

How socio-cultural factors affect cervical cancer screening adherence and treatment in disadvantaged communities in the Greater Cape Town, South Africa.

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A dissertation submitted in fulfillment of the requirements for the award of the degree
of Master of Social Science in Research Psychology

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Dedication

In loving memory of Avó, granny [Maria Correia Mestre Da Silva (1942-2012)]

For always being there for all your grandchildren and children, for showing us what it meant to be a strong woman even when life had not been kind or easy. Although as a young girl I did not realise it, I've learnt so much about what it means to give back and be there for my family from you. For always being a gran that would drop anything to help me. For all your love and prayers, a true woman of faith and love. Watching you battle the last stages of cancer was so hard, knowing the joy and energy you always had for life. Yet despite it all, you never once complained in your battle. Sadly the cancer was too much in the end, but I know you are in a better place, a place with God filled with peace and love where there is no pain. Although you are not with us anymore, you still inspire me to be a strong woman, and I see your love and strength play out through your own daughter, my mom. *Everything that I do, I do it for you*, always and forever, I love you.

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Abbreviations

ACCP	Alliance for Cervical Cancer Prevention
CAM	Complimentary and Alternative Medicine
FG	Focus Group
MKI	Medical Knowledge Institute
Pap	Papillomavirus
WHO	World Health Organisation

Abstract

Approximately 85% of the global cervical cancer deaths occur in women living in developing countries. In South Africa, cervical cancer is the second most common cancer amongst women, with Black South African women having the highest risk of developing cervical cancer. Previous research with the same population group found that there are structural (time, health education, age) and psychosocial (fear of screening and stigmatization) influences to cervical screening. The purpose of this research was to identify socio-cultural factors affecting cervical cancer screening adherence within a disadvantaged community in South Africa, a developing country.

To identify the social-cultural factors four focus groups consisting of men and women between the ages of 18 and 60 were conducted. A combination of the Health Belief Model (HBM) and Theory of Reasoned Action (TRA) provided a theoretical framework for this study. Thematic analysis was used to identify themes that emerged from the focus groups and participant observation.

Through conducting these focus groups, themes emerged which strongly highlighted the role of cultural norms, gender roles, the western medical model and traditional medicine in a woman's decision to adhere to cervical screening. It was found that factors such as knowledge and stigma, found previously in research, were also shared amongst this sample group. However, spiritual and religious beliefs (traditional healers, religion, and balancing paradigms), gender beliefs, social construction and acceptance of disease were factors which also emerged as exerting influence in a woman's decision to adhere to cervical screening.

This knowledge highlights the need to invest in public health outreach that has a social and culturally relevant approach for the population group being targeted. The findings also indicate that women in disadvantaged communities require medical and health knowledge dissemination which is both socially and culturally relevant for such knowledge to have a positive impact.

Keywords: Cervical cancer, socio-cultural factors, Pap smear screening, South Africa, screening adherence

Table of Contents

Plagiarism Declaration	2
Dedication	3
Acknowledgements	4
Abbreviations	5
Abstract	6
Chapter 1	9
Introduction	9
1.1 Focal Research Question.....	9
1.2 Rationale for Research Study.....	9
Chapter 2	10
Literature Review	10
2.1 Background Research for Study	10
2.1.1 Global and South African Context	10
2.1.2 Cervical Cancer Prevention Screening and Treatment	12
2.1.3 Influences on Screening Adherence	13
2.1.3.1 Gender Factors	13
2.1.3.2 Socio-economic Factors	16
2.1.3.3 Socio-cultural Norms	17
2.1.3.4 Beliefs	18
2.1.3.5 Social Support.....	18
2.1.3.6 Health Service System.....	20
2.1.3.6.1 Patient Satisfaction	20
2.1.3.6.2 Accessibility	20
2.1.3.7 Marginalised Position	21
2.1.3.8 Language.....	22
2.1.3.9 Knowledge	22
2.1.3.10 Complementary and Alternative Medicine in South Africa ..	23
2.1.4 Integrated Prevention Programme	25
2.1.5 Psychological Theories of Cervical Screening Behaviour.....	27
2.1.5.1 The Health Belief Model	27
2.1.5.2 The Theory of Reasoned Action	28
2.2 Theoretical Framework.....	30
2.2.1 Combination of the Health Belief Model and the Theory of Reasoned Action	30
2.3 Summary	33
Chapter 3	34
Methodology	34
3.1 Aim of Research	34
3.2 Participants and Sampling Procedure	34
3.2.1 Inclusion Criteria	35
3.3 Data Collection Methods	35
3.3.1 Focus Group.....	35
3.4 Data Collection	37
3.5 Data Analysis	44

3.5.1 Thematic Analysis	44
3.5.2 Validity	45
3.5.3 Reliability.....	46
3.6 Reflexivity.....	46
3.7 Ethical Considerations	47
3.7.1 Consent and Confidentiality	47
3.7.2 Voluntary Participation.....	48
3.7.3 Risks and Benefits for Participants.....	48
3.8 Limitations	48
3.9 Summary	48
Chapter 4	50
Discussion and Analysis.....	50
4.1 Gender.....	52
4.1.1 Loss of Womanhood.....	52
4.1.2 Male’s Role.....	55
4.1.3 Practitioner Gender	57
4.1.4 Privacy	58
4.2 Spiritual and Religious Beliefs	63
4.2.1 Traditional Healers.....	64
4.2.2 Religion.....	71
4.2.3 Balancing Paradigms	74
4.3 Home Remedies	75
4.4 Knowledge	76
4.4.1 Lack of Knowledge.....	77
4.4.2 Desire for Knowledge.....	84
4.4.3 Misperceptions.....	87
4.4.4 Disease Social Identity.....	90
4.5 Stigma	93
4.6 Summary	98
Chapter 5	99
Conclusions and Recommendations.....	99
5.1 Summary of Findings.....	99
5.2 Reflexivity.....	105
5.3 Limitations	106
5.4 Recommendations for Future Research.....	108
5.5 Conclusion	109
Reference List.....	111
Appendices.....	125
Appendix 1A: Take Home Information Sheet.....	125
Appendix 1B: Take Home Information Sheet (isiXhosa).....	127
Appendix 2A: Informed Consent Form.....	129
Appendix 2B: Informed Consent Form (isiXhosa).....	130
Appendix 3: Focus Group Interview Guide	131
Appendix 4: Diagram 1. Combination of HBM and TRA model.....	132
Appendix 5: Diagram 2. Flow diagram of themes	133

Chapter 1 Introduction

1.1 Focal Research Question

This research is focused on investigating social and cultural factors that influence the uptake of cervical cancer screening in disadvantaged communities in South Africa, and the impact that these factors have on cervical cancer screening adherence.

1.2 Rationale for Research Study

Although cervical cancer is easily preventable, it is still the second most common cancer experienced by South African women (World Health Organisation [WHO], 2010). This investigation will highlight obstacles to screening for the prevention of cervical cancer. Knowledge and discussion of these obstacles will increase screening adherence of cervical cancer. By understanding the social and cultural factors that may act as facilitators and barriers towards cervical screening adherence, a more effective and culturally sensitive approach can be taken when trying to increase adherence to cervical screening. In addition, the screening adherence increase may extend into other health-seeking behaviours.

The findings of this study can be used to create and implement a culturally appropriate community educational programme around cervical cancer screening. This educational material can be used to train community health information providers who can educate the community using materials that are culturally appropriate and also medically accurate. Furthermore, the value and importance of culturally appropriate educational messages with regard to health-seeking behaviour will be emphasised. Understanding barriers to cervical screening adherence is very important for South African public health developments. Findings from the study can serve to assist health policy planners in South Africa in order to improve the acceptance of, and adherence to, cervical cancer screening services available at local clinics. With this information, perhaps cervical cancer prevention interventions can be prioritised. These findings can serve to guide other health policy planners in settings similar to that of Khayelitsha, South Africa; a disadvantaged community in a developing country. These experiences of women can be helpful to influential global health organisations, which can utilise the information for further development of prevention methods for other diseases in disadvantaged settings.

Chapter 2 Literature Review

Much of the research on cervical cancer and screening adherence has had an international focus with few research studies having concentrated on the South African context. The following review will highlight the global and national statistics and effects of cervical cancer, then focus on the cervical cancer prevention screening protocol and policy as it stands in South Africa. It will then review previous research highlighting factors that have an influence on cervical cancer screening adherence. Finally, it will outline the psychological theories used to understand adherence behaviour related to cervical cancer screening.

2.1 Background Research for Study

2.1.1 Global and South African Context

Globally, cervical cancer is the fourth leading cause of cancer death amongst women, and the third most common cancer among women (Wright & Kuhn, 2012). Worldwide, there are approximately 500 000 annual cases of cervical cancer, with 280 000 deaths from cervical cancer (Wright & Kuhn, 2012). This indicates the global mortality incidence ratio to be 53%. According to research, approximately 85% of global cervical cancer annual deaths and new cervical cancer diagnosis occur amongst women living in developing countries (Bradley, Barone, Mahe, Lewis, & Luciani, 2005; Denny et al., 2005; Miller et al., 2007; Sherris et al., 2005; Wright & Kuhn, 2012), while cervical cancer accounts for 13% of all cancers in women of developing countries (Wright & Kuhn, 2012).

Overall, cervical cancer is still the most common cancer that occurs amongst women in developing countries (Mosavel, Simon, Oakar, & Meyer, 2009; Wright & Kuhn, 2012). In sub-Saharan Africa, cervical cancer accounts for approximately 20-25% of newly diagnosed cancers (Abotchie & Shokar, 2009). Amongst South African women, cervical cancer is the second most common cancer (WHO, 2010). It has been indicated that approximately 5,743 South African women are diagnosed with invasive cervical cancer each year. Despite the available screening and treatment for early stage cervical cancer, 3,027 (53%) of the 5,743 South African women will die each year (WHO, 2010).

Cervical cancer, being the most common cancer occurring in women in developing countries, is largely due to the failure of sustaining or initiating a cervical screening programme within these countries. Without the initiation and maintenance of a screening programme, this preventable and treatable disease will continue to cause high levels of mortality amongst women residing in disadvantaged communities and countries (Wright & Kuhn, 2012). This is because, unlike many cancers, cervical cancer is one of the most easily and effectively preventable types if detected at an early stage (Sherris et al., 2005). Within South Africa it has been indicated that population coverage of screening is often very low. Although screening services are available in urban and peri-urban areas, previously it had been found that 80% of South African women had not ever been screened (Bradley et al., 2005). Research shows that, if all women could avail themselves of the existing screening (Pap smear) programme (a two-visit plan of a Pap smear and a follow-up colposcopy and treatment), there would be an immediate reduction of 19% in cervical cancer rates in South Africa (Bradley et al., 2005).

South Africa is known as a high-risk region with regard to its age-standardised incidence rate of all cancers in women of over 20 per 100,000 (Wright & Kuhn, 2012). In a study in South Africa, it has been documented that women having had a once off Pap smear had 70% lower odds of developing cervical cancer than their counterparts who had not had a Pap smear (Mosavel, Simon, Oakar, & Meyer, 2009). However, the risk of disease differs for the various ethnic populations in South Africa (Redelinghuys & Van Rensburg, 2004; Smith, Moodley, & Hoffman, 2003). Due to the injustice apartheid system and the past social inequalities it created, there were large disparities created, including that many Black South Africans have not always had optimal access to best medical services and therefore knowledge about diseases such as cervical cancer (Francis et al., 2010; Moodley, Kawonga, Bradley, and Hoffman, 2006; Mosavel, Simon, van Stade, & Buchbinder, 2005; Pillay, 2002). Amongst Black South African women, cervical cancer is the most common form of cancer (Mosavel et al., 2009). In South Africa, Black women have a 1 in 34 risk, while for Coloured women it is a 1 in 52 risk, for Indian a 1 in 54 and for White a 1 in 93 risk (Redelinghuys & Van Rensburg, 2004).¹ Previously, it had been found that

¹ In South Africa, these are the accepted terms that are used to describe various ethnic groups.

60.5% of Black South African women had never been for a Pap smear (Peltzer, 2001).

2.1.2 Cervical Cancer Prevention Screening and Treatment

As the development of cervical cancer is relatively slow, screening that takes place infrequently is still able to reduce mortality rates (Bradley et al., 2005). In populations which have never undergone Pap smear screening a large reduction of between 60-90% in invasive cervical cancer incidence is shown if a successful three-year period of Pap smear screening is achieved (Suba et al., 2006). Screening every three years creates almost the same impact as screening annually, while disease can be reduced by up to 40% if screening is done every 10 years (Bradley et al., 2005). The aim of the screening programmes is to reduce the cervical cancer mortality rate. This is achieved via early screening and detection of abnormal cells lining the cervix (Kelaher et al., 1999).

When there is an abnormal Pap smear result, a follow-up visit of either repeat Pap smears or, when required, colposcopy and biopsies of abnormal areas is needed (Chigbu & Aniebue, 2012; McKee, Lurio, Marantz, Burton, & Mulvihill, 1999; Miller et al., 1997; Paskett, Carter, Chu, & White, 1990).

Bradley et al. (2005) cites projects by the Alliance for Cervical Cancer Prevention (ACCP) that have indicated that the requirement of multiple visits results in a loss of returning patients for follow-up of up to 10-25% at each visit. Yet, despite this, it is still more advantageous to have this system of screening in place as opposed to no screening plan. The alternative to not detecting the lesions at an early stage is that cancers will only be detected when they are at an invasive stage. Invasive cancer of the cervix requires more drastic and more expensive treatment. In most situations, the treatment for invasive cancer of the cervix includes radiation therapy, radical hysterectomy or palliative care (Bradley et al., 2005; Marcus et al., 1992).

The five-year survival rate for stage I invasive cancer of the cervix is estimated to be between 80-90% if appropriate treatment is acquired. At stage II, the rates drop dramatically to between 50-60%, and even more significantly at stages III (less than 30%) and IV (less than 15%). These survival rates highlight the importance of early detection and therefore screening adherence. This is necessary in order to reduce morbidity and mortality rates of cervical cancer sufferers (Thomas et al., 1995). It underlines the necessity for patients with abnormal smears to follow the treatment protocol (Berget & Lenstrup, 1985).

A critical link to the development of cervical cancer is the influence of the human papillomavirus (HPV). HPV plays a role in the onset and progression of the disease, being responsible for 62.8% of invasive cervical cancers (WHO, 2010). HPV infection is commonly found in the anogenital tract of women (Clifford, Franceschi, Diaz, Munoz, & Villa, 2006). Previously, a strong link was established between HPV and cervical cancer amongst young women (WHO, 2010). With the highly stigmatising nature of HPV, and the strong relationship between HPV and cervical cancer, it is imperative to consider the influence of this HPV related stigma and how it might have an effect on adherence to screening and treatment. This is particularly worrying as approximately 21% of South African women carry this sexually transmitted disease (WHO, 2010).

In light of available statistics, the South African National Department of Health has since introduced a free screening policy. This policy ensures that every woman aged 30 years and older has the right to a free Pap smear every 10 years (Mosavel et al., 2009). South Africa has integrated cervical screening into existing primary health service centres (Bradley et al., 2005; Tsu & Pollack, 2005).

Some of the recommendations from the ACCP are to primarily reach the unscreened women first and then to focus on women who are at the high-risk age (30-49 years) (Bradley et al., 2005). With regard to these recommendations, South Africa has attempted to adhere to them in forming the screening policies. This is crucial, as a survey by the World Health Organisation indicated that only 13.6% of South African women had received a Pap smear in the 2001/2002 period (WHO, 2010). Purely ensuring that the service of cervical screening is of good quality is not enough to promote utilisation. Disadvantaged, low-resource populations present with an extra challenge as this preventative screening serves a primarily asymptomatic population that is already struggling to cope with the pressing day-to-day problems of survival (Tsu & Pollack, 2005).

2.1.3 Influences on Screening Adherence

There are many reasons for the poor uptake of screening services. Some reasons include domestic gender factors, socio-cultural norms, social support, awareness, economic factors and barriers within the health system (Busingye, Nakimuli, Nabunya, & Mutyaba, 2012).

2.1.3.1 Gender Factors Women have been known to have an overall subordinate position in the family and society (Markovic, Kesic, Topic, & Matejic,

2005). In many sub-Saharan African countries, including South Africa, women are raised to be subservient to their male counterparts, and this extends specifically to their sexual relationships (Heunis, Wouters, & Kigozi, 2012). Women are seen to show a great concern to live up to the expectations placed on them of what the correct female behaviour should be, thus further indicating the power of the male partners' attitude and belief (Holroyd, Twinn, & Adab, 2004). This position has poorly affected women's ability to access preventative cervical cancer screening.

A Khayelitsha ACCP project recognised the crucial and influential role that men in South Africa can have in increasing women's involvement and adherence to screening (Agurto et al., 2005). Both men and women have said it is crucial to involve the sexual partner in the process of deciding if the woman is to get screened for the prevention and/or treatment of pre-invasive cervical cancer (Blumenthal et al., 2007). It is indicated that, if partners knew that the treatment that was offered was to further prevent cervical cancer, they would be more supportive (Chigbu, Onyebuchi, Ajah, & Onwudiwe, 2013). It was also indicated that it was useful to include male partners in the counselling sessions when women required treatment for an abnormal Pap smear (Agurto et al., 2005). This resulted in higher levels of compliance with regard to post-screening treatment (Agurto et al., 2005).

