The possibility and flexibility of movement makes it less likely for Mercy to have her cervical screening exam conducted by the same nurse twice. Thus, it is possible for

Mercy's clinical network to be entirely separate from her immediate social network, allowing her more freedom to be herself in the cervical screening room.

At a glance, there is nothing inherently special about the cervical screening room at a distant hospital that allows for a greater sense of freedom. However, the anonymity that is possible in a distant hospital protects women from judgment, which helps foster that sense of freedom. When a nurse, who is part of a clinical network, is located outside a patient's social networks, there is less possibility of nurse and patient seeing each other again after the cervical screening exam. Should a chance meeting happen, the likelihood that the nurse will recognize the patient is minimal. Nolwazi, who had recently attended cervical screening at NGH, explained it this way:

> Because now we are old, and it is the children who are looking at us, *(laughter).* But then it came to me that she doesn't know me, we don't know each other. Even if we meet on the road, she will not recognize that I once examined this one.

As an older woman, Nolwazi had felt some hesitation when she first went into the gynecological clinic and realized that the attending nurse was much younger than her. She might, at that point, have chosen to leave the hospital without going through the cervical screening exam. What made it possible for her to stay was the veil of anonymity: the nurse did not know her, and will likely not recognize her if she ever sees her again. Thus, any negative thoughts or judgments the nurse may make about Nolwazi's body cannot be associated to a specific face. Serwah commented on the fear that arises in a situation where that veil of anonymity is lifted:

> I had the fear of, they are going to see me. I thought maybe I should do it far, where they will not, where they do not know me. Because these ones know me. They may, when they see me, they may say, "Ah, this one, hers is like this!" But yah… that thinking is there.

In the absence of anonymity, the possibility of judgment creates a nudging sense of fear. Serwah was one of the very few women I interviewed who had attended cervical screening at a clinic closer to home, rather than a distant one. As a teacher at the elementary school just next to the Uthando clinic, Serwah knows the clinic staff, and they know her. She sees them on a regular basis on her way to and from work. She feels a sense of fear each time she sees nurse Nancy, who conducted her cervical screening exam. Serwah wonders what Nancy thinks of her body. Thus, she fears Nancy's judgment of her body and, consequently, of her. It is important to note here that Serwah does not assume that Nancy will make a positive judgment about the beauty or symmetry of her body. Rather, she assumes that the judgment will be negative. This echoes the thoughts I discussed in chapter two, regarding the ways in which African women's bodies have historically been objectified. Anonymity provides women a shield from this kind of judgment. No wonder then that Serwah told me it would have been better if she had gone to a distant clinic.

For some women, social standing makes the quest for anonymity a particular challenging one. Maria, a local high school administrator who is well loved and respected in the community, has never gone for cervical screening. This is in part because it is difficult for her to find a hospital where she can have some measure of anonymity. Maria has been teaching for well over twenty years. Many of her former students have gone on to nursing careers in different parts of the country. The last time she went to NGH for a blood pressure related complaint, she saw two of her former students in the nurse consultation rooms, attending to patients. Both former students recognized and greeted Maria while she was in the waiting room. She asked me, "Now, what if I go there for this, and it is my former student who will do the VIA screening for me?" In a sense, because of her social standing in the community, Maria's range of options for distant cervical screening sites – where she can have a degree of anonymity – is greatly limited. Admittedly, this is not the only reason behind her hesitation to attend cervical screening, but it is most certainly one of the important considerations in her decision-making.

Summarily, pathways to cervical screening are often mapped out so as to avoid social proximity to nurses, and assure anonymity and freedom. These pathways necessitate travel to distant hospitals, where women can experience cervical screening away from home, and with people who are not from home. In this setting, an otherwise fearful clinical encounter becomes inapprehensive. This is because the anonymity that is possible in distant sites dissociates women's bodies from any negative judgments that may be made on them. In a study on health blogging, Rains argues that anonymity may mitigate fears of social disapproval or rejection, allowing individuals who may feel embarrassed about their illness to feel more comfortable disclosing their health experiences (Rains 2014). In the case of cervical screening in Swaziland, anonymity isn't about mitigating fears of social disapproval or rejection, but it is about mitigating fears of what I might call a clinical disapproval and pejorative judgment of women's bodies.

Anonymity does not stop these kinds of judgment from happening, but it does dissociate the judgments from the bodies being judged. When nurses do not know a patient, any bodily judgments they make or talk about are general, rather than specific to a particular woman. Thus, anonymity is a veil, shielding women from negative bodily judgments. Distant sites protect women from judgment, and they further mitigate the fear of clinical gossip, which I discuss in the next section.

3.3 Pathways of Gossip

In addition to securing anonymity, pathways to cervical screening are also mapped out so as to avoid clinical gossip. In this section, I limit myself to a working definition of clinical gossip as the sharing of information about a patient that should otherwise be kept confidential. Women fear clinical gossip because it threatens anonymity, privacy and confidentiality of the cervical screening exam. Fear of gossip thus tends to redirect pathways to cervical screening, and is another motivation for women's travel to distant sites. Distance does not necessarily stop clinical gossip from happening, but it offers social safety for women.

In a recent study, Dreby describes how gossip tends to provide entertainment for community members, an informal means of obtaining and passing on information to others, and a mechanism for influencing others in the immediate social group. Gossip can articulate community norms and values, while simultaneously providing community members with opportunities to help define those values and norms (Dreby 2009). It can provide a crucial means of self-expression and solidarity for the subordinated (Spacks 1985). Brennan's analysis of gossip among sex workers in a sex tourist destination shows how gossip can either bring people together or pull them apart (Brennan 2004). Blank argues that gossip can cause either social integration or disintegration, and has the potential to force victims into social isolation. A fear of gossip can thus lead people to make deliberate choices to avoid situations out of which gossip can arise. As such, gossip can reduce help seeking behavior (Blank 2010).

For some women I interviewed, fear of gossip did reduce or drastically discourage health-seeking behavior relative to cervical screening, echoing some of the themes in the literature. For most women, however, fear of gossip redirected health-seeking behavior to distant hospitals and nurses. Women attribute territoriality and geography to clinical gossip: it is more important where and with whom gossip happens, rather than whether or not it happens at all. I was sitting with Leanne and her colleague Mercy, who I introduced earlier, when our conversation turned to the subject of gossip. Leanne commented:

> Maybe you find others or maybe someone that you know and you are used to *(laughter from all).* You will be afraid that ah, this nurse! You see to you, I will go in and take off my clothes and just be free. I don't know you and you don't know me, so I will just come in. I know that ah even if [you] see me [you] will help me. But for the one I know, ah, she will say, "Ah this one is like this?" You see?

While Leanne was still talking, Mercy added, "Because some of them [nurses] gossip." Leanne then concluded with, "Yes some talk about you, they really talk about you!" Together, Mercy and Leanne spoke about clinical gossip as a possible reality when cervical screening happens in an encounter between a nurse and a patient who move within the same social networks. Later in our conversation, I asked both Leanne and Mercy what they would do if they went to the hospital for a cervical screening exam and found that the nurse on duty was someone that they know, perhaps a person they go to church with or someone who lives in their neighborhood. Both women were adamant that they would leave the hospital without going through the cervical screening exam. Mercy added:

> Others change, like at this hospital there was a nurse there who… when you go to take your ARVs, you see the ones for HIV? When you leave, and she sees you outside the hospital, she says, "Ah you see this one, though you see her walking around like this, she is actually like this [HIV-positive]!" You see that it doesn't help? Even if you are walking in town! This nurse was really proud. It is not right! It is better with people who do not know you, who are far away.

Evidently, previous experiences of clinical gossip often feed the fear of a lack of confidentiality in the context of cervical screening. The experience Mercy describes is one she had recently gone through, after she went to the hospital to refill her ARVs. Unfortunately for her, while out shopping in town one afternoon, she walked past the nurse who had refilled her ARVs. Without greeting or acknowledging her, the nurse had exposed Mercy's HIV-positive status to the person she was with. That she spoke loud enough for Mercy to hear her was both disrespectful and careless. This is an obvious breach of practitioner-patient confidentiality, one that affected Mercy deeply. Hence her conclusion that it is better to attend a distant hospital, so that one is removed from the immediate sphere within which such gossip can happen.