Studies done in developing countries in Latin America indicated that the partners' lack of acceptance of cervical screening is found to be a barrier amongst women (Agurto, Bishop, Sanchez, Betancourt, & Robles, 2004). In some rural areas, the lack of acceptance is particularly strong when the practitioner conducting the screening is male. Some men also view the label a woman receives after screening, as a problem. If a woman receives a positive result from a cervical screening test, she is labelled and seen as dirty. Men view their wives' positive screening result as a challenge to their "ownership" of their wives. By having a positive screening result, women are suspected of sleeping around, indicating that their husbands have no control over them (Bingham et al., 2003).

Internationally, as well as in South Africa, gender inequalities are one of the main driving forces increasing the spread of disease (Heunis et al., 2012). When an illness affects a society, those who are most vulnerable will suffer the most. Women are at a higher exposure to the cycle of poverty and high-risk survival behaviour due to the gender inequality, culturally subservient position and discrimination that they face (Heunis et al., 2012). Women living within a patriarchal society are often

powerless against coercive sex. South Africa is perceived to have one of the highest sexual and gender-based violence rates against women, with so many women remaining vulnerable to injury and sexually transmitted disease (Mullick, Teffo-Menziwa, Williams, & Jina, 2010).

Another gender barrier to women obtaining screening is their domestic role and understood gender role (Holroyd et al., 2004; Markovic et al., 2005). Despite society having evolving gender roles, there is still a great imbalance with women performing most of the household chores. As waiting times at government clinics can be unpredictable, ranging from a few hours to the entire day, women are often away from the house for a full day to get a screening done (Bingham et al., 2003). Thus, men are reluctant to allow women to leave the house, as chores remain undone.

A study in Ecuador and Venezuela showed that some men expressed that they considered cervical screening beneficial for both women and themselves (Agurto et al., 2004). All the men expressed that they knew about the relationship of cervical cancer and HPV. This knowledge has been interpreted in two different lights. One view is that some men viewed the screening test as a STI diagnostic test to determine if their partners had other sexual partners (Agurto et al., 2004). Another stance is that the men thought screening should be frequent if their partners had previously had many sexual partners. Most of the men did not object to the practitioner being male, so long as he was experienced and well informed. In Ecuador, men partaking in a study took the stance that the disease is difficult to prevent because the population has to live with poor quality of life and overall poverty (Agurto et al., 2004).

Research has indicated that a large cultural trend is that women associate a hysterectomy with a loss of womanhood and sexuality (Bingham et al., 2003). They view the loss as jeopardising family life, failure to acquire a husband, loss of and disabling their sexual pleasure and thus resulting in divorce (Agurto et al., 2004; Chigbu & Aniebue, 2012; Mosavel et al., 2009). This causes great anxiety in women as they view themselves as lesser women, as do their partners and community members (Agurto et al., 2004). Often cervical cancer, a disease suffered by females, is framed in traditional terms as opposed to biomedical vocabulary (Mosavel et al., 2009). Women from both South Africa and Botswana described cervical cancer in terms of it eating the inside of the womb (Mosavel et al., 2009).

A study carried out in South-eastern Nigeria showed that many women prefer for their spouses to be notified of their colposcopy result, while the majority preferred

that their spouses be present during the colposcopy process (Chigbu & Aniebue, 2012).

Many women and their male partners, particularly in rural areas, are not well informed about diseases affecting female reproductive organs. It is therefore not uncommon for women, their community and their partners to incorrectly think that cervical screening purely tests for the presence of HPV or other STIs (Agurto et al., 2004; Bingham et al., 2003). Due to this association, many women choose not to get screened. In South Africa, as well as countries like Kenya, many women often incorrectly believe that, if they receive a positive result from a Pap smear, it means that they are HIV positive (Bingham et al., 2003). There is also the link with HPV to cervical cancer. Due to this link, a positive screening result is confused with a positive STI result and thus viewed as proof of infidelity (Bingham et al., 2003). Due to this, there is huge stigma attached to the process of screening. The thought of having to explain a screening result to their partners induces fear that often affects a woman's decision to attend cervical screening (Bingham et al., 2003).

Even though research has indicated that in other developing countries such as Venezuela and Ecuador, a woman's partners' lack of acceptance of screening may act as a barrier to cervical screening, or as in Nigeria, that women prefer to have their partners notified of their colposcopy results, there seems to not be much information on whether this is also true for South Africa (Agurto et al., 2004; Chigbu & Aniebue, 2012).

2.1.3.2 Socio-economic Factors Susceptibility to disease and infection is influenced by environmental threats and socio-economic factors (Heunis et al., 2012). Research has indicated that women with a higher income, access to private health insurance and constant availability of instant healthcare are more likely to have attended a cervical cancer screening than women with less income and less access to adequate healthcare (Lee, Ju, Der Vang, & Lundquist, 2010). Statistics in South Africa indicate that a large proportion of White South Africans use privatised healthcare (about 80.8%), whereas the vast majority of Black South Africans (about 84.2%) utilise public healthcare services (Heunis et al., 2012). With the public healthcare services being underfunded and overburdened, the population using these services are at a greater risk of disease than their counterparts using privatised healthcare (Krombein & De Villiers, 2006). In addition, the formal/informal divide, where there is an uneven distribution of wealth, access to healthcare and

unemployment, also influences the risk of disease for various ethnic populations in South Africa (Heunis et al., 2012). It has been well documented that poverty plays a large role in inhibiting health-seeking behaviours such as that of cervical cancer prevention screening (Holroyd et al., 2004). As seen above, the population with the highest risk for disease are disadvantaged Black women. These are women who live in informal areas and utilise an overburdened public healthcare system while dealing with unemployment, poverty and violent, life-threatening crime. Thus, the study was undertaken in Khayelitsha, an urban informal settlement inhabited predominately by Black South Africans who are disadvantaged in accordance with the above-mentioned factors.

2.1.3.3 Socio-cultural Norms Some developing countries, although they have Pap smear screening available, face many cultural barriers to the screening process and hence many women do not get screened (Miller et al., 2007). Often underserved populations in disadvantaged communities are difficult to reach with healthcare screening, as these populations tend to have connectedness with other social institutions that provide them with a stronger sense of belonging (Agurto et al., 2005). Cultural beliefs around cervical cancer and pre-invasive cervical cancer contribute to poor adherence to screening as they influence people's decision-making practices (Mosavel et al., 2009). If treatment was different to any experiences from a woman's cultural practices, then it would not be adhered to (Baldwin, 1996). Among low-income African groups, it is usually the whole family that is involved with decision making (Baldwin, 1996). In addition to the family decision-making practices in African culture, traditionally women occupy a subordinate position (Heunis et al., 2012). This position further adds to the difficulty faced should a woman want to adhere to a health behaviour that differs from that of her family and/or culture. Women also often live in settings where allopathic healthcare is sought out only when other traditional or home-based methods fail (Bingham et al., 2003). Often in these situations the understanding of prevention is extremely limited. If a woman is not feeling ill, it is a struggle to convince her partner for either the need to go to the clinic or for the money for transport to attend screening (Bingham et al., 2003). A study with rural South African women showed that they often believed that if they felt no pain, or were not ill, then they didn't need to attend screening (Mosavel et al., 2009). Patients at clinics would often present to a practitioner for curative rather than preventative healthcare (Markovic et al., 2005). The role of cultural factors in

screening needs to be investigated as research in Nigeria has indicated that there are many cultural barriers resulting in few women being screened (Miller et al., 2007). It would be beneficial to be able to highlight what cultural factors act as barriers in a South African context.

2.1.3.4 Beliefs A woman's belief can be seen to act as a type of barrier with regard to cervical screening adherence (Agurto et al., 2004). Women reported a lack of motivation to seek screening in the absence of symptoms. Women also felt that they were being compromised when they underwent a pelvic examination. Research done with women in developing countries in Latin America and in Serbia, indicated that women did not perceive cervical cancer as a disease that could be prevented (Agurto et al., 2004; Markovic et al., 2005). The literature indicates that there are some beliefs that women hold that are shared even if some of the women live in Serbia and the others in countries as far as Venezuela (Agurto et al., 2004; Markovic et al., 2005). However research does not indicate if these beliefs are shared amongst South African women.

Women also viewed the process as highly embarrassing, deterring them from attending screening (Byrd, Chavez, & Wilson, 2007; Holroyd et al., 2004; Markovic et al., 2005). In addition to embarrassment many women have a fear around the actual process of a Pap smear, believing the screening will be painful (Busingye et al., 2012). Women have been reported to hold powerful and fearsome images of cancer. Women have used words like "plague" or "eating" or "rotting of the womb" when referring to the womb and cancer (Bingham et al., 2003).

A study in Uganda by Busingye et al. (2012) showed that many women thought that, while screening for pre-invasive cervical cancer, they would be screened for HIV, and they did not want to know their HIV status. The fear of a positive screen for pre-invasive cervical cancer and thinking that knowledge of diagnosis would result in an early death prevented women from attending screening. Many women had an overwhelming sense of anxiety and fear should they receive a positive result from the Pap smear screening (Chigbu & Aniebue, 2012). This was due to the fact that a positive cervical screening result could carry with it the implication that a woman had been promiscuous (Bingham et al., 2003).

2.1.3.5 Social Support Research has indicated that the presence of social support networks of low-income women influences their decisions of whether to avail themselves of cervical screening (Chigbu et al., 2013; Markovic et al., 2005). A key

source of information comes from community health workers who have a large amount of knowledge about their communities (Agurto et al., 2005). As these workers are both a part of the community and a part of the medical services provided, they have substantial influence in their communities. Volunteers who underwent screening themselves at clinics were able to better talk to community members about their personal experiences around screening. This was seen to help increase clinic attendance (Agurto et al., 2005).

Studies suggest that clinic staff in communities have a large influence on women's likelihood to get screened (Mosavel et al., 2009). This is because community clinic staff members are seen to have high credibility. Along with community clinic staff, women's groups and church groups provide information on cervical screening which is seen to positively influence women to attend screening (Bingham et al., 2003).

However, one of the most powerful influences for whether women present for screening or not is the experience of their friends or family. It was shown that women who were more satisfied with their clinic experience often related their positive experience to their friends and family (Agurto et al., 2005). Women who had friends, or family members, who had a pleasant experience with screening and would encourage others to attend, would themselves be more likely to attend screening (Markovic et al., 2005). Women who experienced face-to-face visits by community health workers were more likely to return and adhere to screening (Bingham et al., 2003). Social networks and significant others play a large role in influencing women to attend screening (Chigbu et al., 2013; Mosavel et al., 2009).

Positive emotional and financial support from a woman's partner is a key factor in her decision to adhere to cervical screening (Bingham et al., 2003; Chigbu et al., 2013). Closely linked to the influence the partner's support has is that of the community leaders. Chigbu et al. (2013) indicated that, if women have support and encouragement from their community leaders, they are more likely to adhere to cervical screening practices. One of the most effective ways of creating awareness for cervical cancer is through using community-based advocacy methods (Chigbu et al., 2013). It is crucial to take these cultural influences into consideration when attempting to educate women and eliminate any screening barriers (Mosavel et al., 2009).

2.1.3.6 Health Service System There are many factors that can act as barriers which influence a woman's decision to adhere to screening practices for cervical cancer. The health service system is one barrier to cervical screening (Agurto et al., 2004). With regard to the actual screening service, women often face barriers of poor quality service, lack of accessibility, privacy and cost of service, as well as having a long waiting time for service access (Mosavel et al., 2009).

2.1.3.6.1 Patient Satisfaction Patient satisfaction with medical services delivery is an important aspect of healthcare services (Agurto et al., 2004; Chigbu & Aniebue, 2012). If patient satisfaction is low, then it can become a barrier in encouraging the uptake of screening services. If patient satisfaction can be increased, then usage of and adherence to service will likely be increased. This would result in disease incidence and mortality decreasing and, therefore, the overall burden of disease decreasing. Affecting patient satisfaction is the negative attitude of practitioners (Mosavel et al., 2009). Practitioners not showing respect or sensitivity to the patients are amongst the reasons that women chose not to return to clinics (Markovic et al., 2005). Women often cited that the most dissatisfying aspect of screening was the lack of privacy. This lack of privacy during the process of a Pap smear has been reported to be a deterrent to women considering attending cervical screening (Busingye et al., 2012). Even amongst women who knew the benefits of screening, this fear of lack of privacy was cited as a reason not to attend cervical screening (Busingye et al., 2012; Chigbu & Aniebue, 2012). Women cited interruptions during the screening test resulting in them feeling that they had no privacy (Agurto et al., 2004). The potential discomfort of the procedure and the distrust of the western medical system could also affect screening attendance (Agurto et al., 2004; Mosavel et al., 2009).

2.1.3.6.2 Accessibility Usually, passiveness is associated with a lack of interest. However, research has suggested that the passiveness in the attitudes of some South African women come rather from a point of access issues and other obstacles, rather than from passivity towards proactive health screening (Mosavel et al., 2009).

Another important factor is that of location. If the location of the screening service is difficult to access, this will deter many women, who live in poorly resourced communities, from attending (Agurto et al., 2004; Bingham et al., 2003). The long waiting times at clinics and a lack of staff are reasons that women do not make health promotion visits (Agurto et al., 2004; Markovic et al., 2005). In addition

to this there is also the poor work ethic of the staff at clinics contributing to women not making health promotion visits (Agurto et al., 2004; Markovic et al., 2005). Having to wait a long time for test results, or results that are lost also result in women being deterred from returning for screening (Agurto et al., 2004; Wright & Kuhn, 2012).

Often women also face the access barrier with regards to cost. In some countries like Nigeria, Pap smear screening is not free and women are not able to pay for both the transport and the screening service (Miller et al., 2007). Even in many countries where Pap smear screening is free, many women are unaware of the free service (Bingham et al., 2003). Often Pap smears are not offered to women but only administered to them on request, thus leading some women to believe they are not entitled to one (Bingham et al., 2003).

At times, travelling to attain screening is not just a financial burden but is also time consuming. Some women in rural Western Kenya have to rely on private transport, which is more expensive, to travel long distances that often require travelling at night. Many partners do not allow their wives to take such trips as the danger of travelling through the night is too great and not having the woman at home to carry out her duties and earn an income may not be feasible (Bingham et al., 2003).

2.1.3.7 Marginalised Position Another factor that acts as a barrier in influencing screening adherence is that of a woman's marginalised position. This refers to the social, economical and political marginalised position of some women. Studies have shown that there are certain commonalities amongst South African women who are less likely to know about or attend a Pap smear. Some of the commonalities are that these women tend to be poorer, unemployed and less educated (Mosavel et al., 2009). Their position with regard to the aforementioned factors can be seen to play out in their decisions regarding health services (Baldwin, 1996). Being part of a marginalised group affects how women view and respond to their decisions, with this not always being aligned with the views and beliefs of western medicine practices (Baldwin, 1996). Being part of a lower socio-economic background, which normally is associated with a lack of health insurance, compromises the access that women have to screening, as well as negotiation powers regarding safe sex practices (Heunis et al., 2012; Markovic et al., 2005). Women who receive an abnormal Pap smear result show lower rates of adherence to treatment if they come from a poor and low socio-economic status (SES) community (Anderson, Mullins, Siahpush, Spittal,

& Wakefield, 2009; Lee et al., 2010; McKee et al., 1999). Even within developed countries, screening adherence is poorly shown in the disadvantaged communities in comparison to their advantaged counterparts (Anderson et al., 2009). This further shows the strong link between low SES and cervical cancer risk (McKee et al., 1999).

2.1.3.8 Language Language difficulties and ineffective communication are structural barriers that contribute to low rates of adherence (McKee et al., 1999). A study in a rural area in Mexico found that women experienced health practitioners communicating to them as if they were small girls. This condescending communication creates mistrust between practitioner and patient, with the patient less likely to adhere to repeat visits (Agurto et al., 2004). The only way that the correct meaning and interpretation of an abnormal result can be explained is through effective communication (Tung, Nguyen, & Tran, 2008). Therefore, if there is a breakdown in effective communication, women may return to their community with misconceptions about screening and cervical cancer. An appropriate message needs to be communicated in order to address women's concerns and misconceptions in order for screening to increase (Agurto et al., 2005).

2.1.3.9 Knowledge Women have a human right that falls under the United Nations Millennium Development Goal of promoting full and equal participation in all areas of life for women (Agurto et al., 2005). This human right is the right to make informed decisions about their reproductive right (Agurto et al., 2005). Yet, in some studies, it has been shown that, irrespective of socio-economic background, women still had poor knowledge with regard to cervical cancer screening (Markovic et al., 2005). Unless women have access to enough knowledge about healthcare services, they will be unable to make an informed decision regarding their reproductive health.

This absence of knowledge means that women are less likely to attend screening, or only attend once symptoms are present and cancer cannot be as effectively treated. Many women do not distinguish between the various forms of cancer that affect the reproductive organs, thus they do not understand that cervical cancer can be easily prevented (Bingham et al., 2003). In a study by Busingye et al. (2012), there is a significant association shown between education level and uptake of cervical screening. Research has shown that women's knowledge about Pap smears and of cervical cancer in general is exceptionally poor (Mosavel et al., 2009). It is seen that well-educated women are more likely than less educated women to attend screening. It has been shown that in general a higher education is positively

associated with the majority of health indicators (Busingye et al., 2012). Women with low literacy skills, as well as poor public health knowledge, are also at a disadvantage in accessing screening (Markovic et al., 2005).

In a study in Nigeria that ran education sessions on cervical cancer, there was an appreciated increase in knowledge for both men and women (Miller et al., 2007). This is as most men and women do not receive education around health issues. Practitioners only have a limited time during or after screening in order to educate patients on health services, which is what adds to the influences of poor screening rates (Markovic et al., 2005). In a South African study, women reported that they enjoyed attending group education sessions in which they could bring along their friends and neighbours to learn about cervical cancer (Bingham et al., 2003). Women were eager to learn about the services in order to consider being screened.

Knowledge amongst women in a Cape Town community has been identified as being far from optimal (Mosavel et al., 2009). Many women view Pap smear as a process of cleaning out the womb (Mosavel et al., 2009). They often refer to cervical cancer in non-medical terms and rarely use the term *cervix* when discussing screening. However, Mosavel et al. (2009) indicated that some women in the community have identified that they are considering attempting to prevent illness as a primary option as opposed to waiting for illness and symptoms to occur.

2.1.3.10 Complementary and Alternative Medicine in South Africa In 2006, the World Health Organisation announced that 80% of the world's population relies on alternative medicine when seeing to their healthcare (Duraipandiyan, Ayyanar, & Ignacimuthu, 2006). Since the early 1980s, the African Union (AU) and Southern African Development Community (SADC) governing bodies and member states have been advocating for the protection of traditional healthcare (Pretorius, 2012). Presently in South Africa, complementary and alternative medicine (CAM) has 11 of its modalities registered according to the Chiropractors, Homeopaths and Allied Health Service Professions Second Amendment Act 50 of 2000 (Pretorius, 2012). From this Act, the *Allied Health Professions Council of South Africa* was established in order to regulate the CAM practitioners. In South Africa, it is evident that there has been a movement, however slow, towards CAM being considered legitimate, as opposed to how it was previously considered, that is as a deviant type of healthcare (Pretorius, 2012).

Overall, the support is in favour of CAM healthcare on the African continent and abroad (Frass, Strassl, Friehs, Mullner, Kundi, & Kaye, 2012; Pretorius, 2012). This is because these practitioners have the privilege of intimate knowledge of both the social and cultural background of the populations they attend to. Traditional healthcare was outlawed by the Health Act 19 of 1974, but despite this traditional healthcare survived in South Africa (Pretorius, 2012). Some of the reasons for this is that traditional healthcare was more available, accessible, affordable and acceptable than that of westernised healthcare. While the ratio of traditional healers to population varied between 1:190 and 1:400, the ratio of biomedical doctors to population was 1:20 000 or more (Pretorius, 2012). Thus, traditional healers were much more available than western doctors. Traditional healers are also more closely linked to the population they serve in terms of culture, social norms and geographical location. This thereby makes traditional healers very accessible to their clientele. Overall, traditional healthcare is also considered cheaper than that of westernised healthcare. One of the strongest factors encouraging traditional healthcare is its acceptability. When commenting on the South African healthcare system, Ramjee and McLeod (2010) indicated that 72% of the population would select a traditional healthcare option as the first point of call for advice and treatment.

In conjunction to the above stated reasons, there is also the role of the apartheid era which contributes to the lack of utilisation of western medical care (Heunis et al., 2012). During apartheid there was a separate provision of healthcare provided to the population. This separate provision was based on a race discriminatory basis. There was also the promotion of privatising healthcare, with the delivery of healthcare being split based on race and socio-economic status (Heunis et al., 2012). Therefore there existed, not only inaccessible western healthcare, but also a mistrust of the type of healthcare a person would receive when choosing to attend western clinics. Hence, the provision of prevention messages is alone not enough to encourage screening adherence. There needs to be included a process to reconstruct the concept of western healthcare in the context of many of the community's members (Nene et al., 2007).

Another explanation of the high use of traditional healthcare stems from how health, disease and disease causation is viewed and interpreted. Within the African context, disease ontology is focused on the imbalance or harmony between cosmic life forces (Pretorius, 2012). Therefore, disease can be seen as the result of discord

amongst the cosmic forces due to either sorcery or an ancestor's unhappiness with the person. An African isiXhosa term used for health, *mpilo*, refers to more than just the biomedical condition. This term also refers to the social and physical surroundings of the individual, the entire cosmos (Pretorius, 2012). Therefore, people seek out treatment that will be in alignment with these beliefs. Treatment that is aimed not just at correcting the physical symptoms, but also the relationship between the person and their surroundings is more likely to be sought by people sharing the above belief system. This type of treatment would then naturally not be restricted to just one type of medication or method, but extend to include herbal medication, behavioural changes and different rituals performed. Adherence to the above-mentioned practices and beliefs is enforced by years of history, culture, customs and tradition. This is all in an effort to try to attain psychological wellbeing (Pretorius, 2012).

One of the results of the above African view on disease and its ontology is that it creates a fatalistic attitude amongst people who share this view (Pretorius, 2012). Research has found that Black African women are prone to entertain a more fatalistic view of diseases, thus preventing them from attending screening or preventative treatment (Mosavel et al., 2009). With this attitude, people often accept disease as something that is out of their control, since it is controlled by the ancestors and cosmic forces. As a result, they prefer to seek treatment from healthcare providers who share similar beliefs and views. Yet at the same time a finding is also seen across other cultural groups of women, where the fatalistic view women held about diseases stemmed from their poor access to education, as well as dire poverty situations and not just their fatalistic view of disease (Holroyd et al., 2004). When healthcare loses sight of these facts and focuses purely on disease, it is in danger of neglecting to treat the patient (Pretorius, 2012). In order to increase adherence to screening (a healthcare action) all the above needs to be taken into account to be able to provide a culturally sensitive approach.

2.1.4 Integrated Prevention Programme

In order to achieve adherence to cervical screening and behaviour change and maintenance, there needs to be careful consideration into developing an intervention that does more than just provide information. Research has shown that one of the major barriers to screening adherence is, amongst other barriers, the lack of knowledge (De Abreu, Horsfall, & Learmonth, 2013). Yet studies show that information provision alone cannot increase adherence to screening (Blomberg,

Ternstedt, Tornberg, & Tishelman, 2008; Byrd et al., 2007). Even women who have sufficient knowledge about cervical cancer do not always avail themselves of the screening which is available (Blomberg et al., 2008).

In order to successfully promote cervical cancer screening, there needs to be implementation of a programme which takes into account aspects of the social-cultural system in which the women live (Holroyd et al., 2004). Cervical screening programmes and policies need to take into account the differences within their healthcare consumers. Different groups that use the same healthcare may have different languages, as well as varying social, spiritual, and cultural views about cervical screening practices (Lee et al., 2010). As indicated above, culture provides a structure for certain behaviours and beliefs amongst the people belonging to it. Following the cultural guidelines assures an individual a place within their social community and thus provides them with acceptance (Holroyd et al., 2004). An effective screening promotion programme will take into account both the health beliefs and practices of an individual's culture, as well as the social setting of the individual.

Based on the literature review it can be seen that there are key areas which need to be explored within the South African context with regard to cervical cancer and screening adherence. Some of the key areas which have been researched in other developing and developed countries which need to be further researched in South Africa are: the role that gender factors play in a woman adhering to cervical screening, how socio-economic status affects a woman's decision to attend cervical screening, as well as a woman's cultural beliefs, marginalised position in society and a woman's view and belief with regard to complimentary and alternative medicine. These key areas are relevant to explore in this study as this study sets out to investigate the social and cultural factors influencing disadvantaged women's decision to screen for cervical cancer. Some of the key areas identified such as gender factors, cultural beliefs and views about complimentary and alternative medicine can contribute to an individual's subjective norm, which can be seen to impact on their intention to carry out behaviour to screen for cervical cancer. Other key areas such as a woman's beliefs impact on her attitude which also affects her intention to carry out cervical screening behaviour. Both these factors, namely, subjective norm and attitude, as well as other factors affecting cervical screening are accounted for in the combined theoretical model that was used for this study that is discussed below. It is

for this reason that the below psychological theories were used to provide a scaffolding for the research being carried out.

2.1.5 Psychological Theories of Cervical Screening Behaviour

2.1.5.1 The Health Belief Model Since its development in the 1950s, the Health Belief Model (HBM) has been one of the most widely used theories to investigate and explain health-related behaviour (Burak & Meyer, 1997; Gillam, 1991). The HBM is composed of six constructs: perceived susceptibility, perceived severity, perceived benefits minus perceived barriers, cues to action and self-efficacy (Burak & Meyer, 1997; Johnson, Mues, Mayne, & Kiblawi, 2008). *Perceived susceptibility* is an individual's perception of the likelihood of suffering from a condition that would negatively affect their health. *Perceived severity* is an individual's belief of the seriousness of the effects of the condition. *Perceived benefit* is an individual's view of the effectiveness of the recommended health behaviour to reduce risk and impact of the condition. *Perceived barriers* are the psychological or tangible costs that might prevent an individual from undertaking certain behaviour. Here is where the cost benefit analysis occurs. *Cues to action* are events, whether physical or environmental, that motivates individuals to take up health-related behaviour. Cues can be internal or external. Lastly, *self-efficacy* is the individual's belief in their ability to successfully carry out behaviour which will result in desired outcomes.

The HBM has been revised to include several modifying factors that could influence the aforementioned factors (Burak & Meyer, 1997). These factors are defined as: social-psychological (socio-economic status (SES)); demographic (ethnicity); and structural (knowledge about the condition) (Gillam, 1991; Lee, 2000). There has been much support in using the HBM to investigate cervical screening behaviour (Fylan, 1998). Studies have used constructs from the HBM in order to investigate screening beliefs and behaviours of women (Burak & Meyer, 1997). The HBM is useful in obtaining information on what an individual's current beliefs are, yet it is not useful in predicting the intention of screening behaviour. However, women's perceived barriers to undergoing screening, as well as their perceived susceptibility to cervical cancer, has been found to predict screening behaviour (Hill, Gardner, & Rassaby, 1985). It has also been documented that amongst individuals with a higher self-efficacy there is a greater incidence of screening adherence (Fylan, 1998).

Although the HBM has been used extensively across studies, it does have a variety of limitations (Johnson et al., 2008; Poss, 2001). Firstly, the HBM does not include concepts that reflect the larger societal layout. Concepts such as public policy, poverty and social discrimination may affect individuals' access to healthcare, and therefore are influential in explaining behaviour (Poss, 2001). Secondly, as the HBM is a psychosocial model, it only accounts for the health behaviours that can be explained by individuals' views and attitudes (Poss, 2001). Other factors such as demographic variables, social support, language barriers, previous health experiences and cultural norms that may influence behaviour are not a central part of this model (Johnson et al., 2008; Poss, 2001). Rather, they are viewed as influencing one of the six variables of the HBM. Thirdly, the HBM does not account for cultural factors or societal norms, which are two factors that can be important in explaining health-seeking and adhering behaviour (Poss, 2001). It has been questioned whether the HBM can possibly explain behaviour across different cultural settings as it lacks a culturally specific concept (Poss, 2001). Even though Rosenstock (1966, as cited in Poss, 2001) has stated that the norms and pressures of an individual's social group will influence their beliefs, there is no normative concept in the HBM.

Despite its limitations, the HBM has been a key tool to understanding health behaviours across a variety of settings. The HBM has been used as the theoretical framework for looking at self-care behaviour and Pap test intentions (Burak & Meyer, 1997). This model is useful as it is applicable across settings, explains health behaviours and can generate questions for future testing. As opposed to altogether abandoning the HBM due to its limitations, a better approach may be to adapt its use by incorporating another more culturally sensitive model (Poss, 2001).

2.1.5.2 The Theory of Reasoned Action The Fishbein and Ajzen's model of Theory of Reasoned Action (TRA) was developed towards the end of the 1960s, with some viewing it as refining and taking forward approaches set out in the HBM (Taylor et al., 2007). The TRA explains the relationship between intention, behaviour, attitudes and beliefs (Poss, 2001). It is based on the assumption that human beings are rational and apply information in a systematic manner in order to conduct a cost analysis of a particular action (Poss, 2001). The TRA contains two sets of belief variables: behavioural attitudes and subjective norms (Taylor et al., 2007). It assumes that, instead of attitude, it is behavioural intention that is the immediate cognitive precursor to behaviour. If there is an opportunity to act, then it will be intention that

will result in certain behaviour (Poss, 2001). Intention is affected by two components: the attitudinal component, which is an individual's attitude towards carrying out the behaviour, and the social norm component, which is the general subjective norm of carrying out the behaviour (Poss, 2001; Taylor et al., 2007). Underlying the attitudinal component is the behavioural belief-based structure. The behavioural belief is the likelihood that the action performed will either promote or negate a specific outcome. It is the person's overall evaluation of whether the behaviour is beneficial or costly (Poss, 2001; Taylor et al., 2007). Underlying the social norm component is the normative belief-based structure. The normative belief is the individual's view of the pressures to act or not in a certain manner. It is the individual's perception of what important referents expect her to do and the degree to which she would want to comply with these norms (Poss, 2001; Taylor et al., 2007). It is the combination of the behavioural attitude and subjective norm that drives intention. Intentions are then the primary cognitive precursors to carrying out behaviour.

Like the HBM, the TRA has its limitations. Firstly, it does not include any variables such as demographic characteristics. Like the HBM, the TRA terms these variables as external variables that may influence belief, but only affect behaviour through influencing some of the other major variables of the theory. Secondly, the TRA has its focus on the explanation of intention while most health behaviour researchers are interested in understanding behaviour (Poss, 2001).

Yet there are reviews in which it has been documented that the TRA has the capacity to predict intention and behaviour across a variety of contexts (Cooke & French, 2008). In light of these reviews, the TRA has the capacity to be useful in health behaviour research. This is as it was highlighted that intentions to attend screening services strongly correlated with both an individual's attitude and subjective norms; two factors from the TRA. It was then also indicated that intention to attend screening services correlated with the perceived behavioural control, a predictor of behaviour (Cooke & French, 2008). Therefore the use of the TRA to predict behaviour of cervical screening adherence outweighs its limitations mentioned above.

2.2 Theoretical Framework

2.2.1 Combination of the Health Belief Model and the Theory of Reasoned Action

There are various researchers who have chosen to either use the HBM or the TRA or a combination of them both. Researchers studying influenza vaccinations utilised, (in addition to the HBM variables), physician's recommendations, social influences and behavioural intent (Poss, 2001). The latter two concepts both come from the TRA. Other studies using the HBM framework have also utilised the concept of intention (Poss, 2001). These studies have shown that intention is a good predictor of behaviour, and that the effects of the HBM factors can be seen as mediated through intention (Poss, 2001).

There have also been studies utilising the TRA with the addition of some external variables that fall under the HBM (Poss, 2001). Poss (2001) concluded that the model best utilised to explain the health adhering behaviour is that of TRA with the addition of susceptibility and fear. The additive factors, which are both seen to be virtually the same to the concepts from the HBM, did significantly increase the power of intention to predict behaviour.

Many studies have either used the HBM or incorporated TRA variables or vice versa. A group of researchers formally combined the two models and utilised it as a basis for their research investigation of adherence to health behaviour (VanLandingham, Suprasert, Grandjean, & Sittitrai, 1995). Other studies have not formally combined models but have selected variables of interest for their relevant studies. For this study, a synthesised model of the HBM and TRA will be used (see Diagram 1. on page 32). This model has been used successfully to study screening programme intention, health behaviours and beliefs across a culturally distinct population (Poss, 2001). The mixed model has combined many concepts to improve its measurement.