Ultimately, gossip threatens confidentiality. There are two aspects to the kind of confidentiality that women often seek in the context of cervical screening. First, women express a need for confidentiality of status or diagnosis arising from the exam, as described by Mercy above. Second, women also want confidentiality of the cervical screening exam itself. I introduced Serwah earlier in the chapter, and described the gnawing fear she has after getting her Pap smear exam done at a clinic very close to her place of work. She wishes she had gone to a hospital or clinic further away from home, where she would have had a sense of anonymity. She further added:

> The thought of opening your legs for someone, you feel that if you meet the person, or you feel that the person will tell someone that, "Ah, this one, when she is naked, she is like this…" Because some times [there is] the fear that someone will talk, you see. [You need] someone who will keep it to herself, she won't tell anyone…

By very nature, the clinical encounter of cervical screening necessitates a close examination of a woman's body by a nurse or other healthcare provider. This examination itself merits confidentiality. Serwah, quoted above, is not bothered by the bodily scrutiny inherent in the cervical screening exam. However, she does not want what is seen during the exam – the contours of her body – to be disclosed outside the screening room. This is an important distinction relative to the literature. Most studies that discuss client-practitioner confidentiality tend to focus on confidentiality of diagnosis, personal health records and/or private matters discussed between a patient and a healthcare practitioner (Mechanic and Meyer 2000; Lo and Parham 2010; Sanjobo, Frich, and Fretheim 2008). A recent study on HIV stigma in Swaziland argues that there are instances where health care providers are insensitive about patient confidentiality, and may expose a patient's HIV status (Zamberia 2011). Most of the women I interviewed do want their diagnosis, status or private personal health records kept confidential, of course. But they also want confidentiality of the screening exam itself: the assurance that the shape, structure or smell of their bodies will not be disclosed outside the cervical screening room.

This need for privacy and confidentiality does not imply that women feel a sense of shame or embarrassment about their bodies. Many of the women I interviewed were very open with me. Some shared information I felt uncomfortable receiving, about sores on their bodies or particular smells they were concerned about. I observed other women openly discussing such information together in small groups, indicating that they are not necessarily embarrassed or afraid to talk about it. Regardless of the motivation behind their need for privacy, women have a right to it. Privacy not only protects the right to confidential health information, it is also thought to protect individual integrity (Spacks 2002). The protection of this integrity necessitates confidentiality of the cervical exam itself, as earlier discussed.

Clinical gossip threatens both aspects of confidentiality sought by women in the context of cervical screening, hence the preference for distant hospitals. This does not mean that nurses in distant hospitals do not gossip; fallible human beings exist everywhere. However, when gossip springs out of a distant hospital, it happens outside a woman's immediate social network. This geography and territoriality matters. Often, during the course of my interviews, women would ask me if I was able or willing to conduct cervical screening exams. Several of them told me that if I offered screening exams, they would not hesitate to come. I smiled when Maureen, who I introduced at the beginning of this chapter, told me in a casual conversation, "Ah, you, even if you talk there in Canada, they don't know me, they will never see me!" Her colleague Paula had immediately added, "Because those who don't know you, even if they talk, it happens far away." While they had confidence that I would not gossip about them, most women agreed that it didn't matter even if I did gossip, because I would not come in contact with their social networks. In other words, the kind of clinical gossip that women fear is territorial, in the sense that it matters where and with whom it happens. As long as clinical gossip happens outside the vicinity of one's immediate social networks, it is nothing to worry about. Fear arises, however, when clinical gossip infiltrates a woman's immediate social network. Distance, while not foolproof, helps guard against this.

Further, the possibility of conflict within close social relationships increases the possibility of gossip. Private information from a cervical screening exam can deliberately be used against a patient in a situation of conflict, especially when that conflict happens in the context of a close social relationship. My conversation with Gugu reinforces my earlier point about the geography and territoriality of gossip, and adds the dimension of interpersonal conflict:

> Even the nurses are human, they also have their weaknesses. One day, if maybe you stay together… you quarrel, then it can happen that she says, "Ah you! Keep quiet, you are like this!" You see this thing? It really is hard for that reason, that everyone has his or her own faults. *[I ask: But if you don't know her?]*… If you don't know her, *hawu!* Even if you argue or quarrel, where will you quarrel when someone is seeing you for the first time? This is my first time to see you now, and maybe this is the last time I [will] see you. You see? She will just say that at this hospital I found people like this and like this. But in reality for her to come from here and go to your home and talk this thing, ah, no! It is not something that can happen.

Fear of clinical gossip forces a medical migration to distant hospitals or distant nurses. Distance, in turn, provides social safety. Thus, in the context of cervical screening, nurses from home are socially dangerous. This is because gossip moves through social networks. As social actors, nurses themselves belong to social networks, just as women have friends, neighbors, fellow church members and others with whom they share health information. When nurses are "people from home," they live within the same social networks that their patients do. While this does not create clinical gossip, it facilitates its movement.

The social movement of gossip is minimized and disrupted when a nurse's social network does not intersect with a patient's social network. Thus, in order to be socially safe, women minimize possible pathways of gossip by seeking out socially distant nurses or health workers. Distance protects social integrity, in the sense that it keeps clinical gossip from infiltrating women's immediate social networks and reaching their close family and friends. I discuss the local importance of social networks in the next section.

3.4 Social Networks and Fear

Women’s decisions about travel for cervical screening – which distant sites or nurses to seek out or avoid – are mediated through social networks. I use the term social networks simply to describe relationships women have with family members, friends, co-workers and/or neighbors. Women’s social networks are an important influence and source of support for them as they navigate decisions about cervical screening use. This influence is both positive and negative: it can either dispel or encourage fear of screening. As such, it helps women negotiate safer clinical encounters.

Berkman et al argue that social relationships and affiliations have significant effects on health, both physically and mentally (Berkman et al. 2000). This is in part because human beings are social actors, residing in social environments where there are varying degrees of support and resources (Lee, Arozullah, and Cho 2004). People use the available support and resources in any given social context in different ways. Not all social ties are supportive, and the type, frequency, intensity and extent of support provided varies (Berkman and Glass 2000), as can be expected. Merino finds that social support is often divided into three types: emotional support, informational support and instrumental or tangible support (Merino 2014). Social relationships shape and are often reflected in women’s health (Smith-Oka 2014), regardless of the varying configurations of informational, emotional or tangible support available in any given social context.

Among the women I interviewed in Swaziland, social networks function as spaces within which narratives of care – and specifically of nurse-patient interactions – are shared, discussed and influence cervical screening use. As such, social networks provide informational support. I use the term informational support as it is defined in the literature: the receipt or availability of advice or guidance (Merino 2014). The informational support thus provided, mediated through social networks, is an important influence on decision making about cervical screening use.

This influence is exerted in two ways. First, narratives of care tend to either encourage or dispel fear of cervical screening, thus facilitating decisions about cervical screening use. Leanne and Phephisa’s stories illustrate how this happens. Leanne, who I introduced earlier in this chapter, is a successful entrepreneur who runs her own hair salon, located less than a ten-minute walk from NGH. She works in her salon from Monday to Saturday every week. On most days, she sits directly facing the NGH main entrance. She has heard about the cervical screening program at NGH, but has never personally gone for screening herself. Just the day before my interview with her, Leanne had talked to a friend about cervical screening at NGH:

> Yesterday, there was someone I was talking to here. She had just come from the hospital and she said, "Hey you must go for screening, I just came from there." I asked her how they treat people and she said, "Ah no they are ok, they give you time, and even for you to ask [questions]. They help you." She said for her, they helped her.

Hearing a positive narrative of kindness and care moved Leanne from a position of total avoidance of cervical screening to one of relative willingness. Kindness in the clinical encounter fosters a sense of safety, and women use social networks as a guide to kind clinical encounters. When her friend encouraged her to consider cervical screening, Leanne's first question was not procedural or financial. Rather, she wanted to know how the nursing staff generally behaves towards patients. Are nurses respectful? Are they helpful? Are they kind? In this case, Leanne's friend had had a positive experience at the hospital, and she characterized the nurses as kind, helpful and patient. This was encouraging to Leanne, and it was something she would take into consideration in her own decision-making. She told me, "You know, it really helps when you hear from someone who has been there, who was well taken care of." She was much more open to screening after hearing her friend's experience, though she was yet to make a firm decision to attend.

Phephisa's mother, Noma, had died of cervical cancer just three weeks before I met Phephisa. Before her death, Noma had visited several hospitals, seen quite a few doctors, and had also been hospitalized. Phephisa had been with Noma through all her hospital visits and stays. In our conversation, she talked at length about the poor quality of care that Noma had received at most of the hospitals she had visited before her death. For Phephisa, these negative experiences were not easy to forget:

> So like… if I tell a friend like, I went to this hospital this is how they treated me, she wouldn't go! She wouldn't! She would fear, and she would tell another friend,

> you see? But if they treat me well, then it's easy for me to tell her, "You can go its comfortable, everything is, its ok." Then they would go, they would go.

Fear of cervical screening can move through social networks, and it can be dispelled through the same networks. In this context, narratives of hospital care are a form of social solidarity. By this I mean that women share these narratives as a means of helping each other avoid some of the negative experiences of nursing care that I described in chapter two. Thus, women either encourage or discourage each other to attend cervical screening based on positive or negative experiences of care, respectively. Phephisa's case is an example of a negative narrative of care discouraging cervical screening use. On the other hand, Leanne's case is an example of a positive narrative of care encouraging cervical screening use.

It is significant to note here that the influence of narratives of care on decision-making is not entirely negative. As demonstrated here, the willingness to encourage another woman to attend cervical screening is based on the quality of clinical care received. Given the importance of the clinical encounter, it is understandable that women fear screening in situations where negative narratives of care are circulating through their social networks. Conversely, the circulation of positive narratives of care and kindness tends to mitigate such fears.

Second, beyond just encouraging or discouraging cervical screening use, narratives of care also provide women with informal social guidance about which nurses to seek out or avoid, thus encouraging or dispelling another aspect of fear relative to cervical screening. Serwah, an elementary school teacher, explained it this way:

> You need [a nurse] who will respect you and treat you well, so that we can even tell each other to go. There is one nurse whom they talk about, he is a male. They tell each other, "Ah if you find that one, he will treat you well!" Not only the Pap smear, just everything. "Ah he will treat you well, he doesn't scold, and the treatment he gives you, the medication, he will give you the right one."

Rather than avoid cervical screening completely, women use social networks to make informed choices about which nurses to seek out or avoid. They pursue kind nurses and avoid rude or judgmental nurses. Kindness, which is another aspect of clinical care that makes women feel safe rather than fearful in the cervical screening clinic, is blind to gender difference. The women within Serwah's social network tell each other about Dumo, a male nurse at a small government clinic. Dumo is kind and good at his job, as women remark that he conducts pap smear exams well, and prescribes the proper medication for any given illness or complaint. Thus, women actively encourage each other to seek clinical care and Pap smear exams from Dumo. It is important to note here that women do not necessarily consider Dumo's gender as of significant importance. This matters because some epidemiological studies have argued that African and immigrant women tend to shy away from having cervical exams performed by male healthcare providers (Lofters et al. 2011; Wood, Jewkes, and Abrahams 1997; Kivuti-Bitok et al. 2013). While some women I interviewed did express fears of being examined by male nurses, most women cared more about kindness and respect than gender. Safety is not based on gendered sameness, but on kindness.

I must here note that I have made a conscious choice to not label women's shared conversations about clinical care as gossip. Gossip has historically been gendered female, and negatively associated with women (Adkins 2002). Rather than problematize women's conversations with other women, I focus on the functionality of the social sharing of narratives of care. As shown in this section, socially shared narratives of care are a weighty influence on women's decision-making processes.

Social networks are especially important in Swaziland. Building on Hilda Kuper's work on personhood in Swaziland (Kuper 1986 [1963]), Root argues that for people living with HIV/AIDS, survival of body and self depends heavily on how multiple social networks respond to disclosure (Root 2014). Though Root's analysis is in the context of HIV disclosure, it provides a useful lens for thinking about the importance of social networks within the realm of healthcare in Swaziland. In the context of cervical screening, survival of self is not necessarily dependent on how multiple social networks respond to disclosure, as argued by Root in the case of HIV/AIDS. Rather, how people within one's social networks respond to hospital encounters influences personal decision-making. The social network thus provides a platform for sifting through health information and narratives of care. As such, social networks are a social resource, providing socially shared evidence that helps women navigate the healthcare system relative to cervical screening. Ultimately, in a society where social networks can be crucial for personal survival, the value of the clinical experiences of one’s family, friends or neighbors cannot be overstated.

Thus, narratives of care, circulating through social networks, help women map safer, less fearful pathways to cervical screening. Narratives are shared to help each other get the best care possible, which translates into avoiding negative experiences, and seeking out positive experiences of kindness and care. Women’s willingness to listen to and heed each other’s advice in this way demonstrates openness and humility. In that sense, per Whyte’s analysis about the social contagion of non-communicable diseases (Whyte 2012), awareness of cervical screening is socially contagious in Swaziland, spreading through social networks.

Because this awareness primarily spreads through narratives of care, fear arising from negative experiences of nursing care is also socially contagious. Equally important, this social movement of fear is punctuated and mitigated by positive narratives of kindness and care, which act as encouragers of cervical screening. Lee et al have shown how social support and resources can help improve a patient’s ability to acquire and understand medical information and negotiate the health system (Lee, Arozullah, and Cho 2004). In this case, social support, in the form of socially shared narratives of care, helps women navigate safer, less fearful pathways to cervical screening.

3.5 Conclusion: Social Safety

Fear of cervical screening is socially and geographically specific – located within sites where nurses gossip and breach confidentiality. This social and geographic specificity tends to redirect pathways of cervical screening to distant, socially safer sites. Rekdal has argued that in African therapeutic systems, a patient is treated not necessarily as an individual, but as part of a social and cultural whole (Rekdal 1999). I would argue that women in Swaziland approach cervical screening not as individuals, but as part of a social whole. This social whole incorporates their families, friends, neighbors and anyone else within their social networks. Women value information about their bodies as private, not to be disclosed to their social networks by a nurse who may have examined them.

Thus, clinical gossip threatens social safety, in the sense that it threatens to disrupt a woman's immediate social network through a disclosure of information that should otherwise be kept confidential. Depending on where and with whom it happens, cervical screening can leave open a pathway of gossip. Women avoid this by seeking cervical screening services from distant hospitals or nurses, where they are not known, and are thus safer than they would be closer to home. This pursuit of anonymity does not remove the possibility of gossip. Rather, it shields the patient – and her social network – from the proliferation of that gossip.

The impact of social distance in this way reveals another layer of fear that affects cervical screening use among women in Swaziland. Like the fear of being judged or scolded, this fear revolves around nursing practices and previous negative experiences of care. Admittedly, the nursing voice is missing from this chapter, as I did not talk to nurses about clinical gossip. At the very least, however, the findings presented in this chapter are not only contrary to a global health default paradigm that tends to locate fear in cultural otherness, but they have practical implications for policy and practice. If fear of cervical screening is located more within social realities and different aspects of nursing practice than cultural norms, the primary focus at policy level needs to address these concerns. By mapping the fear of gossip and lack of confidentiality, we can better understand how to address it, and consequently better deal with the gaps and challenges to cervical screening use among women in Swaziland.

Summarily, women manage fear of gossip by either avoiding cervical screening, or navigating pathways to screening that minimize social proximity. Yet and still, even those pathways face the realities of cancer treatment scarcity and expense. In the next chapter, I discuss and contextualize these realities, and their impact on women's fears.

CHAPTER 4: Politicizing Fear: Worse than HIV

4.1 Introduction: Medicoscapes and Chronotopes

> You see, cancer it is as if you die badly, you die badly in my thinking. I am, if it can be said that I am HIV+, I won't be afraid too much, but cancer, ha! It is bad! The way you become sick, it's very painful, it's very painful, but on this side (HIV), the person can live some days. But with cancer nothing, that's how it seems. There, you burn until you die, still burning…

Andile was highlighting a stark and painful comparison between HIV/AIDS and cancer. At 19, she is the youngest staff member at the Bhele primary school, where she is doing her teacher-training practicum. I first introduced Andile in chapter two of this thesis, where I shared some of the negative experiences of nursing care that have deterred her from attending cervical screening. Andile's hesitations about cervical screening are not solely the product of negative experiences of nursing care. She has seen many HIV-positive people continue to live their lives for many years, because of ART. She has not, however, heard of anyone recover from or live long after a cancer diagnosis. What she knows, based on what she has seen and heard, is that cancer leads to a painful illness: one that cuts a person's life short, and leaves them "burning" until they die. Andile's fear of screening is situated in the context of a social and clinical differentiation between HIV and cancer.