The concept of perceived barriers and benefits from the HBM is equivalent to the concept of behavioural beliefs in the TRA. The barriers and benefits aspect from the HBM, namely the behavioural beliefs in the TRA, explains the role of what the literature identifies as the health service system acting as a barrier in cervical screening. The concept of intention, although not in the HBM, was retained in the model as it has been previously shown to be a good predictor of behaviour (Poss, 2001). Intention is also seen as an integral part of the TRA, which states that intention

should predict behaviour. In a study investigating the intention to adhere to screening practices, the behaviour was best explained by the model containing four variables: cues to action, subjective norm, susceptibility and attitude (Poss, 2001). The cues to action variable explains how social support may encourage women to attend cervical screening. The subjective norm factor allows for the explanation of the role of gender, socio-cultural norms and complementary and alternative medicine on intention. Susceptibility and severity factors in the model explain how knowledge affects intention to carry out behaviour to attend cervical screening. Lastly the attitude factor of the model explains how a marginalised position of a woman may affect her attitude and therefore intention and then behaviour of cervical screening. The combined model's strength lies in the previously proven performance of the HBM and the TRA, as well as the culturally based concepts from the TRA that are included. Although there exists quantitative studies using the combination model there is support for qualitative studies effective use of the combined models (Manhart, Dialmy, Ryan, & Mahjour, 2000). Qualitative research by Manhart et al. (2000) focused on identifying determinants of health behaviour related to a sexually transmitted disease, which HPV is. The focus of the research was to define areas for potential intervention. Manhart et al.'s (2000) focus is shared with this current research. The utilisation of this model (HMB/TRA) with a qualitative approach allows researchers to better gather and understand the health-seeking behaviours of individuals from varying cultural backgrounds (Manhart et al., 2000; Poss, 2001). This combined model is able to explain the influences on cervical screening which the literature focused on. For this reason this model was seen to be relevant to this study and was used as a scaffolding for gaining more knowledge on the research question of which social and cultural factors influence disadvantaged women's decision to carry out cervical screening behaviour.

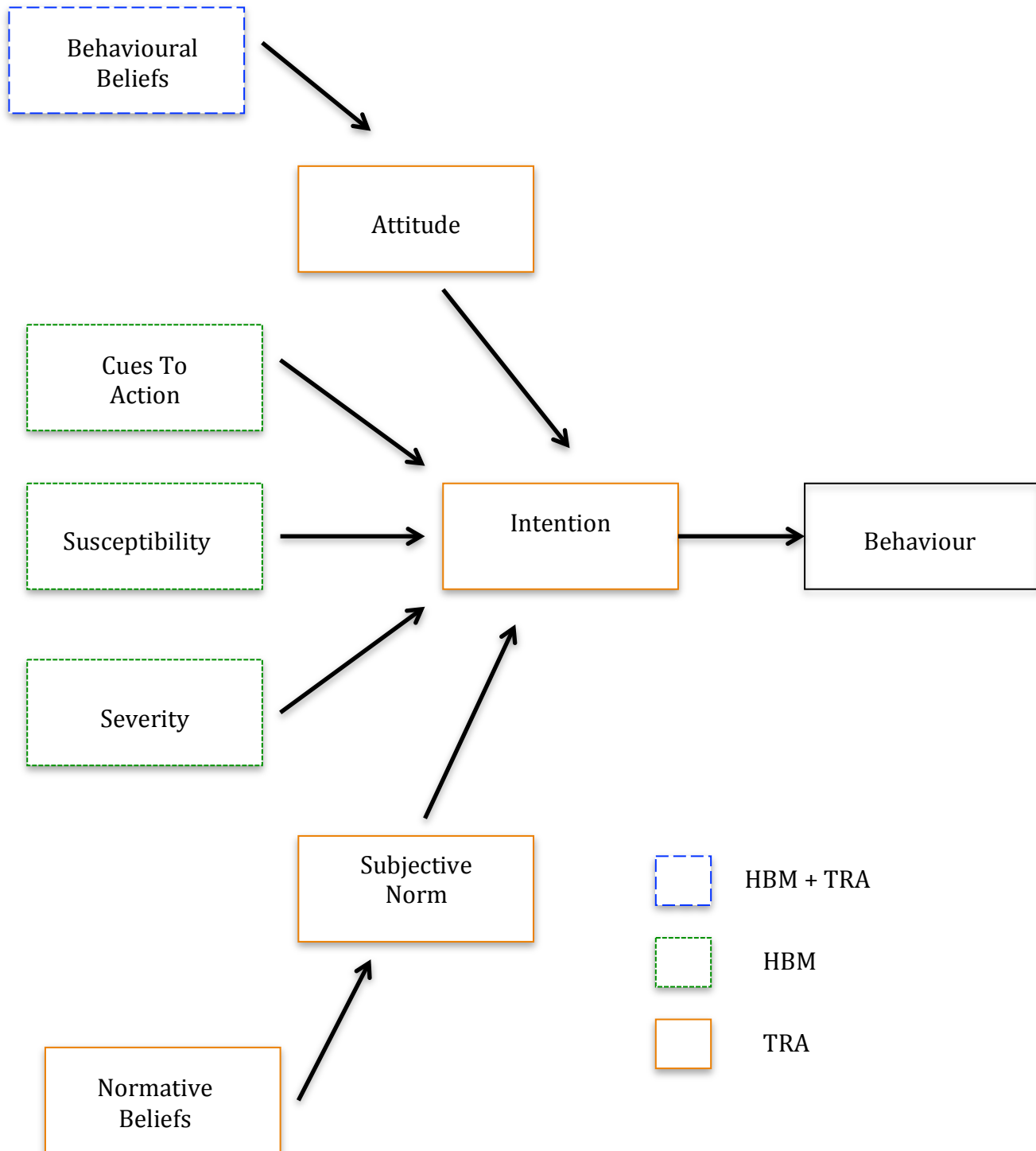


Diagram 1. Combination of HBM and TRA model

2.3 Summary

This chapter started with reviewing the current literature regarding cervical cancer screening and adherence behaviours. It provided background on the global and South African context of cervical cancer, indicating that cervical cancer is the second most common cancer amongst South African women, and globally the fourth leading cause of cancer death amongst women. Then the chapter focused on the influences on screening adherence, namely, gender factors, socio-economic factors, socio-cultural norms, beliefs, social support, the health service system, a woman's marginalised position, language and knowledge as well as complementary and alternative medicine in South Africa. The chapter then looked at the importance of an integrated prevention programme and identified the key areas in literature in which there were gaps in knowledge with regard to the South African context. Some of these key areas were gender factors, how socio-economic status affects a woman attending cervical screening, cultural beliefs, marginalised position in society and beliefs with regard to complimentary and alternative medicine and how these affect cervical screening adherence. By investigating the social and cultural factors that disadvantaged women in South Africa experience, this study aimed to address the gaps in the knowledge. The chapter concluded with introducing psychological theories of cervical screening behaviour, and indicated how the combined model of the HBM and TRA was the theoretical framework chosen to provide scaffolding for this study's research topic.

Chapter 3

Methodology

3.1 Aim of Research

The aim of this research was to investigate what played an influence on the uptake of cervical cancer screening in disadvantaged communities in South Africa. The research also aimed to investigate what implications these influences had on cervical cancer screening adherence. This investigation was done by evaluating the experiences of low-income women with regard to cervical cancer screening which is provided within a western medicine framework in a disadvantaged setting.

3.2 Participants and Sampling Procedure

The Medical Knowledge Institute (MKI) was approached and was offered a training day on cervical cancer to all their MKI trainers. MKI is an international non-profit organisation that is committed to providing healthcare education to underserved communities. This training took place in an informal disadvantaged community within the Greater Cape Town area, namely, Khayelitsha. In turn the MKI trainers went out and held their own training sessions with members they recruited from their communities. These recruited members also came from the informal settlement of Khayelitsha.

Khayelitsha is located on the Cape Flats, lying between the two bays, namely False Bay and Table Bay. Under the apartheid laws there was a massive forced relocation of Black people from the towns and suburbs to the outskirts of towns (Nleya & Thompson, 2009). The new collective township was called Khayelitsha, meaning 'New Home'. In the late eighties conditions in townships had worsened, and by 1990 the population of Khayelitsha was roughly around 450 000 with unemployment reaching 80% of its population. After the 1994 elections many people moved to the city and urban area in search for work and education. The influx of people into this area with no formal housing structure caused an even higher-density area to form (Nleya & Thompson, 2009; Puoane et al., 2005). Most houses were made of cardboard, tin and wood. The township predominately consists of small dwellings without electricity, with poor sanitation, and a lack of running water (Puoaane et al., 2005). The high density of people located in a poor resource setting only further exaggerates the state of poverty that the community face.

The recruited participants were people living in Khayelitsha. For the first phase, training the MKI trainers with cervical cancer education material, two focus groups were held with the MKI trainers. In the second phase, the MKI trainers training their community members, a further two focus groups of 4-6 people run by a MKI trainer were held. These last two focus groups were the sessions that the MKI trainers gave the educational training on cervical cancer to other community members. Participants of all the focus groups were male and female members residing in communities in and around Khayelitsha, Cape Town. With regard to the female participants there was a mixture of women, some who had had pap smears before and others who had not.

3.2.1 Inclusion Criteria

For the first phase only MKI trainers were included in the educational training on cervical cancer. This is because there had been a relationship and rapport already established between the researcher and both the NGO MKI and the MKI trainers. Thus there was already a ground of trust between the researcher and the MKI trainers, which allowed for more open and honest sharing of experiences and perceptions. For the second phase, only community members recruited via the MKI trainers were included in the study. The community members recruited already had an existing relationship with the MKI trainers. Therefore as the trainers were seen to trust and welcome the researcher, this encouraged the community members to also trust the researcher.

3.3 Data Collection Methods

3.3.1 Focus Group

For the first phase of data collection focus groups run by the researcher were used. Focus groups have been greatly utilized in qualitative research and have recently found popularity within the health psychology field (Wilkinson, 2008; Willig, 2001). In the following paragraphs the rationale for using focus groups will be presented by firstly providing a brief description of focus groups followed by how focus groups were used in this study.

The composition of focus groups can differ on various factors. Some factors may be the number of participants per group, or whether the group is homogenous or heterogeneous, or if it is a pre-existing or new group of participants (Willig, 2008). With regard to the size of focus groups many scholars have recommended a focus group size to be between 4 and 12 participants (Bloor, Frankland, Thomson &

Robson, 2001; Hennink, 2007; Krueger & Casey, 2009; McLafferty, 2004). In this study four focus groups (n=8, n=8, n=4, n=6) of varying sizes were run.

The second factor affecting focus group composition is how homogeneous or heterogeneous the group is, that is, how similar (sharing key features) or different participants are. The factor of homogeneity and heterogeneity is determined by what the purpose of each study is (Bloor et al., 2001; Krueger & Casey, 2009). The focus groups of this study were both homogenous as well as heterogeneous. The focus groups were homogeneous in that all participants who attended were members of the same surrounding disadvantaged community. The focus groups were also all homogeneous in that all attending participants expressed a desire to know and learn more about cervical cancer screening and treatment. At the same time the groups were heterogeneous: focus group 1 and 2 consisted of participants who had been trained by MKI with knowledge regarding other healthcare topics such HIV/AIDS, substance abuse, diabetes and vaccinations; focus group 3 and 4 were participants without this training that is provided by MKI. Focus group 1 and 2 were slightly more equipped with medical knowledge regarding healthcare while focus group 3 and 4, although receiving some knowledge through the MKI trainers, had not been intensively trained by MKI.

It has been argued that unlike participants from pre-existing groups, it is sometimes easier for participants in new groups to open up to and discuss topics with strangers as they have less fear of any repercussions following them sharing their opinions (Bloor et al., 2001). Yet pre-existing groups also have their advantage in that participants in these groups already have an existing relationship with others in the group and thus feel comfortable in sharing with other participants in the group. The interaction amongst participants and the depth of disclosure across all four focus groups in this study supports both hypotheses above; that both pre-existing and new groups can generate valuable data.

Focus groups allow for attention to be paid to the interactions between individuals. This is one of the strengths of focus groups. It encourages participants to interact and respond to each other's opinions (Wilkinson, 2008; Willig, 2001). In this manner statements that are made by a participant can be challenged, developed or made comprehensive through the responses of the participants (Willig, 2008). This generates a rich data source for the researcher. One of the research questions is to investigate what influences the uptake of cervical cancer screening in a community.

Part of the influences being investigated is that of beliefs and attitudes towards certain sources of healthcare help. This type of data allows for the investigation of how attitudes can be formed and then changed, as well as how participants construct meaning with one another (Willig, 2008).

Another strength of focus groups is that it is ideal for investigating a relatively unknown topic (Frith, 2000). This is because the relatively unstructured nature of focus groups allows the participants to guide the discussion in the direction of what is personally concerning them. Thus the participants bring forth their own themes and worries (Espin, 1995). In this way unexpected insights may arise when participants are allowed this type of freedom in expression (Frith, 2000), giving the researcher a fuller understanding of the topic in question.

Focus groups also allow for the power balance to be shifted in favour of the participants. This strength means that the researcher's influence is reduced and the participants' opinions become a priority (Wilkinson, 1998).

Overall there is much evidence that supports the use of focus groups as a method to qualitatively investigate sensitive topics. Various studies have found that the focus group environment encourages more personal disclosure (Överlien, Aronsson, & Hydén, 2005; Wilkinson, 2008). Relatively little is known about the topic being investigated, as well as it being sensitive in nature. Thus, focus group data collection was an ideal data collection method.

3.4 Data Collection

This research involved two phases of data collection. During the first phase the researcher held a training session with MKI appointed trainers. A MKI assistant contacted the MKI trainers in order to inform them of the training day details. The training took place at a MKI training center, which is based in the community from which most MKI trainers are from, where the trainers usually receive their training. A light lunch of sandwiches and tea was provided to the participants. Phase one of data collection ran over two days. Session one ran over the course of a full day (09:00-14:00) with a lunch break. During the first day the researcher guided the trainers through the pilot educational program around cervical cancer. The researcher researched and designed the materials needed for the educational program according to guidelines set out by WHO and ACCP. A medical doctor from MKI reviewed the material in order to ensure that it was medically correct. The educational program has been designed in a manner so as to impart and gain knowledge from the audience it is

being delivered to. The training session first started with an opening game in order to put all the MKI trainers at ease. The MKI trainers chose a game of their choice that they had previously used in their own training sessions with community members. Initially questions were asked to the participants that allowed the researcher to see how much knowledge was known about cervical cancer before the educational program was delivered. Some of the questions were “What is the community knowledge around cervical cancer? What do you know about cancer of the cervix? What would you like to know about cervical cancer?”. The teaching part of the educational program was then started. The teaching segment covered topics such as the physiology of cells and cancer, prevalence, incidence, mortality statistics, as well as symptoms and risk factors for cervical cancer. The teaching segment was lead by both the researcher and the medical doctor who had helped to design the educational program. Throughout the teaching segment there were always opportunities where the trainers could ask for clarification on any segment, which perhaps was not explained adequately. At the same time the MKI trainers were able to share their knowledge and experience from the community sessions and teaching segments that they had previously done on other chronic ill health diseases. The MKI trainers were able to share their thoughts on what images or words that were in the educational program, that they thought would be useful or not when using the educational program in their own teaching sessions within their communities. This feedback was helpful so that the researcher was able to alter certain images and phrases for the educational program to be more useful when used in future trainings. Some of the questions asked throughout the training program were “What is cervical cancer? What are the symptoms of cervical cancer? What are the risk factors for cervical cancer? What types of barriers prevent community from accessing screening for cervical cancer at clinics?”. After the questions were asked then the relevant teaching segment was done on each section. This was to allow participants the opportunity to express their knowledge or opinions before being biased by what was taught.

Data was collected via recordings during the discussions and the focus group held in the training. Throughout the session the researcher took note of non-verbal and other interesting factors and behaviour. During the focus group the researcher also participated in the group discussions and feedback sessions with the MKI trainers. Rapport had already been established with some of the MKI trainers, through continuous involvement over the past year of the researcher attending various MKI

events and MKI information sessions. This part of data collection was done via focus groups. This was overt data collection as the participants were constantly aware of the position of the researcher as collecting and recording data, as it is the researcher who was delivering the training. This training was designed to equip the MKI trainers with a broad variety of information and innovative ways of educating other members in their community.

Session two of phase one was conducted during the second day. During day two the trainers were allowed to select a part of the previous day's training program to deliver to the other MKI trainers and researcher. This was to allow the trainers to practice their delivery of the educational program and ask any more questions which they discovered problematic while presenting. Using the feedback from day one of the focus group with the MKI trainer, the researcher was able to alter the images and certain phrases within the educational program. These changes were shown to the MKI trainers on day two. Once they were satisfied with the changes the presentations for day two commenced. Throughout the various presentations the MKI trainers worked together giving each other feedback on what and how they thought each trainer could improve their presenting and teaching skills. This was a useful opportunity whereby even experienced MKI trainers were able to identify areas where they could improve, as well as assist newer MKI trainers in what techniques work best when delivering an educational program. Day two of this phase of data collection also allowed for the researcher to observe how the MKI trainers would carry out the teaching of the content for phase two of data collection. This meant the researcher was allowed to check that the trainers had understood the information and were also capable of delivering the training in a manner that would yield useful data for the researcher. Some MKI trainers were unsure of certain parts of the educational program, so together the MKI trainers and the researcher spent time explaining and teaching these segments to the MKI trainers that requested clarification. In this manner the educational program was made to be as user friendly as possible. At the end of the presentations a lunch break was held, there after a group discussion was had to summarise all the previous factors which had emerged over the two days. The MKI trainers were divided into four groups whereby each group set out to discuss a different factor and how it related to cervical cancer. The four group discussion points that were assigned to the groups were, namely, beliefs, access to clinic services, culture (social and gender factors), and knowledge. There was then the opportunity

for each group to present what they had discussed. At this point the group members of the other groups were also able to contribute if they felt something different to what was being said, or if they felt there was something lacking from what was being said.