Within Swazi public health, HIV and cancer are differentially situated, a product of their unequal placement within global medicoscapes. By contrasting unequal space and place making for HIV/AIDS and infertility in Mali, Horbst and Wolf al argue that globalizing processes can have varied impacts on different health conditions. Their analysis shows how a therapeutic citizenship has emerged for HIV, but not for infertility, an ailment for which there has not been a global solidarity or lobby. Thus, they define the theoretical concept of "medicoscapes" to describe the complex arrangements of individuals, organizations, institutions, practices, artifacts and things, which are positioned hierarchically, and constitute specific power topographies within global health (Horbst and Wolf 2014). These individuals, organizations, institutions, practices and/or artifacts –

medicoscapes – converge in different ways around different diseases, creating inequalities of place that directly impact illness experience. The concept of medicoscapes is useful in thinking about the varied local and global arrangements converging around HIV and cervical cancer in Swaziland. Worldwide, HIV has acquired a global quality as a disease of importance in terms of global health security (Horbst and Wolf 2014). This global quality is evident in Swaziland, where AIDS has siphoned off a disproportionate amount of local and global health funding (Root 2014; Okonda 2009). There is an abundance of local and international organizations, as well as billions of dollars in foreign aid pouring in for HIV/AIDS prevention and treatment services (Hickel 2012). These services include everything from HIV testing and counseling, to the provision of ARVs. In Swaziland, HIV thus exists within a transnational arrangement of programs, funds and organizations – a global medicoscape – providing ready access to testing, treatment and continuing care. Cervical cancer is, however, relatively neglected in global medicoscapes converging around Swazi public health.

This unequal convergence of global medicoscapes reveals a chronotopic construct of Swazi health as temporally removed from the global north, and as a space devoid of cancer. Brada applies the concept of a chronotope in her analysis of the configurations of space and time in global health. She argues that global health is mobilized to act in in spaces marked by difference, which are often constructed as temporally removed from richer contexts. Practicing medicine in resource-limited settings is thus like traveling back in time, to the temporal history of “developed” world medicine (Brada 2011). HIV’s dominance of Swazi clinical space is a product of a chronotopic construct of cancer relative to African health. As I discussed in detail in chapter one of this thesis, the popular image of African health often obscures cancer, which has historically been constructed as a disease of civilization. The magnification of HIV and relative neglect of cancer in global medicoscapes converging around Swazi health essentially constructs Swaziland as a pre-carcinogenic space. This evidences the outworking of a chronotopic construct, whether intentional or not. More importantly, it facilitates a spatial inequality, where HIV dominates Swazi clinical space and crowds out cervical cancer. This is illustrative of how injecting resources into vertical health interventions can deflect attention away from other health problems (Nichter and Pfeiffer 2008).

In this chapter, I situate fear of cervical screening in the context of the politics of these differential arrangements of space and place. I argue that against the backdrop of unequal clinical space making, women's fears of cervical screening are logical, situated by complex political and clinical contexts. The clinical inequality between HIV and cervical cancer results in a social inequality, directly impacting women's fears about cervical screening use. Thus, fear of cervical screening is inevitably political, a product of human and organizational choices. This further challenges assumptions about culture-based fear, and highlights the intimate consequences of the syndemic confluence of local contexts and global health agendas.

4.2 HIV: Relatively Ordinary

HIV has a long and complicated history in Swaziland. Initial reports of HIV first emerged in the country in 1986. Following these early reports, the government established the Swaziland National AIDS Program, and was among the first to include HIV/AIDS in its National Development Plan (Root 2010). The government was, however, fairly relaxed in its initial efforts against the epidemic, and its efforts were fraught with controversy. For example, in the year 2000, some members of parliament proposed legislation calling for mandatory sterilization of HIV-positive citizens, who had been accused of intentionally transmitting the virus to their sexual partners. However, the Swazi Ministry of Health considered massive sterilization unscientific (Ahmad 2000), and the bill was never passed. HIV/AIDS had been declared a national disaster the previous year, in February 1999, after UNICEF published a report in the *Times of Swaziland* on the long-term impact of the epidemic, projecting a large number of orphans (Daly 2001). This strengthened the government's resolve for a much more aggressive intervention. Currently, there is a large number of international organizations, working alongside the government to decentralize services, and ramp up both testing and treatment efforts for HIV/AIDS (Sibbald 2013).

The configuration of local and international organizations and funds is indicative of a global medicoscape converging around HIV in Swaziland. This has led to some gains in recent years. For example, in 2012, Swaziland exceeded the UN target of ensuring that at least 80% of HIV positive individuals who need ART are receiving it (Root 2014).

However, problems remain. With its heavy focus on individual behavior change, the HIV/AIDS intervention in Swaziland has obscured and neglected the wider structural context in which transmission occurs, including such factors as rising unemployment, entrenched labor migration, deteriorating healthcare infrastructure, and the effects of international trade agreements (Hickel 2012).

Perhaps one of the most significant gains made by the local and international mobilization of funds and organizations is the creation of a clinical claim to care, which has rendered HIV ordinary. Clinical and political configurations can rewrite social histories, so that diseases that were once dreaded become ordinary. Writing about the syndemic confluence of communicable and non-communicable diseases in South Africa, Mendenhall and Norris argue that syndemic suffering has weaved a new social history where HIV has become ordinary, and diabetes new (Mendenhall and Norris 2015). Like Mendenhall and Norris, I argue that HIV has become ordinary in Swaziland. While the complicated arrangement of foreign aid, government programs, and local and international NGOs – in a global medicoscape – has not completely eradicated the problem of HIV/AIDS in Swaziland, it has facilitated a clinical claim to and expectation of ART.

While it facilitates a form of citizenship, this clinical claim is different from the political claim often discussed in the scholarship on therapeutic citizenship. In their study of the historical context of ART adherence, Nguyen et al describe therapeutic citizenship as both a political claim to belonging to a global community offering treatment access, and self-transformation as a result of personal engagement. They also use the term to describe the ways in which people living with HIV/AIDS appropriate ART as a set of rights and responsibilities (Nguyen et al. 2007). Therapeutic citizenship often develops in a context of intervening transnational NGOs and international philanthropies (Horbst and Wolf 2014), which is the type of context that situates HIV/AIDS in Swaziland. In such a context, active treatment engagement enables claims to a variety of medical, material and other resources, thus making citizenship (Rhodes, Harris, and Martin 2013). Admittedly, relative to African contexts, the concept of therapeutic citizenship is very complex (Mfecane 2011). I focus here on how engaging ART enables both a clinical claim to and expectation of care, rendering the disease ordinary.

In individual interviews, most women expressed a clinical claim to and expectation of ART, making citizenship. This claim is experienced through the clinical system, rather than politically through the vehicle of the nation state. Women remarked especially on the ease of availability of and access to ART. As Leanne, who I introduced in chapter three, told me, “With AIDS I know that if I test today then in another month I can go again, because I know that if you find I have it, you will help me quickly.” The help Leanne refers to here is specifically ART, which she expects to be given for free at a government hospital if she is found HIV-positive. In this sense, Leanne expresses both an expectation of and a claim to ART.

The availability and ease of access to ART is part of the social and clinical order for HIV. In other words, for a person confronted with a positive HIV diagnosis, there is a clearly established, accessible and relatively quick pathway of entrance into ART. This pathway passes through the clinic gate, as women experience ART in the context of clinical provisions and programs. At a publicly funded hospital like NGH, patients typically receive their first set of ARVs after a confirmation of their CD4 count. They are then expected to return to the hospital for refills every month, and sometimes every two weeks, depending on hospital regulations and how far the hospital is from a patient’s residence. Additionally, most remote areas are reasonably close to a community health center or clinic that dispenses ARVs. This accessible clinical pathway to care creates a form of citizenship.

Additionally, the clinical claim to and expectation of care relative to HIV facilitates a sense of normalcy and responsibility, mitigating fear and further making citizenship. The appropriation of ART as a set of responsibilities echoes thoughts in the analysis by Nguyen et al (2007). However, the responsibility expressed by women is clinical, more than it is political. It enables a life disrupted by HIV to retain some sense of normalcy. Eunice told me that with HIV, “There are ARVs… and you are normal, because you use them.” Sindi added, “Because with HIV now you can, if you take the ARVs and do what they say, you can continue with your life.” Sindi here associates the ability to live a normal life after HIV with a patient’s willingness to follow through with treatment recommendations: the patient must do “what they say.” Sindi uses “they” to refer to the nurses, doctors or HIV/AIDS counselors who dispense ARVs. Ma R. was even more emphatic in how she expressed this:

> You see this… the HIV, its better, because if you do what they tell you to do, your doctors, you continue to live. This [cancer]? No! But HIV, *hawu*, there is no fear! No fear at all! (*laughter*)

Ma R. affirms the responsibility to follow clinical instructions, and also expresses a sense of fearlessness around HIV/AIDS. Many of the women I talked to echoed this sentiment, talking about an HIV test as something one can now do without fear. Hickel affirms that the availability of effective treatment options, coupled with evidence of their success, can and does encourage people to seek HIV testing (Hickel 2012). This alleviation of fear of HIV testing is a notable achievement for global health, made possible by the clearly accessible clinical pathway to ART.

Further, the alleviation of fear represents a major change in the social status of HIV/AIDS. In the early days of HIV in Swaziland, when ART was not publicly and freely available, a positive HIV test was equivalent to a death sentence. Not anymore. The local social history of HIV has changed: the dreaded has become relatively ordinary. This social transformation is visible, as many women told me that they have seen and know of several HIV-positive people living normal, ordinary lives.

Most of the nurses I interviewed echoed women’s thoughts about the ordinariness of HIV/AIDS. Anne is the nursing sister responsible for supervising the cervical screening program at NGH. I first introduced Anne in chapter two, sharing her thoughts about the challenges of nursing within a publicly funded hospital. She began working at NGH in 1986, and has been there ever since. In the past twenty-nine years, she has seen the hospital, and Swazi public health, go through many changes. When she and I sat down for an interview in her office, she talked a lot about the differences between cancer and HIV:

> You know HIV/AIDS is better, HIV/AIDS is better than this [cancer], because this one it kills you silently, you find that you are on the other side when you cannot cross the river again. With HIV, you are that side but you can still come back… You can take the ARVs, you can take the treatment and the therapy and you move on. So many interventions have been done. And now we see results, babies born without HIV, people prolonging their lives, doing bigger projects, you know, restoring lives, restoring the humanity of the person. A lot has been done…

I will return to the idea of HIV being better than cancer in section 4.4 of this chapter. For now, I focus on how Anne's comments highlight the productivity of global medicoscapes relative to HIV/AIDS. When Anne compares the current clinical context of HIV/AIDS to what it was in the early days of her own nursing career, she affirms many positive changes resulting from years of intervention. Many of these interventions have centered around the scale up of HIV testing and ART access, as well as continued public health education and awareness. Importantly, Anne talks about "restoring lives" and "restoring humanity." National HIV/AIDS interventions, made possible by the transnational arrangement of funds and organizations within the country, are helping to arrest HIV's destruction of the human body. HIV is no longer the dreaded killer it used to be, a difference that was articulated by most other nurses I spoke to. This transformation has led to real changes in people's lives.

This change in the social status of HIV is evidence of the ways in which global medicoscapes, by influencing clinical arrangements, can change the lived realities of diseases. It is important to note here that when I talk about the ordinariness of HIV, it is in the context of therapeutic citizenship, and relative to cancer. That HIV has become ordinary in this sense does not necessarily mean that there is no longer any HIV stigma. Recent studies do document evidence of various forms of HIV stigma in Swaziland (Root 2010; Shamos, Hartwig, and Zindela 2009; Kennedy et al 2013). I did not go to Swaziland intending to research HIV stigma, and it is not my intention to discuss stigma here. For the purposes of this thesis, I have argued that HIV has become ordinary because ART access has made it possible to live a decently normal life with HIV. Further, the ordinariness of HIV in Swaziland is relative to cancer, a point I will return to in section 4.4 of this chapter. Suffice it to say, by facilitating a clinical form of therapeutic citizenship, global medicoscapes converging around HIV/AIDS have re-written some of the social history of the disease in Swaziland.

4.3 Cancer: the Logics of Fear

The social and clinical situation of cervical cancer in Swaziland, is however, vastly different from that of HIV/AIDS. While a convergence of local and global solidarity has facilitated a sense of citizenship and alleviated fear of HIV/AIDS, this has not extended to cervical cancer, despite the often-occurring co-infection between HIV and HPV. HIV's dominance of clinical space is a sharp contrast to cervical cancer's clinical invisibility. While public hospitals provide free cervical screening programs to the public, viable treatment options for cervical cancer are much harder to access. Many of the nurses I interviewed told me that cervical cancer has been neglected in Swaziland. Nurse Nontobeko was critical of this:

> I only know one NGO focusing on cervical cancer. All the others, it is just HIV/AIDS. Even government, it is HIV/AIDS, all the time. I have never been invited to any workshop or training on cervical cancer. But HIV, they invite us all the time, to come for more training. All the time…

Unlike with HIV, there is no clinical claim to or expectation of care for cervical cancer. Rather, the pathway to cervical cancer treatment and therapy is long, expensive, complicated and fraught with difficulty for patients and their families. The lack of a clear, easily accessible pathway to treatment creates and sustains fear of cervical screening. Noma's story, which I tell in its entirety below, is the most poignant illustration of the challenges involved in seeking cervical cancer treatment in Swaziland. Her struggle and eventual death painfully evidence the intimate consequences of the macro global and local configurations that situate cervical cancer in Swaziland.

I met Noma's daughter, Phephisa just two weeks after Noma's funeral. I introduced Phephisa in chapter two, where I shared a brief portion of her narration of the clinical care Noma received in the days before she died. When Noma first went to the doctor, she had already been experiencing vaginal bleeding and problems defecating for a little over a month. The doctor, who was in private practice, referred her to NGH. Phephisa accompanied her to NGH, where Noma was told that her cervical exam showed possible signs of cervical cancer. She would need to make an appointment to come back in a week's time so the doctor could take a biopsy specimen for further testing. Noma complied. After the biopsy specimen was taken, she was advised to take it to a private fee-paying laboratory in a major metropolitan area, which would process her specimen faster than the free government lab.

Anxious to know if she really had cancer, Noma took the sample to the private lab. She was asked to return for her results in a week's time. On Thursday of the week after that, feeling too weak to travel, she asked Phephisa to collect the lab results for her. When Phephisa picked up the sealed envelope and opened it, she could not make sense of the scientific jargon. So she went to Dr. M, a family friend, and asked him to help her. Dr. M told Phephisa that he could not fully understand the results either, since oncology is not his field. He advised her to go back to the gynecologist back NGH.

When she finally arrived at NGH, exhausted and anxious, Dr. S, the gynecologist, took one look at the laboratory report and confirmed her worst fears: Noma had advanced stage cervical cancer. "What do we do now?" Phephisa asked tearfully. Dr. S shrugged his shoulders. What he said next was disheartening: "There isn't much we can do for her here. Even if she comes, we can't help her, the cancer is too advanced. The only thing we can do is refer her to the Mercy Memorial Hospital (MMH).

Phephisa and Noma made the four-hour journey to MMH with sadness, though clinging to the hope that they would get the assistance they needed. Phephisa admits that not knowing what to expect was nerve wracking. Unfortunately, when they got to MMH, their hopes were dashed yet again. Dr. K, the gynecologist on duty at MMH, told Noma that there was nothing they could do to help her. Phephisa narrated what happened to me:

> They told us they can't help us at MMH, they will refer her to South Africa. I don't know. Ok, we were hoping that in Mbabane, they will help us, but it was the same story. They can't help us, it's more advanced now. I actually begged uh, like I begged that they help her or else just remove the whole thing, you know. But they said no because she is an elderly woman now, and it is advanced. So they said it's out of their hands, she should go to South Africa.

Following the conversation with Dr. K, Noma was admitted to MMH for observation. In order to go to South Africa, she would need a referral letter from MMH and formal funding approval for out-of-country treatment. Such funding is typically provided in cases where treatment is not locally available. In the case of cervical cancer, hysterectomies can be and are routinely done at NGH, MMH and other hospitals around the country. However, chemotherapy and radiation therapy are, as of the time of writing, not available anywhere in the country. All patients needing chemotherapy or radiation therapy are thus often referred to hospitals in South Africa. The referral and funding process is a long and complex one, often involving months of waiting. Both Anne, the supervising nursing sister, and Lindy, the gynecological nurse in the cervical screening clinic at NGH, told me stories of cervical cancer patients who waited almost a year for funding. Most of those patients died before they ever got a chance to go to South Africa.