The last discussion was held after a tea break. In this final discussion the MKI trainers engaged in problem solving with regard to some of the barriers to cervical screening. Some of the questions asked were “How is cervical cancer affecting our communities? Why is cervical cancer affecting our communities? Can you think of any possible solutions to the barriers discussed?”. This discussion was most useful as the MKI trainers were able to discuss what they, as community members and insiders, thought would be beneficial to increase adherence to cervical screening.

For the first two focus groups the majority (56%) of the participants were aged thirty years and younger, while 11% of the participants were aged thirty-one to forty and another 11% fifty-one to sixty years of age. The majority of participants, 71%, lived under thirty minutes in distance from the closest clinic, with 29% living under one hour in travel time from the closest clinic. With regard to number of children, only 25% of the participants had between three and four children, while the majority of participants (62%) had two or less children. Only 13% of participants had five or more children. These focus groups had the most participants out of all the focus groups that knew of a family member who had had cervical cancer. 22% of participants in these focus groups knew of a family member who had had cervical cancer. With regard to marital status, these two focus groups had fairly equal amounts of participants either identifying themselves as single (56%) or as married (44%).

Pre-workshop Questionnaire Question	Percentage of Participants (%)
Age: thirty and under	56
Age: thirty-one to forty	11
Age: forty-one to fifty	22
Age: fifty-one to sixty	11
Travel time to closest clinic: under 30 min	71
Travel time to closest clinic: under 1 hour	29
Number of children: 2 or less	62
Number of children: 3 to 4	25
Number of children: 5 or more	13

Has a family member diagnosed with cervical cancer	22
Has not had a family member diagnosed with cervical cancer	78
Marital status: single	56
Marital status: married	44

Table 1. Focus Group 1 & 2 Quantitative pre-workshop questionnaire: background characteristics

The characteristics indicated in Table 1 indicate that the participants in focus groups 1 and 2 were fairly heterogeneous.

The second phase of data collection was held at various locations when each MKI trainer delivered the educational program to their community members. During this phase the researcher did not lead the focus groups. The researcher took the stance of observing as a participant, which allowed the researcher to partake in the activities if desired, but also to maintain the main role of collecting data as a researcher (Kawulich, 2005).

Each session in phase two lasted between 60-90 minutes. At the start of the session the MKI trainer giving the session introduced the researcher as well as the fact that the MKI trainer would be translating if needed. The purpose of the researcher being present as well as the fact that the session was recorded was explained. The information sheet (Appendix 1A and 1B) and the consent form (Appendix 2A and 2B) were read out. Although the information sheet and consent forms were in English there were also isiXhosa information sheets and consent forms available. Nonetheless the MKI trainer leading the session read through the information sheet and consent form and explained any areas which participants had questions about. The researcher also addressed any questions from the participants.

Thereafter, the MKI trainer led the session. During this session the researcher participated as well as wrote down field notes, including incidents and non-verbal communications that were not detectable in recordings. The session was run as it had been during phase one of data collection. The MKI trainer started with the opening game and then proceeded with the educational program. Throughout the session the

MKI trainer assisted and translated for the researcher when at times the researcher did not understand what was being said in the session.

The first focus group had was with a MKI trainer that did weekly sessions with university attending young adults that were from the same community as the MKI trainer. The MKI trainer had been doing these teaching sessions with this same group of university students through an organisation. This organisation provided a quiet environment where students were able to spend the afternoon to be able to complete their studying or homework. Before the MKI trainer taught the educational program, a pre-workshop questionnaire was administrated to all participants. From the pre-workshop questionnaires handed out to participants it was recorded that all participants in this particular focus group were less than thirty years of age. The travel time to the closet clinic ranged from ten minutes to two hours, with 50% of the participants taking under one hour to reach the closest clinic from their homes. None of the participants had given birth to any children as well as none of the participants had known of any family that had been diagnosed with cervical cancer. Also none of these participants were married.

Pre-workshop Questionnaire Question	Percentage of Participants (%)
Age: thirty and under	100
Travel time to closest clinic: under 30 min	25
Travel time to closest clinic: under 1 hour	50
Travel time to closest clinic: 1 hour or more	25
Number of children: zero	100
Has a family member diagnosed with cervical cancer	0
Marital status: single	100

Table 2. Focus Group 3 Quantitative pre-workshop questionnaire: background characteristics

These background characteristics indicated that for this focus group, the group of participants shared many of the same background characteristics. So although there was some difference in their answers and expressed beliefs, this focus group was fairly homogenous.

This same process was repeated when a different MKI trainer lead her training group. This time the training session was held at the MKI center within the community of where the MKI trainer lived. This MKI trainer had also been doing consistent training sessions with this particular group of participants. The participants trusted the MKI trainer which meant they were more trusting of the researcher, as the MKI trainer indicated that the researcher would be present to assist and work together with the MKI trainer. It was explained that if there was anything about the educational program that the participants would like further explaining or perhaps provide feedback on, then the researcher would be present for these purposes as well. From the pre-workshop questionnaires handed out to participants it was noted that 50% of participants were thirty years of age or younger, 17% were aged from thirty-one to forty, while 33% were between the ages of forty-one and fifty. With regards to traveling time to the nearest clinic, 50% of the participants indicated they were under thirty minutes away from the closest clinic. While 42% of participants indicated that they were under one hour away from the closest clinic. Only 8% of participants were one hour or further away from a clinic. With regards to having children, 69% of participants had two or fewer children, while 23% had three to four children, and only 8% had five or more children. Only 8 % of participants knew of a family member of theirs who had been diagnosed with cervical cancer, while the majority of participants (92%) did not know any family member to be diagnosed with cervical cancer. With regard to marital status, 45% identified themselves as single, 10% indicated they were living together with their partners, and 45% indicated they were married.

Pre-workshop Questionnaire Question	Percentage of Participants (%)
Age: thirty and under	50
Age: thirty-one to forty	17
Age: forty-one to fifty	33
Travel time to closest clinic: under 30 min	50
Travel time to closest clinic: under 1 hour	42
Travel time to closest clinic: 1 hour or more	8
Number of children: 2 or less	69
Number of children: 3 to 4	23
Number of children: 5 or more	8

Has a family member diagnosed with cervical cancer	8
Has not had a family member diagnosed with cervical cancer	92
Marital status: single	45
Marital status: living together	10
Marital status: married	45

Table 3. Focus Group 4 Quantitative pre-workshop questionnaire: background characteristics

This focus group presented more of a heterogeneous group of participants. There was a difference amongst their ages, number of children had, marital status as well as a more even spread of how long it took to travel to the closest clinic.

For both the last two focus groups described above, once the session had been conducted the researcher had a short debrief session with the MKI trainer who gave the session. This was in order to clarify any queries that may have arisen for the researcher during the session. Overall two sessions were run with two different MKI trainers. After each session the researcher transcribed the recordings. Thereafter the researcher arranged a session with an independent translator in which the researcher worked alongside the translator as the translator translated the transcripts. Only one of the four focus groups (the last focus group) was conducted partially in isiXhosa. That particular focus group transcript was approximately 60% in isiXhosa and 40% in English.

3.5 Data Analysis

3.5.1 Thematic Analysis

Thematic analysis was used to analyze the data that was generated by this research. Thematic analysis is a theoretically flexible way, in which themes can be identified, organized, analysed, and reported (Braun & Clarke, 2006). Not much is known of the specific factors that the research question is addressing in this specific context. Therefore the nature of thematic analysis was useful in providing an overall rich description of the entire data set (Braun & Clarke, 2006). Writing was a key aspect that took place throughout the entire process of data analyses. Writing commenced in the first phase of analysis with the description of possible coding

schemes and ideas (Braun & Clarke, 2006). This was useful to ensure that the themes produced were relevant to the research question being investigated.

This study followed the recommended steps to thematic analysis laid out by Braun and Clarke (2006). This consisted of six phases. During the first phase the researcher read through the transcripts to become familiar with the data. During the reading and re-reading of the data the researcher jotted down any ideas to be used in coding which was relevant to the research question. During this phase any field notes that were made were referred to.

In the second phase the actual initial codes were constructed. All the relevant data for each code was collated, while any interesting features of the data was coded.

The third phase involved searching for themes. Within each theme the relevant data was organised.

Reviewing of the themes took place during the fourth phase. A second and third independent researcher were given a list of emergent themes, as well as extracts of the transcripts, to review whether they were in agreement with the emergent themes. The researchers checked that each theme had data, collated codes, which formed a coherent pattern. The next step was to check that the themes related to one another across the entire data set.

The themes were then defined and named in phase five.

Finally, in the last phase a production of a coherent and concise description of what the data seemed to highlight was produced. The extracted themes were utilized to make an argument in relation to the research question.

3.5.2 Validity

Validity refers to the extent that the research that is generated explains, measures, or describes what the research stated as the aim of the research; that is that the data answers the research question (Babbie & Mouton, 2008; Willig, 2008). Very often validity can be a concern within qualitative research, but there are ways that qualitative methods address these concerns, which this research study incorporated (Willig, 2008). Firstly, reflexivity ensured that throughout the research process the researcher consistently reviewed her own role in the research while the entire research process as a whole was scrutinized. This discourages assumptions and impositions of meaning by the researcher (Willig, 2008). Thus validity is promoted. Secondly, as this research took place in a real-life setting, namely, a community center, and not a laboratory, there was no need to extrapolate from an artificial setting to the real world.

This then promotes the ecological validity of the research study (Willig, 2008). In addition to this, focus groups (a qualitative method used in this research study) create a more natural environment than one-on-one interviews. This is true in this study as community members were already accustomed to attending monthly meetings in small groups to learn and discuss various health related topics. During these monthly meetings there would always be either an MKI intern from abroad, volunteers or the visiting non-community doctor. Thus, community members were accustomed to having non-community members present during the monthly meetings in which they would discuss various health topics. Therefore making the focus group style used for this study a more natural environment and resulting in the data that is collected bearing a high ecological validity (Willig, 2008).

3.5.3 Reliability

Reliability refers to likelihood that a measurement will yield the same answer or description of a given phenomenon if the measurement is repeated on different occasions (Babbie & Mouton, 2008; Willig, 2008). Qualitative research tends to explore specific, at times unique, phenomena in great detail (Willig, 2008). It is for this reason that at times qualitative researchers are less concerned with reliability, as its primary aim is not to measure a phenomenon in large numbers of people. However, Silverman (1993, as cited in Willig, 2008) argues that if qualitative methods are applied rigorously then there should be results generated which are reliable. That is data, which when collected and analysed by different researchers using the same methodology, will generate the same results. Research has indicated that at times the use of more than one analyst can improve the reliability of a study (Pope, Ziebland, & Mays, 2000). Therefore in this study during the data analysis phase, two independent researchers within the research field reviewed the data, to establish the reliability of the primary researcher's analysis.

3.6 Reflexivity

Reflexivity can be defined as the process of dealing with both historical and personal aspects that exist within the research relationship (Parker, 2005). There are two different phases of data collection: overt and covert sessions. During the overt phase the researcher played an important role, as the researcher was the person asking the questions, encouraging discussions and imparting knowledge during the training sessions. However, during the covert phase, it was the MKI trainers and not the researcher who played the important role in giving the training to the participants. It

was however, the researcher who interpreted the verbal and non-verbal behaviour during both the types of training sessions. There is therefore a need to acknowledge both the personal values and beliefs of the researcher which, although not purposefully, may affect the interpretation of the data.

With regard to personal values and beliefs the researcher acknowledged and was aware of the differences that there may have been between the researcher and the participants. Coming from a culture that prioritises western medical care, the researcher took a step back and reflected on the perceptions of what was considered to be normal adherence behaviour and health beliefs. The researcher had to be aware that not all families and cultures consider western medicine in the same light. Another factor was that the researcher was part of a culture in which cancers, including cervical cancer, were openly spoken about and this may not have been the situation with the participants. The researcher also had to be aware of the beliefs that the researcher held which the participants may not have shared. Such a belief was that the researcher believed that women should have the right to decide for themselves which healthcare option to choose without suffering the consequences of family or society members. This belief may not be the reality that many of the participants faced.

Other factors that may have influenced the manner in which the questions were answered were the researcher's subjectivity and chosen data collection method. Although during the covert phase of data collection the researcher was not playing a principal role, the position of the researcher as a white, English-speaking, middle-class female, with a different culture from that of the participants may have affected the manner and content of what was shared in the sessions. The researcher needed to remain reflexive during the process of conducting and interpreting the data and research, so that the researcher did not impose personal views on the meanings that emerged from the data.

3.7 Ethical Consideration

This research project adhered to the University of Cape Town's ethical guidelines for research with human subjects. In addition, this research met the ethical requirements of the Research Ethics Department of the Department of Psychology.

3.7.1 Consent and Confidentiality

Before each training session was held informed consent was obtained from each participant (See Appendix 2A and 2B). Where direct quotes from participants were used in the research pseudonyms were used to ensure that the participants'

identities were concealed. Lastly, the participants were informed that the researcher could not ensure that other participant members in the session would have kept confidentiality, as the researcher had no control over any participant. Participants were informed that this might have posed a threat to the confidentiality.

3.7.2 Voluntary Participation

The participants were informed that their participation in the research was completely voluntary. They were made aware of their right to withdraw from the study at any point without experiencing negative consequences. If they wanted to withdraw they were able to and then attend a separate (non-recorded) training session on the educational material.

3.7.3 Risks and Benefits for Participants

This research posed no threat or great risk to any of the participants. The researcher had no control over the behaviour of any of the participants; therefore any harm thereof could not be controlled for. This was conveyed to all participants at the start of the sessions.

This research aimed to inform and develop a psycho-educational intervention programme, which the MKI trainers and the organization as a whole could use in their daily trainers of other community members. The benefit the participants received from this research was in the form of a knowledge capacity. The participants also had and currently have access to the developed psycho-educational program that focused on cervical cancer and screening practices.

3.8 Limitations

The first limitation in this study is with regard to generalisation. As the sample consisted of members from only one disadvantaged community in the Greater Cape Town region, the results from this study cannot be generalized to the entire population of disadvantaged members in South Africa. In addition, these findings, from a disadvantaged setting based in the Greater Cape Town region, may differ to that of disadvantaged settings based in other surrounding African countries such as Zambia or Botswana. Thus generalisation between these contexts would be inappropriate.

3.9 Summary

The chapter started by re-looking at the aims of the research, which is to identify what factors play an influence on cervical screening uptake in disadvantaged communities in South Africa. This chapter then discussed the methodology employed. The chapter indicated that participants were recruited from MKI, an organisation that

provides healthcare education to underserved communities. MKI trainers were offered a training day on cervical cancer, which they in turn taught to their respective community groups. Only MKI trainers and their group members were included in the study as there had been a relationship and rapport already established between the researcher and MKI and MKI trainers. The type of data collection method used was also explored, this being focus groups. The chapter then looked at how thematic analyses was used to analyse the data. Finally, reflexivity was explored and ethical considerations and limitations were discussed.

Chapter 4

Discussion and Analysis

Research has shown that amongst other factors, low socio-economic status, poor education, and poor access to health services are factors which act as barriers towards cervical cancer screening (Bradley, Risi, & Denny, 2004). South African research by Moodley et al. (2006) has indicated that women of colour are in fact disproportionately affected by, and in fact are more vulnerable to, cervical cancer than other ethnic populations. This chapter discusses the findings of this study, namely, Gender, Spiritual and Religious Beliefs, Home Remedies, Knowledge and Stigma (see Diagram 2. on page 51). Gender as a theme is composed of four sub-themes; namely, Loss of Womanhood, Male's Role, Practitioner Gender, and Privacy. The theme Spiritual and Religious Beliefs is composed of three sub-themes: Traditional Healers, Religion and Balancing Paradigms. The theme of Knowledge is composed of four sub-themes: Lack of Knowledge, Desire for Knowledge, Misperceptions, and Disease Social Identity. The findings are discussed within the themes and sub-themes according to a structure; firstly, identifying what the beliefs and norms are and then secondly, what the outcomes of such beliefs and norms are.