In Noma's case, she managed to secure an initial meeting with a board that could approve her funding. The meeting was scheduled for a Wednesday afternoon at 2pm, one month after her admission to MMH. Unfortunately, Noma died at 1.20pm that Wednesday afternoon, just 40 minutes before she was to meet the board. Phephisa was in tears as she narrated what happened:

> She died while they were trying to put a drip, because they said her BP [was] very low. So they were just trying to stabilize it until 2pm for us to go to, I mean to go to the board… So I had to go there [to the board] to cancel the appointment and yah. So I, I don't know if she had gone to South Africa whether she was going to get help or not. I would have loved to see that day. It was unfortunate.

Noma's story is painfully illustrative of the challenges faced by women after a cervical cancer diagnosis in Swaziland. Socio-structural challenges within the public healthcare system make the process of seeking cervical cancer treatment a long, complicated and expensive one. The burden of paying for transportation to and biopsy analysis at private laboratories, the lengthy referral and funding approval process, the uncertainty of treatment in South Africa, the possibility of death away from home, and the pain of unrealized hopes all converge to create a terrifying scarcity around cancer treatment in Swaziland.

In her ethnographic account of cancer in Botswana, Livingston addresses a similar relative scarcity of tertiary care for cancer, where there often aren't enough beds, machines, expertise or drugs. This scarcity occurs amidst growing hopes in oncology's ability to prolong life and ease suffering, as well as cases of therapeutic futility (Livingston 2012). In her work on cancer hospitalization in Kenya, Mulemi shows how cancer patients enter the hospital holding high expectations of recovery, believing that admission guarantees a high chance of rehabilitation (Mulemi 2008). In Swaziland, the collision of structural barriers to cervical cancer treatment and hopes of recovery create an incredibly complex clinical space.

Further, therapeutic travel to South Africa, which can lead to death away from home, creates and sustains fear of cancer. This is a contrast to how travel works to create safe spaces for cervical screening as I discussed in chapter three. Sindi, who I interviewed in a private room at NGH, first went for screening in 2012. She told me that she was supposed to have gone back for a follow up screening exam in 2014, but she did not. I quoted Sindi earlier in reference to her thoughts about HIV and ART access. She went on to tell me:

> I think, as for me I fear cancer, because there are many that I have heard "so and so has died, because of cancer." There are many who have had cancer and end up… they end up dying. One person went for chemo, she went to South Africa, and she came back from South Africa dead… When she had the chemo the first time, when she returned, the cancer came back again. Then the second time, she went back where they had treated her [South Africa], and she couldn't reach, it defeated her. She returned dead.

The woman whose experience Sindi narrates was her neighbor, Amanda. Like Noma, Amanda had gone through the usual referral and funding process. Fortunately for her, after a wait of five months, Amanda was able to get the funding and proceed to a hospital in South Africa for chemotherapy. After the first round of chemotherapy, she came back home and told her neighbors, Sindi included, that she felt much better and was on the road to recovery. Unfortunately, her cancer relapsed soon after that. She then embarked on a second trip to South Africa, accompanied by her husband and an elderly aunt. Sadly, she died on the way to South Africa. Her husband and aunt brought a lifeless Amanda back home to Swaziland.

Amanda’s death away from home, en route to South Africa, was a devastating shock to Sindi and the rest of Amanda’s neighbors, friends and family members. The thought of such a tragic death terrifies Sindi, and makes her hesitate to return for screening. Stories like Amanda’s – of death, therapeutic failure and futile travel – are shared through social networks among women in Swaziland. They converge to create and sustain a narrative of cervical cancer as virtually hopeless, feeding fear of the disease. This fear of cervical cancer, in turn, leads to fear and avoidance of cervical screening.

Further, it contributes to a local narrative of cancer as fatal. During my interview with Phephisa, she asked me several times if cancer is really curable. She told me, “I don’t know if maybe she [Noma] would have lived, I don’t think so. This cancer kills.” Most other women I interviewed echoed the idea that cancer is inevitably fatal.

When discussing fear of cancer, most international public health literature often focuses on fatalism. What I encountered in Swaziland was logical fear, rather than irrational fatalism. Cancer fatalism has been classically defined as the belief that “death is inevitable when cancer is present” (Powe and Finnie 2003, 454). Straughan and Seow have argued that fatalism influences self-efficacy, which in turn affects the acceptability of screening tests such as the Pap smear, mammography and breast self examination (Straughan and Seow 1998). A recent study among women attending cervical screening in Zambia also discussed elements of fatalism among participants, who associated cervical cancer with pain, imminent death and hopelessness (White et al. 2012). Medical anthropologists Drew and Schoenberg have criticized the fatalism construct because it tends to further stigmatize populations that are viewed as problematic or ignorant. They argue instead that social and economic constraints that shape women’s health seeking strategies allow for a more nuanced explanation. In a context where women have witnessed friends or family members diagnosed, hospitalized and succumbing to cancer, it is rational to perceive cancer as a death sentence (Drew and Schoenberg 2011).

In keeping with Drew and Schoenberg, I argue that the data here presented from women in Swaziland does not necessarily show irrationally fatalistic beliefs as feeding fear of cancer and avoidance of cervical screening. Rather, women express fear of cancer pragmatically, as a logical conclusion based on personal experiences or observations of therapeutic failure and the structural challenges involved with accessing cancer treatment in Swaziland. As Ayanda, who I met at a private diner in town, told me:

> Because once you have cancer, there is nothing, you are just waiting for the grave. Many have died, many. We see them, they look fine, then suddenly they get sick, this cancer thing, and they die. Some even go to South Africa, and they still die. As for me if they say I have cancer, I will just take a weevil tablet and end it [kill] myself. No, this cancer is too strong.

Ayanda here expresses a sense of hopelessness and fear relative to cancer, again based on what she has seen and heard about cancer patients around her. Her fear is rational, given the reality of the structural challenges one is faced with when seeking cervical cancer treatment. These challenges are the result of the macro global and local configurations around cervical cancer treatment in Swaziland. In this context, fear of cervical cancer and screening makes logical sense.

4.4 When HIV is Better

The clinical inequality between HIV and cervical cancer, in terms of treatment availability and access, has created a social inequality. This inequality positions HIV as better than cancer, directly impacting women's fears and their choices about cervical screening use. Nolwazi's response to my question about HIV and cancer captures the thoughts of many of the women I interviewed:

> You know HIV is now better than all other diseases. Cancer kills, diabetes kills. HIV is better, at least you continue, you just live as a whole person. But this one [cancer], other times you don't live really… But with HIV, you take your ARVs, and there is no one who will point at you and say, "This one is HIV-positive." You will just live like all other people…

HIV is better because of a convergence of the multiple configurations already discussed: the global medicoscapes around HIV, ART accessibility, a sense of therapeutic citizenship, as well as the clinical and social gains that have been made over years of local and international intervention. Conversely, the lack of these factors positions cervical cancer on the opposite end of the spectrum. When women consider, personally experience or witness these differences as people in their social networks succumb to cancer, they conclude that it would be better to have HIV/AIDS than to be faced with cancer. This construction does contribute to a hesitation to attend cervical screening. However, rather than an irrational fear of cancer, it is a pragmatic realization of the unfortunate lack of options, and the uncertainty, that follows a cervical cancer diagnosis in contemporary Swaziland.

Complimentary to women's comments, nurses often talked about the difference in clinical location between HIV and cancer. This clinical difference makes the experience of caring for cancer patients a particularly challenging one. I earlier quoted Anne, the supervising nursing sister for the cervical screening clinic at NGH. Anne had a lot to share based on her nearly 29 years of experience as a nurse and nursing supervisor at NGH. In addition to her thoughts about the productivity of HIV/AIDS interventions, she told me about her experience of working in the gynecological ward at NGH and providing palliative care for cervical cancer patients:

> Working there? It's painful. You see that this thing [cancer] is there, and there to stay. You cannot remove it, and you can't help this person. Even if you give the painkiller, you are not removing the problem from this person. The problem is just permanent and there is nothing much you can do, except to talk to this person and let her understand… It's not an easy thing, its not. It's just like when HIV and AIDS, you know, when there was nothing we could do. It's just like those days. But this cancer is on the rise these days, and its taking young people. Ok even older ones but when you find the young ones, it's difficult.

The clinical scarcity of cancer care reduces the nursing role to one of conversation and emotional comfort. The cervical cancer ward is fraught with difficulty for patients as much as for nurses. Anne describes cancer as an ever present scourge, one against which she often feels powerless. These feelings of powerlessness and despair arise out of the reality that there is so little that Anne can do to "remove the problem" of cancer from her patients. She wishes she could offer some type of radiation therapy or chemotherapy to give her patients a fighting chance, however big or small. Yet, NGH does not have the resources for these treatment options. For Anne, this clinical scarcity brings back memories of her nursing work in the early days of the HIV/AIDS crisis. It limits the scope of her role to talking to patients and supporting them emotionally, rather than helping to provide viable treatment options, thus putting them on the road to better health. Other nurses I interviewed echoed Anne's thoughts.

Clinical scarcity also complicates communication between nurses and patients. This is not because of a failure on the part of nurses or women. However, uncertainty is inevitable in the multi-step process of diagnosing cancer. A suspicious lesion seen during a cervical screening exam is still only a suspicion, however strong. In order to positively confirm cancer, a biopsy test is necessary. Getting the biopsy test done often requires additional time and travel. The waiting period between the initial cervical screening exam and biopsy results is a difficult one for patients, as many women told me during interviews. Nurses, for their part, hesitate to put women into such a position of uncertainty. Lindy, the gynecological nurse, explained it this way:

> If it a pre cancerous lesion, but if we suspect that this is cancer, the doctors do the biopsy. It's quite sad but we, but we have to [tell them]. Like even in HIV, when we started telling the patients, it was difficult but you get used to it. You let them know cause its what they want to know.

Summarily, women and health workers alike understand cancer as a fearful disease that destroys lives and leaves little hope of cure and survival. HIV, which has its own complications and tragic consequences, is rendered better than cervical cancer merely because of a readily accessible pathway to ART. ART makes it possible to manage and live with HIV. Cancer, on the other hand, appears unmanageable. This is not necessarily because cancer is clinically incurable. Rather, in the current clinical context in Swaziland, treatment is elusive, expensive and not always successful. Thus, cancer is worse than HIV. Clinical inequality translates into social inequality.

4.5 Conclusion: the Politics of Space Making

In this chapter, I have argued that women's fears about cervical screening are logical, situated within complex configurations of clinical space making. Women's fears need to be understood in the context of clinical configurations relative to cancer treatment that they know, experience or hear about: expensive private lab biopsies, long referral processes, long waiting lists for funding for out-of-country treatment, therapeutic travel to South Africa, the possibility of treatment failure, and death away from home. These configurations result from the unequal convergence of global medicoscapes, which has created social and clinical differences between HIV and cervical cancer.

The differentiation between HIV and cervical cancer is ultimately the result of political choices; choices made not only by the Swazi government, but also by local and international NGOs that continue to drive a heavy focus on HIV. Admittedly, a focus on HIV is necessary in Swaziland, which still has the highest HIV/AIDS prevalence rate in the world. Yet, HIV/AIDS is a political crutch: it has become politically costly for development agencies and governments not to engage HIV/AIDS (Biehl 2007). That political incentive is not yet there for cervical cancer, because a global solidarity has yet to build around cervical cancer in Africa. Thus, to a large extent, the heavy focus on HIV/AIDS is political. This does not necessarily mean that there is an exclusively political agenda behind the over crowding in the HIV/AIDS service provision scene in Swaziland. Rather, it demonstrates how politics can filter into and affect public health programming.

Against this backdrop, the fear of cervical screening is ultimately a fear of what comes after screening. It is a fear of uncertainty. Previous scholarship has shown how an abnormal pap smear may create disorder for a woman (Forss et al. 2004), as well as varying levels of uncertainty and ambiguity (Howson 2001). However, the uncertainty that surrounds cervical screening in Swaziland does not stem from an abnormal Pap smear alone; it is a product of the social and clinical context of cancer treatment. It is uncertainty about when and if funding for treatment in South Africa will be approved, uncertainty about how treatment will proceed, uncertainty about whether or not one will come back from South Africa alive, uncertainty about what life will look like even if treatment is successful. These are real, pragmatic, existential concerns that cannot be ignored if Swazi public health is to make gains in cervical cancer prevention.

Addressing these challenges requires money, and money management is inherently political. This is especially true in Swaziland, where so much of the health system is under government control. As Erikson reminds us, some global health victories inevitably depend on how well international politics are played (Erikson 2008). For cervical cancer in Swaziland, victory will depend on the political will and lobby to redirect funding, and expand cancer treatment and programming.

CHAPTER 5: Conclusion

Within global public health, there is a tendency to make assumptions about fear in the cultural ‘other.’ Specific to cervical cancer in Africa, epidemiological assumptions tend to blanket fear of cervical screening as culturally produced and rooted. Critical of this pejorative construct of African women and their cultures, I set out to understand and examine the layers of fear relative to cervical screening in Swaziland. Specifically, I asked: To what extent do clinical configurations around screening and treatment contribute to fear of cervical cancer and screening in Swaziland? How does nursing practice influence women’s choice about cervical screening use? Responses from women and nurses reveal a very complex yet logical fear, situated within entanglements of clinical, social and political configurations. This argues against culture-based assumptions, and calls attention to the intimate consequences of the syndemic confluence of local clinical contexts and global health agendas.

Each chapter in this thesis has examined a different, yet interconnected, aspect of fear. First, previous negative experiences of neglect, verbal abuse or the pejorative judgment of women’s bodies by nurses influence many women’s fears of cervical screening. For their part, nurses working within public hospitals are often overworked, underpaid and confronted by a host of politically produced resource and personnel challenges. Thus, cervical screening happens in the context of a laborious clinical encounter, affected by socio-structural factors that impact both women and nurses. Second, women express a preference for experiencing cervical screening at geographically distant hospitals, with socially distant nurses. They do this because of a fear of nurse-initiated gossip. Distance thus provides social safety, and helps women experience freedom rather than fear in the clinical encounter of cervical screening. Third, the scarcity of cancer treatment options, combined with the lengthy and often expensive diagnosis and referral process, deters many women from seeking cervical screening. Combined with knowledge of therapeutic failure and death – often gained through social networks – treatment scarcity lends to a local construction of cancer as a death sentence. Rather than denouncing this fear of cancer death as irrational fatalism, I have argued that this fear needs to be understood in the context of the extremely complex social, clinical and political configurations of cancer treatment in Swaziland.

These complex configurations converge to create a syndemic influence on women's choices about cervical screening use. Ribera and Hausmann-Muela describe a syndemic confluence of adverse conditions that influence health-seeking behavior relative to malaria. They argue that these adverse conditions converge at cyclical moments or periods in time to create conjectures of vulnerability. Thus, they conclude that dealing with malaria calls for actions that go beyond interventions solely focused on health, and advocate for approaches that address the roots of the problem, considering factors such as gender inequities, political commitment and long-term approaches (Ribera and Hausmann-Muela 2011). As such, effective action must seek to both understand and address the conjectures of vulnerability that impact health-seeking behavior.

Similar to Ribera and Hausmann-Muela, I argue that decisions about cervical cancer screening are made by women at conjectures of suffering, where social, clinical and political factors converge in a complex arrangement that directly impacts women's lives. At these conjectures of suffering, negative experiences of nursing care collide with fears of clinical gossip to create and sustain a context of fear around cervical screening. This fear is logical, in so far as it comes out of women's experiences, either personal or shared through their social networks. Women manage fear by either avoiding cervical screening, or navigating less fearful pathways to cervical screening, as discussed in chapters two and three. Yet and still, even those less fearful pathways face the politically produced realities of cancer treatment scarcity and expense discussed in chapter four. These factors collide to create a syndemic influence on women's choices.

Inevitably, progress in dealing with cervical cancer in Swaziland will require changes to the clinical context in which screening and treatment occurs. There are promising signs in this regard. As of the time of writing, a chemotherapy unit is under construction at a major public hospital. When I spoke to the manager of an internationally funded local NGO, she could not stop talking about this new development. Undoubtedly, this is a significant step forward, and one that I hope will be followed through with the construction of more cancer treatment centers in other regions of the country, so that treatment becomes fairly accessible to all in need.