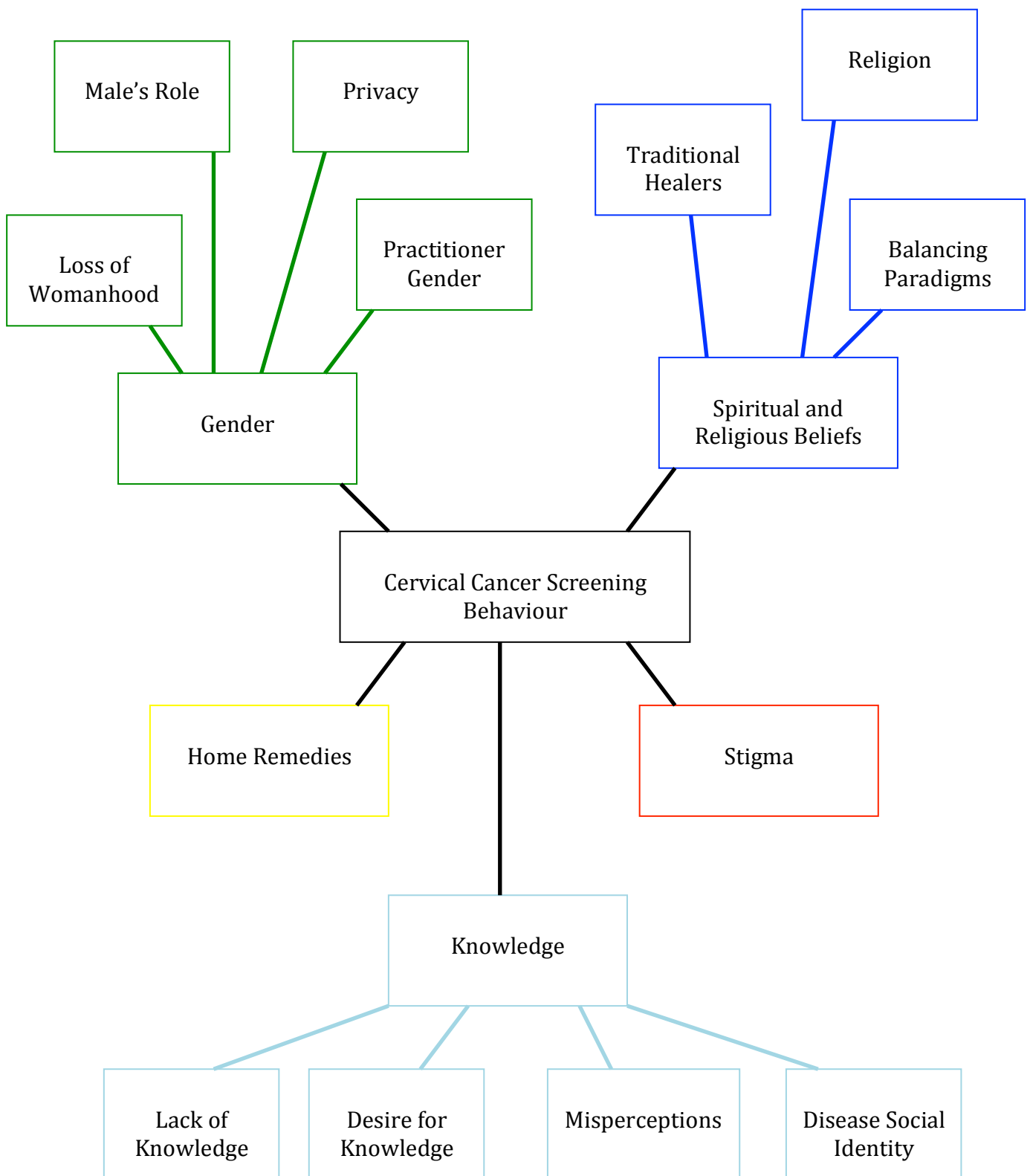


Diagram 2. Flow diagram of themes

4.1 Gender

Gender encompasses beliefs, which are defined as a set of convictions and thoughts about behaviour that is imposed on a specific gender group with regard to gender roles, health behaviours and cervical cancer. Beliefs are defined as convictions or a confidence in something or someone that is accepted as true and trustworthy to the individual holding the belief. There were four sub-themes that emerged from the data: Loss of Womanhood, Male's Role, Practitioner Gender, and Privacy.

4.1.1 Loss of womanhood

The sub-theme loss of womanhood includes the identification of what is believed to define womanhood by males and her society, namely, to have children and sexually satisfy her partner. This sub-theme also includes the consequences of being diagnosed with cervical cancer, namely, a woman's partner leaving her, losing her position in her cultural context and being treated differently.

The belief that emerged amongst men was that, after a woman has had her womb removed, any sexual intercourse will be less pleasurable for the male, as well as the woman having a lower sex drive.

FG2 P4: "We also have this belief that, in women, that once you have cervical cancer or you have the womb removed that you have like a low sex drive and that chases guys away."

FG2 P5: "... 'Cause the belief is: if you having sex with someone who has their womb still has their womb, it's more than nicer than someone who has their womb removed."

From the data, it emerged that, although a man sees a woman without her womb as less sexually desirable, there is a similar reaction held by women towards other women who have had to have a hysterectomy. The data indicated a belief that a woman without her womb is seen as less of a woman. This belief was indicated to include the notion that, without a womb, women believed that men perceive them as less attractive than their counterparts who have not had a hysterectomy.

FG1 P3: "If you take the womb out ... then the man ... he doesn't want the woman anymore. If the man, the boyfriend, knows that the woman doesn't have the womb, then they don't want that girl because she is not hot anymore."

These beliefs are consistent with other research that indicated a loss of womanhood and sexuality with the loss of a womb (Bingham et al., 2003).

It emerged strongly from participants that the above beliefs of lessened sexual drive would result in an outcome of a woman potentially losing her partner.

FG2 P6: "... Black women in particular, I think they fear that any detection or any diagnosis of that kind of a cancer that affects their sexuality or their sexual productive this then, they are made they are afraid that they can lose their man, that's their husband or boyfriend. If the man can realise that they have that kind of a disease, then the future with that man is not certain anymore so ... there is that fear of even thinking that I can have a cervical cancer."

FG2 P4: "... men are the ones which usually leave after they find out their partners have cervical cancer or they have their womb removed ..."

In conjunction with the belief that a woman without a womb will not be sexually desirable, there is the added dread of the male's response of leaving their partners when it is known that she has cervical cancer.

A possible explanation of men leaving their partners is that there is a strong association that emerged from the data of cervical cancer with childbearing abilities. It was indicated that many communities, including the men in the community, perceived that, if a woman has cervical cancer, she would most certainly never be able to have children.

FG2 P6: "People who know about the disease knows that it affects women, people of the community who know about it, and they also think that, uh, women can't have kids when they have cervical, cervical cancer."

FG2 P4: "Maybe some men will be scared that they won't be able to give them babies, children."

The data indicated that men believed that a woman diagnosed with cervical cancer would not be able to bear any children. For this reason, it was believed that a man would leave his partner. This was viewed as one of the reasons that men were seen to leave their partners if the woman was diagnosed with cervical cancer (Raynolda, 2013). Previous research has also indicated that cervical cancer is believed to be associated with not being able to have children (Summers, 1998). This is problematic as this loss of partner is associated with a woman not being able to acquire a family life, and thus, her position in a culture that so highly values the role of a woman within a conventional family structure is uncertain (Agurto et al., 2004; Chigbu & Aniebue, 2012; Mosavel et al., 2009).

Not being able to have children is something that goes against certain sub-Saharan African cultures, thus understandably women in these cultures would not want to have a disease which results in them going against their culture (Caldwell & Caldwell, 1987). This highlights how cultural factors affect how disease treatment is discussed and adhered to, for example a woman's husband has to be consulted, and therefore informed of her diagnosis, before any treatment can be accepted (Nene et al., 2007). With the above-mentioned fear of losing their partner, this cultural gender factor increases the difficulty of accessing screening.

The data highlighted that the ability of being able to have children is so pivotal that sometimes a man will prefer to marry someone who is already pregnant with his child to ensure that the woman will be able to bear children.

FG2 P6: "It is in a big way 'cause, if you look into our Black communities, you will notice that sometimes men will prefer to get married to a woman that has got a child already."

FG2 P7: "Mmm."

FG2 P6: "... because that's a sign that she's can be having children ... so, uhm, that's a big problem; the woman that can't have children."

It emerged that the total sum of a woman's value can be placed on her ability to have children.

FG3 R2: "What it seemed to me that women's women's, uhm, value is based on their ability to have children."

FG3 P3: "Mmm."

FG3 P7: "Mmm."

Others: [nodding]

These beliefs highlight the emphasis that is placed on a woman's ability to have children, which can be seen as an explanation as to why women in these communities are so frightened to be diagnosed with cervical cancer. If there were a disease that equates with women not being able to have children, then it is thought that this disease would be most avoided. Yet, despite this perception of cervical cancer and inability to bear a child, there are still very low rates of screening amongst Black South African women from these communities (Peltzer, 2001).

Perhaps a reason for the low rates of screening is that if women are diagnosed with cervical cancer not only do women face possible imminent death, but they may lose their social status or social acceptance too (Agurto et al., 2004). In a culture

where there is such importance placed on a woman's ability to bear children, this perceived consequence of cervical cancer is vital (Caldwell & Caldwell, 1987). This loss of being able to have children results in women possibly losing their partner in the process and feeling they have lost a part of their womanhood (Bingham et al., 2003).

These beliefs that emerged all highlight how cervical cancer is often framed in traditional terms as opposed to biomedical terms (Mosavel et al., 2009). This causes an outcome of great anxiety and fear in women, emotions which become barriers to women seeking cervical screening, lest it is found that they may have cervical cancer and therefore result in their partners leaving them (Thomas, Saleem, & Abraham, 2005). This contributes to the already adverse psychological effects that are present when a woman is invited to attend a screening program (Rogstad, 2002).

4.1.2 Male's Role

This sub-theme includes the extent to which men make the effort to be informed about female diseases and how this affects what support a woman receives from her partner, thus influencing her screening adherence.

Yet, despite cervical cancer impacting so largely on a man's partner choice, men were indicated as believing that, if the disease only affected women, they did not need to be concerned about the disease or any implication of the disease.

FG2 P5: "Uhm, we also said men men don't really make a effort to knowing i- things like cervical cancer, because they only believe that, if it effects women, we don't really have to worry about that, they would not be interested if I would going in a room a bunch of men and start talking about cervical cancer and how it affects, they wouldn't really be interested."

Within the focus groups, it was highlighted that in African culture men do not want to know anything about a woman's disease.

FG4 P2: "Ja, it's one of i i problematic area that one, she knows she can't discuss it with her husband."

FG4 P8: "Mmm."

FG4 P2: "Because you you know African men, they don't wanna know about these things, they not interested, so as a woman you scared to discuss these things with your husband, you understand."

FG4 P8: "Ja."

FG4 P2: “Ja, a because we are stubborn, ja, men are stubborn. That thing it comes to the knowledge.”

This is regardless of the fact that HPV, which causes cervical cancer, is transmitted by men during intercourse (Schiffman, Castle, Jeronimo, Rodriguez, & Wacholder, 2007).

In sub-Saharan Africa, South Africa included, women are still brought up to be subservient to men (Heunis et al., 2012). This subservient nature extends into their sexual relationships, which may be a reason that some men may not want to know about any matters pertaining to a woman’s concerns about her health and thus offering no support to women (Nene et al., 2007). The participants in these focus groups seemed to associate this behaviour with an African culture.

Therefore, many women felt they were unable to discuss any aspect of their illness with their husbands or partners. Without being able to discuss such matters, the chance of there being emotional support provided by the woman’s male partner is minimal. This is important to consider as research has indicated that positive emotional support from a partner plays a key role for adhering to clinical health-behaviour guidelines, with some people not adhering to screening if their partners were not willing to seek screening for other health tests (Bingham et al., 2003; Lazcano-Ponce, Moss, de Ruíz, Castro, & Avila, 1999; Nene et al., 2007). Without communication between husband and wife or between partners, the woman’s decision to adhere to cervical screening and treatment is difficult. She knows she will most likely not receive any support from her husband or partner as no discussion can be held. Without this support, a woman’s fear of facing a challenging illness is only enhanced (Bradley, 2014).

The data indicated that people were not sure about what it meant to have cervical cancer and it was highlighted that men in particular were not aware of the true meaning of the disease.

FG1 P7: “We don’t know about the dangers, about the cervical cancers. The men, they don’t know about it.”

FG1 P2: “I don’t know how do you get it. How do you get cervical cancer?”

It emerged from the data that although people associated infections with cervical cancer, they, and including men, were not able to identify that the primary STI linked to cervical cancer was HPV.

FG1 R2: “What do you mean by cervical cancer? You were telling me you know something about the causes. Can you elaborate?”

FG1 P3: “Infections.”

FG2 R1: “... do you think men know that they can carry the HPV virus?”

FG2 P5: “... not much info on HPV so obviously they wouldn't know.”

While the WHO (2010) has indicated that HPV is responsible for many cervical cancer cases, there needs to be a focus on knowledge dissemination with regard to the fact that males are able to carry this STI. Thus, by incorporating what the male's role is in the spread of HPV, and therefore cervical cancer, some responsibility can be taken up by a woman's partner. This would help to shift some of the stigma away from women. With cervical cancer having such high rates of mortality and morbidity, and the role that sexual activity plays, it is imperative that provision of preventative healthcare from sexual debut is reviewed and knowledge around the role of HPV, and males as carriers, as a cause for cervical cancer be discussed (Learmonth & Learmonth, 2014).

Also if the man in a woman's life is unable to understand the disease, this could affect how much support the woman would receive from her partner, which in turn has been noted to be a barrier to women attending cervical screening (Nene et al., 2007). Having stated the importance of a woman's partner having the correct knowledge about disease in order to offer her support, it is as important for a woman to have this knowledge in order for her to seek cervical screening and possible further treatment. Therefore, defined gender roles are important to take note of. These roles are paramount as they will dictate what kind of support a woman may have available to her should she partake in cervical screening and treatment (Holroyd et al., 2004).

4.1.3 Practitioner Gender

This sub-theme refers to the barrier of having a male practitioner examining a woman undergoing cervical screening.

For many community members, having their genital area examined by a member of the opposite sex is very uncomfortable and distressing (Byrd et al., 2007).

FG4 P2: “And then also another problem on this, uh ... you find out sometimes the person who is going to that Pap smear it's a doctor a doctor a man ...”

FG4 P3 + P4: “Mmm.” [nodding of others]

FG4 P2: “So y y you as a woman, you don’t want to be touched by a man, although he can help you.”

FG4 P3: “You have that thing inside that you don’t want to be touched, but you go to the clinic and someone is going to touch you, put in a hand.

It was reported that if the gender of the person administrating the cervical screening test was male, then this too induced an outcome of fear and concern amongst women.

FG2 P8: “If you open you have got problems between your legs, you don’t want a lady to come and check for you if you are a man. And if you are a a a woman [light laughter], you don’t want a a male doctor to come and check for you.”

This finding is consistent with other findings that indicated that, if the screening provider was known to be male, then women would feel fearful and uncomfortable (Bradley, 2014; Holroyd et al., 2004). Studies have shown that the gender of the practitioner emerged as a factor affecting the uptake of screening services (Byrd et al., 2007; Holroyd et al., 2004). Women have been reported to conceal their cancer-screening uptake from their husbands, as the husbands do not want a male practitioner examining their wives (Holroyd et al., 2004).

4.1.4 Privacy

This sub-theme identifies how a woman’s culture defines her need for a certain level of privacy, which may influence her choice of treatment and potentially act as a barrier to cervical screening.

Participants reported that in their communities a person’s private area, or reproductive organs, was not commonly discussed.

FG2 P5: “Uhm, the other thing is that, uhm, you say cervical cancer, I think it’s as Black, it’s something that has to do with your genitals and stuff like that, we don’t really talk about that, you don’t go around mentioning that I’ve got i-STI or cervical cancer or ... uhm, even now I don’t know of anyone that’s ever had i-cervical cancer, I’ve never come across anyone who’s said ...”

Over all the focus groups, it emerged that because African communities specifically did not like talking about the body’s reproductive organs they did not discuss diseases such as cervical cancer. This finding highlights the importance of privacy that exists with regard to a culture’s view and belief of how and to what extent a person can discuss a woman’s body.

The participants also highlighted that, at a broader community level, cervical cancer is not really spoken about.

FG2 P5: “I never heard anyone speaking about i-cervical cancer, in the community or just chatting about it whatever, so I don’t think this word or maybe they call it something else but not cervical cancer.”

This is consistent with research by Thomas et al. (2005) that indicated that, amongst Black and minority ethnic groups, discussion of cancer of the cervix or uterus was considered extremely taboo resulting in nobody wanting to discuss these particular cancers. Shame of discussing cancer is another reason added to the list of why cancer is not spoken about amongst the community at large (Thomas et al., 2005).

Linked to the culturally based privacy, it emerged that there is a need to seek out treatment that is culturally appropriate, that does not require a woman to expose her genitalia.

FG4 P3: “So, because we grow up in that environment, in that culture, doctors want to touch underneath. But you don’t want that, you want someone who can stop it without touching you.”

FG4 P5: “And it becomes because it is the private part, for us Black people our private parts are a no-go zone, no-go zone ... I’d rather stay at home and die than go to the clinic and lay out my private parts there.”

This belief is strongly played out within a community setting in that, if the treatment for disease is very different to a woman’s community and cultural practices, then it will not be adhered to (Baldwin, 1996). Research has indicated that participation in cervical screening may leave some women feeling that their private space has been invaded (Summers, 1998). Regardless of cultural beliefs this loss of physical privacy has been seen at times to be the strongest reason why women do not attend or rather delay cervical screening (Watkins, Gabali, Winkleby, Gaona, & Lebaron, 2002). Research with low-income women in other developing countries has highlighted that a lack of privacy includes actual interruptions during screening procedures as well as some pelvic examinations being held in corridors of clinic facilities (Agurto et al., 2004). In these instances of privacy violations the lack of privacy is a barrier that is shared across many different cultures and not just the African community in which the participants are describing their experiences.

It emerged from the data that having a Pap smear was shown to fill women with fear and uncomfortable feelings.

FG2: P8: "... it's another thing to open legs."

FG2 P7: "The instrument they use it is scary you see"

This fear surrounding the clinic attendance and Pap smear procedure has previously been reported amongst women attending cervical screening (Bradley, 2014). This result is consistent with other studies that indicated that fear of undergoing the Pap smear testing contributed to a lack of cervical screening adherence (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Lee, 2000; Lyttle & Stadelman, 2006; Ogedegbe et al., 2005; Taylor et al., 2004; Thomas et al., 2005).

There was also a report of a lack of privacy with regard to communities being portrayed as gossiping to a large extent. It was seen that, with regard to their current community, participants indicated that women were afraid that the rest of the community might find out if they had cervical cancer. This means that often women battle through the illness alone.

FG2: P8: "If you are you are a lady, you scared to disclose your status to another or to a friend of yours because he's gonna spread within a minute."

As explained before, there is an association with having cervical cancer and not being able to bear children. This occurs when the cancer is detected at a late stage and one of the treatment options is a hysterectomy. Women then associate a hysterectomy with the loss of being able to bear children, and with a loss of womanhood and sexuality (Bingham et al., 2003). This loss is crucial as a woman may not be able to acquire a husband, which results in them being viewed as potentially less of a woman to other men and their community (Agurto et al., 2004). This could be a reason as to why women would not want their diagnosis spread amongst the community, and why women would be more modest and discreet with their possible cervical cancer diagnosis. This could lead to potential stigmatisation, which is discussed further in the stigma section in this chapter.

Another factor relating to privacy, which encourages traditional healers being sought over western clinics, has to do with the previously discussed private nature of some cultures that women belong to. It emerged that, if people were seen at clinics, they would experience a lack of privacy, as they would be faced with questions from other community members attending the clinic as to why they needed to attend the clinic. Participants in the focus groups reported that, when attending a clinic, patients often face the curious eyes and questions of the other people waiting in line to receive help.

FG2: P8: “Patients are scary on us ... on the waiting benches.”

FG4 P3: “You don’t want to be asked lots of questions so those are the problems that we have. All of those have got to do with our culture, not wanting to be asked this or that.”

It emerged that, when women are asked too many questions about clinic attendance, this makes them feel uncomfortable.

FG4 P8: “We mentioned at the clinic we are all mixed up, and the next thing somebody come and ask what are you here for ...”

FG4 Others: “Mmm.”

FG4 P8: “And you don’t like that, you feel uncomfortable with that.”

This resulted in women feeling uncomfortable when it was revealed to others why they were attending the clinic.

In addition to feeling uncomfortable participants also indicated that they would feel embarrassed when having to attend clinics and expose their genitals.

FG2 P8: “ja I’ll come next time when the doctor (not a male) comes. That is embarrassing you see so that is why there is the a lot of these...”

FG2 P6: “barriers...”

FG1 P6: “It’s embarrassing to open your legs”

This feeling of embarrassment when having to request and attend a specific screening has previously been reported amongst communities of disadvantaged South African women attending clinics (Krombein & De Villiers, 2006). Feelings of embarrassment associated with attending cervical screening have previously been seen to contribute towards unscreened women’s lack of adherence to cervical cancer (Holroyd et al., 2004; Summers, 1998).

Research has indicated that embarrassment is also decreased amongst women who have already given birth. This is as the birthing procedure itself may decrease the embarrassment a woman may have about her body (Watkins et al., 2002). Although generally there are levels of embarrassment experienced when attending clinics for screening, it emerged that this could be reduced by having the preferred gender (depending if a male or female was the person seeking treatment) provide the cervical screening (Holroyd et al., 2004; Summers, 1998). In order to reduce feelings of embarrassment, research has indicated that there has been a strong preference for female screening providers (Holroyd et al., 2004; Summers, 1998; Thomas et al., 2005). This highlights the importance of having a dialogue with communities and

patients in order to create more culturally accepted screening services. Thus communication is important, as these feelings of embarrassment can at times be so intense that it prevents women from attending cervical screening services (Bradley, 2014; Nene et al., 2007).

Contributing to the intrusion of a woman's privacy is the structure of the western clinics that are established in the disadvantaged communities, as they do not allow for much privacy. It emerged from the data that the structure of many clinics that the participants reported attending are not set up to ensure privacy for their patients. The structure of many of the clinics that participants attended was described as a general big waiting room where all patients would wait together. The clinic structure is such that there are specific rooms (or areas) which deal only with TB, specific rooms for HIV and separate areas for gynaecology. This means when a patient is called from the waiting area to a specific room all other patients waiting to receive medical care can see for what reason that patient is attending the clinic, as they see which room or known area the patient is being called to. This was reported to make a person attending a clinic feel extremely exposed as anyone else at the clinic could see which door they walked into and hence guess what illness they have.

FG4 P3: "But also, when we arrive at our clinics, we are find that there's a container separately they know that that container, it's people that have HIV positive. And even if you go to the clinic for a Pap smear, you go in a separate door, you don't go in the same door, so they already know ..."

Participants reported that, therefore, women felt safety with their infant or child accompanying them to the clinic as opposed to going to the clinic on their own.

FG2: P7: "And then, once they see you ok, like this you having a baby you feel very much safe, because it's like you brought the child, it's not about you."

FG2 Others: "Mmm, ja, ja."

FG2 P7: "But when you alone ..."

FG2 P7: "What do you have? They start seeing, you know, my hair is thin and oh ... they start, you know, now it's building up. And men really stare on you ..."

By having their child with them less attention would be placed on the women and they would gain a sense of privacy.

In response to these barriers, it must be noted that a clinic should attempt to provide services to their patients in a manner that is culturally relevant (Holroyd et al., 2004; Thomas et al., 2005). This means that nurses and doctors involved in the provision of screening services would be aware of the relevant cultural and social aspects of the main population group they aim to serve (Holroyd et al., 2004). In so doing, clinics would be aware of potential barriers that discourage patients from attending screening.

Participants also reported that there were cases where confidential information about a patient had been leaked through the nurses or doctors who work and live in the area where the clinic is situated. The participants reported events where the status of a patient was revealed to other community members.

FG2 P5: “Some of the nurses and the staff, they live in the community, so there’s been instance where people, uhm, some of the staff have disclosed in some peoples status or with their friends so, ja ...”

It emerged from the data that one of the poorest services is that confidentiality between medical practitioner and patient is sometimes broken, because often the doctors and nurses at the clinics live in the surrounding areas. This again highlights, the poor quality of services that patients must face at a clinic (Nene et al., 2007).

This finding was also found amongst Pakistani Muslim women who were happy to attend a cervical screening as long as the screening provider was not of the same cultural community as them in case they were ‘found out’ and ‘outed’ to their community (Thomas et al., 2005). These findings of such negative experiences are of great concern. Women have previously reported not choosing to have a screening procedure repeated due to such negative experiences (Thomas et al., 2005). In a community with already such low screening adherence rates, it is even more devastating to have negative experiences present which will further decrease screening adherence (Peltzer, 2001; Thomas et al., 2005).

With studies reporting the role of such beliefs and modesty acting as a barrier to screening adherence, it is imperative to take into account the need to seek ways of generating a discussion around cervical cancer (Holroyd et al., 2004; Thomas et al., 2005).

4.2 Spiritual and Religious Beliefs

The theme Spiritual and Religious beliefs encompasses beliefs about the supernatural which shape and influence an individual’s subjective norm and therefore

their perception of disease causation, treatment and overall health-seeking behaviours. Beliefs are defined as convictions or a confidence in something or someone that is accepted as true and trustworthy to the individual holding the belief. There were three sub-themes that emerged from the data: Traditional Healers, Religion and Balancing Paradigms.

4.2.1 Traditional Healers

Traditional healers as a sub-theme include an explanation of disease causation, treatment seeking behaviour and barriers that a western clinic presents. This sub-theme also includes the description and acceptance of the role of and place within society that traditional healers have.

With regard to the causation of disease, it emerged from the data that individuals believed that the root cause of illnesses was linked to the supernatural realm. Across all the focus groups, one of the strongest views that was shared amongst the community members, was that if a woman is diagnosed with cervical cancer, then she has had a spell cast on her.

FG2 P4: “People believe that, when they have something wrong with them, it’s either that they been bewitched by someone that doesn’t like them or ... that it’s just like a stream of bad luck that’s running through the family or themselves ...”

FG1 P6: “So, actually, it is cervical cancer but the thing is they don’t know it that way, they see it as a woman being bewitched.”

FG1 P6: “... the general belief in Black communities about women who have, uhm, cancer, this sort of cancer, is that their womb, they have been ... bewitched.”

The data indicated that if a woman cannot fall pregnant and bare a child then the cause of that disease that does not allow a woman to have children could be that she had been placed under a spell.

FG2 P6: “And there is a general belief especially in the African culture that there is a curse, to have a disease that you cannot bear a child is sort of a curse. Someone must have, someone must have placed a a spell on you, in some way for something that you did or maybe that they angry with you.”

This belief extended to the causation of cervical cancer in particular. Many community members in the focus group strongly agreed that there is a belief that a cause of cervical cancer is bewitchment.

FG1 P3: “They don’t want to believe they have the (cervical) cancer. Then they believe they have been bewitched.”

This finding is in agreement with literature that highlights the African belief that ill health may be sent to a person by their ancestors because of ancestral disapproval or through witchcraft and sorcery (Pretorius, 2012). This belief stems from the original African concept of disease causation that identifies causes to be ancestral spirits, violating taboos and failing to adhere to religious duties, as well as natural and supernatural forces (Pretorius, 2012).

While it is believed that ill health from an ancestor can be cured, often ill health from a bewitchment may not be cured and therefore leads to death (Pretorius, 2012). This thinking fuels the belief that cancer is from bewitchment as cervical cancer can be fatal if not detected and treated early. This belief may change shape or form to some degree but remains an underlying guide throughout different generations.

With the explanation of bewitchment as the root cause of illness within the African cultural beliefs, provision is made that the nature of treatment sought should be in accordance with the cause (Pretorius, 2012).

FG1 P7: “... they also believe that they have been bewitched, that’s the reason they go to the sangomas, because the two works together.”

FG4 P2: “And then we see sangomas. When people are in need they run to the sangoma ... when people see that they have cancer, they think they have been bewitched so they go to a sangoma.”

Referring once more to the original African concept of disease causation, when illness is experienced, it is interpreted as possibly being caused by supernatural forces (Pretorius, 2012). Thus, an outcome is that people gravitate towards seeking out traditional healers for treatment as this matches the nature of what they believe to be the causing agent.

This belief is also shared amongst other African cultures, such as that from Nigeria (Thomas et al., 2005). For this reason, the participants explained that, when a woman discovers she is not able to fall pregnant, and she shares that specific cultural belief, she will most likely seek out a traditional healer first. As the African ontology of disease is focused on the balance between cosmic life forces, any illness is seen as an imbalance in this area (Pretorius, 2012). With traditional healers being part of a small group of people seen to be able to manipulate the force involved with ancestral

spirits, they are sought out for issues relating to diseases (Pretorius, 2012). Thus, the belief is that, when there is an illness, the cause may be supernatural; therefore, the type of treatment needs to match the specific type of cause.

Whether or not there is physical pain or symptoms, it emerged from the data that the first point of call will be what the culture and tradition of that woman dictates. For many disadvantaged community members that first point of call is to seek a traditional healer, mostly referred to as a sangoma.

FG1 P3: “They normally go to a sangoma if there's no, nothing painful, they don't see any discharges, but they are just not getting kids. Then they would be like: I don't have any pains. I don't have any symptoms of anything, there's nothing wrong with me but I'm just not getting the child.”

FG1 P7: “It's a lot of, uh, traditional, African method that is around ...”

As previously explored, the health-seeking behaviours of a woman are influenced by her traditional explanations of ill health (Nene et al., 2007). This influence of traditional explanations is therefore what guides a woman's beliefs and, thus, her health-seeking behaviours. As these beliefs guide a woman's behaviour this is an important socio-cultural factor to take into consideration when trying to advocate and promote for cervical screening.

It emerged from the focus groups that in addition to the preference for seeking a traditional healer, was the trusted position that traditional healers held.

FG4 P5: “... to the sangoma that's the first point: a sangoma, because these are our doctors, we don't underestimate them.”

The preferred option when seeking assistance with health for many individuals in disadvantaged communities is often not the western doctor but rather the community's respected and trusted traditional healer (Thomas et al., 2005). This belief in traditional healers as the first point of call with regard to illness is a belief passed on from generation to generation. From a young age, children are constantly exposed to the beliefs and practices of their parents, as well as their community (Krombein & De Villiers, 2006). This exposure to these beliefs and behaviours shape the view of what acceptable practices are. Hence, it is important to highlight how beliefs can affect health-seeking and screening adherence behaviours (Thomas et al., 2005).

The focus groups indicated that these above-mentioned beliefs were taught to children from a young age.

FG3 P4: “I think as we grow up we, in most cases, we believe in using traditional medicine would help healing cervix ... diseases.”

FG3 P8: “Ok, we have a belief of using that.”

FG3 P4: “We have a belief of using traditional medicine.”

It also emerged from the data that often individuals grew up not believing that they could seek medical assistance from western clinics.

FG4 P1: “... and so they grew up in an environment where they didn’t believe the clinic was available to help.”

FG3 P2: “Well, some believe that, if you go to the traditional healer, it’s better to go to the traditional healer than to go to the clinics, it’s better than that.”

Therefore, this results in children being reared trusting traditional healing for the healing of illnesses. Although, in the past, traditional healing was the only source of healing for millions of people who suffered illness, today, for reasons discussed below, it remains a first choice for the majority of African communities (Pretorius, 2012).

The belief that western clinics could not offer the best medical help stems from a variety of reasons. Firstly, there is a history of distrust towards western healthcare, as well as western healthcare being largely unaffordable and inaccessible in comparison to traditional healing (Pretorius, 2012). Western healthcare and medicine being healthcare that is provided by a medical doctor or nurse trained and recognised by the Health Professions Council of South Africa (HPCSA). This history of distrust comes from many years in which the western medical system, during the South African apartheid system, failed to adequately serve the African communities, thus resulting in a loss of confidence in this healthcare system and an increased reliance on traditional methods (Nene et al., 2007; Pretorius, 2012; Thomas et al., 2005). Thus, the tendency for patients to believe in traditional healing comes in part from the failure of the western medical system in the past, as well as the still existing current limitation in accessing this healthcare system. Yet the preference for traditional healing is not only due to the limitations of access to western medicine, but it is also due to traditional sources having been deemed acceptable and practical to the many previous generations (Pretorius, 2012).

The data indicated that, an outcome to the beliefs held is that western medicine is often sought out as a last resort if traditional medicine has not solved the problem. If for example, a treatment from a traditional healer does not seem to

produce the results the woman is expecting, for example falling pregnant, then the woman will seek medical help at the clinics.

FG1 P6: “They will go, they will go for a, for not falling pregnant ... it would believe that somebody has blocked them somewhere, and then maybe when the solution with the sangoma is not not seemingly producing results, then they will take an advice to go to the doctor and see what’s the problem.”

FG1 R1: “But you said that they might believe that they are bewitched but then they still go to the clinic. Do they go to both?”

FG1 P6: “Yes, yes, some do, at the end of the day especially if they have been to the sangoma and it has not worked ...At the end of the day, then they will go to the medical solution.”

Participants indicated that only once traditional methods had been tried and no results yielded will the western medical approach be considered. This follows from the African notion of disease causation, which identifies that a disease cause may also be natural (Pretorius, 2012).

One of the greatest barriers that women face in attending screening for cervical cancer is that of cost and access to medical practitioners (Krombein & De Villiers, 2006; Watermeyer, 2013). It emerged that it was more expensive to seek help at the western clinics than at a traditional healer.

FG4 P5: “A person thinks: if I went to a White doctor, it would cost me thousands and thousands ... but if I go to so and so sangoma, we can negotiate for like R20 ...”

FG4 P1: “... but this person [referring to picture] is not working ... that could be one of the reasons that they not going to the clinic because they don’t have enough money.”

FG4 P1: “Yes, yes, they don’t have enough money because they are struggling. The money that they earn is little and then they can’t use it to go to the clinic.”

FG4 P8: “African people believe that White doctors are expensive so, ja, imagine that other picture that they living in the rural area neh, and the next thing they must go to the doctor neh, where as a traditional healer lives ... just is my neighbour ... So imagine I have to travel those 45 kilometres PLUS [emphasised] then I have to have money, you know, it’s also a big barrier for us neh, ja.”

FG4 P5: “Also, another problem is not having money; environment like that it’s a struggle [finance] a struggle.”