Scaling up treatment alone will not be enough, however. Women need affordable treatment options for cancer, and a clinical environment without gossip and pejorative judgment. Nurses, for their part, need more human, financial and structural resources to be better able to do their work as primary providers of cervical screening services. Effecting these changes will require strong political lobby and will within the public hospital system, the largest provider of cervical screening services in the country.

Further, the scholarly lens through which cervical cancer in Africa is understood needs to shift. As I argued in my introduction, cervical cancer is one of those diseases that often finds itself at a complex intersection of race, culture and disease. Ultimately, fear of cervical screening, and the consequent low cervical screening use in Swaziland, are not an anomaly. They arise from the collision between local clinical worlds and global health funding agendas. Many of the factors that shape and influence fear are outside women's control. Yet, women end up bearing the brunt of the blame for low cervical screening use, in the typical culture-blame paradigm that often persists in global health.

Relative to Africa, this paradigm exists in part because of historically racialized constructs of cancer and pathologizing constructs of African femininity and sexuality. In an era where global public health prides itself on being post-racial and color blind, these pathological constructs of cancer, African femininity and sexuality collide through the exploitation of culture as a euphemism for race. This overemphasis on culture repeats and continues the historical tendency of pejoratively judging and blaming African women. The arguments presented in this thesis contribute to already existing social science critiques about the irresponsibility and inadequacy of making African women, their cultures or their sexualities default scapegoats. I hope to strengthen my contribution to this scholarship in the future by taking up the question of how local constructs of sexuality, cervical cancer and culture interact with prevailing epidemiological understandings.

Ultimately, cervical screening is not a "one-size fits all" hat. Programs that seem to work in the global north cannot just be copy-pasted into the global south and expected to work. This does not mean cervical screening programs cannot work in Swaziland, nor does it condemn attempts to scale up cervical screening services in the country. However, it does mean that the success of such programs demands close attention to the compounding aspects of clinical sociality, politics and scarcity discussed in this thesis.

In the social construction of spaces within global health (Brada 2011), it is easier to construct generic subjects (Brada 2011; Pigg 1992), and thus name enemies that may be more familiar. This is perhaps why it is easier to make scapegoats of women and their cultures, than to understand and deal with the complex clinical and political environments that often produce fear and shape women's experiences. Culture and ignorance are often more familiar enemies in global public health. Fear entrenched in clinical and political realities is harder to confront. This perspective is inherently flawed. The women and nurses I spoke to were anything but generic. Nor were they ignorant about or unreasonably resistant to cervical screening. Their experiences were as different and as unique as they were, and their fears remarkably logical. A one-size fits all approach, insensitive to the local logic of their fears, is both flawed and irresponsible.

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Appendices

Appendix 1: Interview Guide for Women

Cervical Cancer
What do you think causes cervical cancer?
Who is most at risk for cervical cancer?
Do you think women can protect themselves from cervical cancer?
If so, how? What can women do to avoid getting cervical cancer?
How would you compare HIV and cervical cancer? Why?

Cervical Screening
Where is cervical screening offered in Swaziland?
Do you know how cervical screening is done?
Have you ever been screened for cervical cancer?
[If yes] How were you treated by the nurses / clinical aides when you went for screening?
How would you describe your experience? Did you feel safe? Respected?
What happened after you received the cervical exam?
Would you go back for another cervical screening exam?
[If no] How do you explain your decision to refuse cervical screening?
Is there anything that would convince you to go for cervical screening?
What other reasons do you think women have for refusing screening?

Hospital
How would you describe the kind of care you generally receive at the hospital?
Do you feel safe? Respected? Well taken care of?
How would you describe the nurses?
What treatment or care does the hospital provide for cancer patients?

Is there anything else you would like to add that would help me understand cervical cancer in Swaziland?

Appendix 2: Interview Guide for Health Workers

Cervical Cancer

What causes cervical cancer?
Is every woman at risk for cervical cancer?
[If yes], why?
[If no], what kind of women are at risk?
What role does culture play?
How can women protect themselves from cervical cancer?
Is there a relationship between cervical cancer and HIV?
How would you compare HIV and cervical cancer? Why?

Cervical Screening

How successful do you think the cervical screening program has been here?
What support services are offered for women when they come for cervical screening?
Do you think women feel comfortable and safe when they come here for screening?
Why do you think some women are hesitant to come for cervical screening?
Is there anything you would change about the cervical screening program?
What happens after the cervical screening exam?
How do women access cancer treatment?
Do you know of any other cervical screening methods?
If so, what methods do you know of? Do you think they could work here?
Have you ever been screened for cervical cancer yourself? (Only for female health workers)
[If yes], where did you get your screening done? Why?
[If no], why not?

Hospital

How would you describe your work in the hospital?
Is there anything you would change about your job or the hospital? Why or why not?
What methods are being used to teach the public about cervical cancer?
Do you think they are effective?
What else would you recommend?

Is there anything else you would like to add that would help me understand cervical cancer in Swaziland?

Appendix 3: Study Information Sheet

Cervical Cancer Screening and Prevention in Swaziland

This research is about cervical cancer in Swaziland. Although efforts are being made by health authorities to educate the public about cervical cancer, little is known about how people in Swaziland perceive and respond to these programs. I am interested in your thoughts and experiences about cervical cancer and screening programs. I will be talking to many different types of people for this research project to get a 'big picture' perspective about cervical cancer screening in Swaziland.

If you contribute to this research, what is involved? You would talk with me about your experiences, knowledge and views in short, informal chats or in longer interviews. You would act as a guide and help me to understand cervical screening use and avoidance in Swaziland. A written consent form will be given to you before our interview. Participation is entirely voluntary and may be withdrawn at any time.

How will the information be used? I will put together what I learn to write articles and books, as well as to inform fellow students and colleagues about cervical screening use and avoidance. If requested, you will be provided with information about how the data, quotes and case examples they provide may be used, and the kinds of venues in which the research results will be presented.

Will you be identified in any of the research reports? No, your identity will be kept confidential. This may not be completely possible for public figures, such as well-known government leaders, whose activities may be in the public record and therefore recognizable. All participants, including such well-known public figures, will be assigned fictitious names and details of cases may be altered to prevent identification of participants. Research notes and recordings will remain in my possession. After 10 years I may opt to donate the research material to an archive or destroy it.

Who am I? My name is Nomthandazo Malambo, and I am a Master of Science candidate in the Faculty of Health Sciences at Simon Fraser University in Canada. I am studying under the supervision of Dr. Susan Erikson, Associate Professor of Global Health. From 1993-2004, I lived and studied in three towns in Swaziland. I speak SiSwati and Zulu, as well as English and French. The Office of Research Ethics of Simon Fraser University has approved my research project, [list approval reference number].

How can you contact me?
In Swaziland: [redacted]
In Canada: Nomthandazo Malambo, [redacted] [redacted]@sfu.ca, [redacted] You may also contact my supervisor, Prof. Susan Erikson, Associate Professor of Global Health, at [redacted]@sfu.ca, [redacted]

How can you get the results of this research? Contact Nomthandazo Malambo at the above contact details if you are interested in the articles, books, or other uses of this research. If you have concerns or complaints about this research you may contact: Dr. Jeff Toward, Office of Research Ethics, Simon Fraser University at[redacted]@sfu.ca, [redacted] [redacted]

Appendix 4: Intake Questionnaire for Women

Date:

How old are you?

Were you born in Swaziland?

If yes, where in Swaziland were you born?

If no, where are you born?

Where have you lived in the last ten years?

Have you known a man?

Are you married?

If yes, how long have you been married?

Have you heard about cervical cancer before today? If so, where?

How often do you visit the hospital?

Have you had a cervical exam before?

Appendix 5: Intake Questionnaire for Health Workers

Date:

Gender:

Profession: (Nurse, doctor, community health worker or other?)

How long have you worked at this hospital?

Are you involved with the cervical screening program?

If so, how did you become interested in this work?

Would you classify cervical cancer as a sexually transmitted disease? Why or why not?

How important is cervical screening compared to screening for other diseases? On a scale of 1 to 10, with 1 being not important and 10 being very important.

Do you think all women should be screened for cervical cancer?

If no, what kind of women do you think should be screened?

What do you think is responsible for the rise in cervical cancer in Swaziland?

Self-collection cervical screening methods have been tried in other countries. Do you think they would work in Swaziland? Why or why not?