This finding is consistent with research that indicates that the monetary cost of attaining the medical help of a doctor, which some patients may not be able to afford, can act as a barrier to screening (Krombein & De Villiers, 2006). Women who have a poor socio-economic status will remain the most vulnerable to cervical cancer if they are not able to overcome these access barriers to reach a clinic (Watermeyer, 2013). This makes the affordability of traditional healing much more alluring than that of western medicine.

As well as being affordable, traditional medicine is also that much more available and accessible (Pretorius, 2012).

FG4 P8: “... just a traditional healer is my neighbour, just then he can help me easily.”

FG4 P5: “And, because these people [traditional healers] are around us, they are the closest to our to our lives, you know, we all go to churches every day or on a Sunday, we all we all used to the sangomas so so when the person is, when the member of a family is sick we tend to go to the, to the to to the sangoma. That’s the first point: a sangoma, because these are our doctors we don’t underestimate them, they helped us all the years so we we go to the sangomas, ja.”

With traditional healers having a population ratio from 1:190 to 1:400, they are much more available in comparison to the biomedical practitioners which have a population ratio of 1:20 000 or more (Pretorius, 2012). Traditional healers are also that much more accessible as they tend to be in much closer proximity to their clientele, not just in terms of geography but also in psychological, cultural and social perspectives (Pretorius, 2012). Thus, with the access and availability being in favour of traditional healers, their community members seek them out.

There were also other types of costs that emerged from the data. Participants indicated that cost could involve the time it takes to travel to the clinic, as well as the time spent waiting, often for a whole day, at the clinic.

From the data, it emerged that the long distance that is needed to be covered in order to reach a clinic is costly.

FG2 P8: “... so clinics are far from the place we are living, you see, so we are bored for that, when we are coming for the clinic you are getting tired and eh

that pain, we supposed it to be treated at the clinic easy and quickly. Now you are going to have a LONG [emphasised] queue, so most of the people they are getting ... what?"

FG2 P7: "They just leaving ..."

FG4 P2: "It is a health facility a clinics is very, very far, ja."

The second type of cost to emerge from the data was the waiting times in the queue at the clinics.

FG2 P8: "Access barriers ... most of our clinics we are facing long queues. So people are getting bored for that. Next to that, we are travelling from FAR [emphasised] to our clinics. We take a LONG [emphasised] time to go and get, uh, help, because our clinics are very far from the place we are staying."

FG4 P3: "We been shown a clinic here. Firstly, we don't want to wait in queues, we lazy to go to clinics."

FG4 P4: "It gets very full, there are many lines ... you wait a long time."

Due to these costly factors and the unpredictability of waiting times at clinics, women's partners were not supportive of women attending clinics for cervical screening (Bingham et al., 2003; Byrd et al., 2007).

The geographical and economic inaccessibility of clinics play a large role for disadvantaged community members in utilising clinic services (Krombein & De Villiers, 2006; Nene et al., 2007). Simply having the availability of screening and treatment for cervical cancer will not solve the problem of cervical cancer in South Africa (Watermeyer, 2013). Once deciding to attend clinics, there are still many barriers that are faced by community members. The provision of the screening and treatments services need to be matched by the accessibility of these services for there to be a true movement towards solving the cervical cancer problem in South Africa (Watermeyer, 2013).

It also emerged from the data that there seems to be a belief that, if the disease is detected early enough, then there is no need to seek western medical help, instead a traditional healer can provide healing.

FG2 P6: "There is also the belief that, it's a cultural perspective that, when the disease is detected early enough, then traditional medicine can ..."

FG2 P1: "Cure ..."

FG2 P6: “And then the doctor says that you have it but it is still in the early stages, so the person believes that traditional healers can [snaps finger] do something about it.”

Due to this belief, many women who are diagnosed with early stage cervical cancer will not return to the clinics but instead seek out traditional healers. This is in agreement with other studies that have shown that, when an illness is viewed as minor, or at an early stage, people are more likely to consult a form of alternative medicine instead of consulting a western medical doctor (Pretorius, 2012).

Yet it emerged that there is some degree of knowledge that certain illnesses need to be treated by medically trained professionals, but this belief does not seem to come from the traditional healers but rather from the community members themselves.

FG4 P3: “And then the sangoma comes and he forgets that this thing is in the womb and that this is a disease that requires people who are educated.”

Participants in the focus groups indicated that it was at times easier to follow through and adhere to what the surrounding community was practicing.

FG4 P1: “... their culture drove them to get help from medicines, traditional medicines that are not going to help them from the thing ...”

Regardless of the outcome of the help that traditional healers provide, participants indicated that traditional healers are still highly valued in disadvantaged communities.

FG4 P5: “... although, uh, they [traditional healers] might give the help or they might not give the help that’s in that’s another story.”

This is consistent with research that shows that people will trust their traditional healing source despite outcomes that are not necessarily favourable (Pretorius, 2012). Due to the strong barrier that cultural and community beliefs can potentially play in adherence to cervical screening, it is important to note what these beliefs are and how cervical screening programmes can be modified to integrate these beliefs (Mosavel et al., 2009; Thomas et al., 2005).

4.2.2 Religion

This sub-theme identifies a source of healing that is sought from the community, who the faith healers are, and how beliefs that only the church can heal can be potential barriers to cervical cancer screening and treatment. Religion as a sub-theme also includes the association of cervical cancer and promiscuous behaviour.

It emerged from the data that closely tied to the traditional beliefs about bewitchment is that of religion. The belief that emerged was that, if as a certain type of Christian you believed in God, then He is the only one you will need in order to heal you from your illness. This was believed to exist within certain religious orders within Christianity in some African communities, which did not want their members to seek healing outside the church.

FG2 P4: “And then people also believe in being saved ... like when you are a Christian, and that, once you have been saved as a Christian, you can’t go for medical help. The only way you get healed is by God.”

FG2 P4: “And, in the townships, you also have different kind of churches so that specific church will be like: No, you can’t use any medical help, the only way you get healed is through God. So that happens as well.”

This is consistent with findings which indicated that people believed that cervical cancer could be as a result of punishment from God (Thomas et al., 2005). Thus, as it was with supernatural causes, the belief is that healing would need to match the causing agent, that is, if God caused the illness, He would take it away. Research has highlighted that when certain people belonged to a religious group, they were prone to leave illnesses in the hands of God and allow Him to find a solution (Thomas et al., 2005). Thus, religion is seen to play a role in the health-seeking behaviour of these communities.

Literature indicates that a certain type of a traditional healer can be what is termed a ‘faith healer’ or ‘prophet’ (Pretorius, 2012). These faith healers and prophets are associated with the African Independent Churches (AIC) and their healing is carried out within these settings (Pretorius, 2012). Participants reported that these healers place a strong emphasis on the power of prayer with regard to healing.

FG3 P4: “In terms of the priest, many believe that, in praying, prayers do heal.”

FG3 P2: “Yeah.”

FG3 P3: “Mmm.”

FG3 P8: “Mmm, absolutely, absolutely ...”

FG3 P4: “You wouldn’t need hospital.”

Similar to traditional healers, such as diviners and herbalists, these faith healers also have a means of divination, God or the Holy Spirit instead of the ancestral spirits (Pretorius, 2012). It emerged that community members looked to a pastor or faith

leader for health restoration, as the pastors' prayers were believed to heal a person from disease.

FG4 P5: "Ok and and the churches, the churches, we go to the churches, we go to the reverend the pastor to go find out what is happening. My wife is sick and the pastor puts his hands on her and he tells her that that's completely going to go away."

Participants indicated that people choose to believe that, when healing had occurred for someone else in a certain manner, then it was possible for it to occur for them too.

FG4 P3: "Thing is with the pastor, what happens when you have cervical cancer is, in the bible he reads from the bible there's a girl. Uriel, read that story to you that Uriel has a blood disease and then you will think to yourself if that person lives, why can't you."

It was identified that these beliefs came from the community leaders of the church or organisations to which people belonged.

FG2 R1: "Where does that belief sort of come from?"

FG2 P5: "The prophets ..."

FG2 P4: "Ja, the prophets, people that preach to the communities."

FG3 P4: "In terms of the priest, many believe that, in praying, prayers do heal."

As with beliefs about traditional healers, so are these religious beliefs passed on from generation to generation.

It emerged from the focus groups that the message of seeking healing through religion is not only preached at the churches but also in public places of transport.

FG2 R2: "Which sort of Christian belief is it, 'cause it's not across the board"

FG2 P4: "It happens in townships a lot ..."

FG2 P7: "In the train, in the taxi ..."

This is important to note as, although at times religion may inhibit health-seeking behaviour from western medical clinics, it was also reported to be a tool in advocating for screening adherence (Thomas et al., 2005). It is seen that religion can play a pivotal role in providing social support during a time of illness. It was suggested that, amongst Black and minority ethnic community members, coping strategies and the emotional strength to deal with illnesses were derived from their religious beliefs (Thomas et al., 2005). Thus, it had been suggested that health promotion programmes

include religious leaders to disseminate information and endorse health-seeking behaviours.

Beliefs play a large role in how women experience and hold expectations about modesty and their bodies, which in turn form the framework for each individual woman's belief about cervical screening (Watkins et al., 2002). Hence it is important to be aware of the framework in which a cervical screening programme is being implemented.

4.2.3 Balancing Paradigms

The sub-theme of balancing paradigms indicates the intersection of different beliefs and cultural paradigms and how this creates confusion when an individual needs to decide upon where to seek health care from.

It emerged from the data that, when people do not know enough information, they will be more confused about which source of screening and treatment to seek.

FG4 P5: "So, all in all, it's a lack of knowledge. We don't know where to go. When you have X disease, you don't know where to go, you either going to go to the pastor or the sangoma. Again, you don't know where to go when you get that disease."

Yet when there are too many options of treatment for one disease, it can often leave a woman feeling confused about which treatment to seek out and adhere to.

FG4 P8: "... and, uhm, very confused in terms of [listening to] the pastor or traditional healer."

It was indicated amongst the participants that there are times when a woman has to choose between a religious treatment, the traditional healer's treatment and then that of western medicine.

FG3 P8: "... mmm, absolutely ... you see, mmm, so those are the kind of challenges we are facing and this is based on true stories because of what, for instance your father is a priest, your uncle is a traditional healer and then you are highly educated ... so you having three things: you still a child at my house, this is my roof, you must come and tell me, I'm your mom, you must come and tell me whatever is going on with you, and you are free to talk to me. And then, at the very same time, here's uncle: I see people coming here crawling, but when they go out they walking and then, at the very same time, I'm having this education, this information that I know if something happens

to me or something with my body, where to go, I must go to the doctor. So those are the kind of challenges that we are facing, right?”

FG3 P2: “Mmm.” [nodding from others]

The implication of a woman being confused is that it may result in less adherence to screening. Socio-cultural factors that conflict with each other, possibly the cultural acceptance or rejection of western medicine, the religious and traditional medicine beliefs, are part of what generates a woman’s knowledge and therefore contributes towards this sense of confusion in a woman. Research has shown that, when a patient is confused about which treatment plan to seek, they are more likely to be non-adherent to the screening than those patients who are not confused (Jones, Vernon, & Woolf, 2010). Perhaps it is the lack of scientific knowledge or familiarity with western medicine that can be related to a reliance on traditional or spiritual sources of help. Therefore, confusion becomes a barrier to cervical screening and it is necessary to consider when interventions and public health education programmes are administered.

4.3 Home Remedies

Home remedies are an option of healing which individuals may seek or be forced to seek when suffering an ailment.

Participants reported that, within their communities, home remedies were seen as cleaning out procedures and included sitting over boiling water that contains a variety of ingredients such as lemon, cayenne pepper, garlic and sunlight soap.

FG1 P3: “... but then some of them say they even use a green onion, green onion ... I dunno ... they boil it and then they sit on top of the water ...”

FG1 P8: “And the garlic and cayenne pepper ... sunlight.”

It was explained that at times these ingredients would be inserted into a syringe and squirted up the vaginal cavity.

FG1 P3: “And also one lady said she she buys some lemon ... and then she squeezes it into a syringes ... and then she put it in she put in up inside [laughter from other participants] ... and then she’s wearing a pad, maybe when she is wearing the pad all the dirties come out, and you can see the black and the what what ... and then she said that it helped.”

FG1 P7: “Ja ... in our area, what they do is that they took the sunlight, blue blue sunlight, the old one, you know ... and then they boil it and then they

they sit with it and the syringe, and then the bad thing ... the bad thing come out in the pad and then they see that they can prevent cancer ...”

When people learn they are ill, they often try every method available to them to restore their health. Not only are home remedies often cheaper and more convenient than going to the clinics or healers for treatment, but community members return to using traditional remedies when they lose confidence in western medicine (Thomas et al., 2005).

Other home remedies emerged as being less invasive and involved merely drinking some ingredients, such as salt and water.

FG2 P5: “This guy will give you salt and water and you must drink like.”

FG2 P4: “Ja, and they give you the holy water that we use.”

These methods emerged from the focus groups as able to prevent cancerous diseases and infections.

FG1 R1: “Is that why they doing it at home?”

FG1 P7: “Ja, ja, to prevent the infections and diseases that might come.”

These home remedies, a form of alternative medicines, are carried out often not only for the reasons of affordability and confidence discussed above but also as they allow people to feel like the locus of control to treat their illness lies with them (Pretorius, 2012). Thus, these home remedies result in women feeling empowered and having a strong sense of self-efficacy. Self-efficacy is important in cervical screening as research reports that, when this is low, then self-doubt outweighs the knowledge and motivation a woman has to seek out health-seeking behaviours (Holroyd et al., 2004). As cervical screening is a self-directed behaviour, it requires high levels of self-belief that a woman is able to efficiently seek out health directed behaviours. Thus, if self-efficacy is high and internal locus of control is present, then women are more likely to take action to seek out health-related screenings and treatment.

4.4 Knowledge

Knowledge is defined as the understanding and awareness of information regarding cervical cancer. Knowledge regarding cervical cancer was a strong theme that emerged from across all focus group data. There were four sub-themes that emerged from the data: Lack of Knowledge, Desire for Knowledge, Misperceptions and Disease Social Identity.

4.4.1 Lack of Knowledge

Lack of knowledge refers to gaps in knowledge or incorrect knowledge surrounding cervical cancer, Pap smears, at risk groups and health behaviours relating thereto.

It emerged from the data that at times people were less likely to identify specific cancers as opposed to cancer in general.

FG1 P7: “So, they don’t, they can’t identify that, for them, it’s just a cancer umbrella of everyone.”

What was strongly identified across all the focus groups was that, although people in the community were sometimes aware of the disease known as cancer, they rarely knew or called cervical cancer by its actual name.

FG1 P6: “So a lot of women know that there is this disease. I guess they just don’t know that, uhm, it is called cervical cancer. They don’t, that name cervical cancer is not used ...”

FG1 P7: “When we go back to the ground level...it’s a cancer but not cervical cancer.”

FG1 P8: “... they don’t know about the name, they don’t know the meaning of the name, the name what it means...”

FG1 P3: “Certain times they call it ‘cancer of the womb’.”

There is also an indication of avoidance of women going for a Pap smear using the name ‘Pap smear’. This was because there is an association between going for a Pap smear and cancer. Women do not want to be associated with anything to do with cancer, not even the word.

FG1 P5: “Ja, ja, they won’t say it is something for the cancer ...”

It emerged from the data that women are often afraid of the name of the disease, ‘cervical cancer’.

FG1: P8: “... they don’t they they scared about the name [cervical cancer]...”

This fear of the disease’s name could stem from whereby in some cultures it is believed that merely talking about a disease can cause the problem to materialise (Holroyd et al., 2004). This creates a lack of discussion about cervical cancer and gives the disease more power than it already has. It makes cervical cancer an unspeakable topic and encourages the ‘secret status’ of the disease, which decreases the efforts to encourage women to attend cervical screenings (Krombein & De Villiers, 2006).

In this study, there seemed to be a lack in knowledge around what the disease of cervical cancer entailed.

FG2 P2: “First of all, they [community members] don’t know what cervical cancer is.”

FG1 P1: “They don’t know what cervical cancer is.”

From the data, it was reported that community members were not always sure of how to specifically identify that cervical cancer was for a specific body organ and gender.

FG1 P7: “Yes, what it means is that gender ... they don’t know that cervical cancer is particularly for females. So they don’t, they can’t identify that, for them, it’s just a cancer umbrella of everyone.”

FG1 P7: “So they don’t know how to identify the cervical is this, the prostate is for what.”

This gap in knowledge extended towards the actual screening procedures. Although women may attend a screening, they are not always aware of what the actual procedure entails (Roy & Tang, 2008). The data indicated that women often do not identify the Pap smear procedure by its actual name. What emerged from the data is that some women viewed and called a Pap smear the same name as any other cleaning procedure that could occur at their genitalia.

FG1 R2: “Is this [a Pap smear] the same has having your womb scraped?”

FG1 P8: “Yes ...”

FG1 P9: “No, it’s not the same, doc ...”

FG1 P10: “Because maybe, when they do i-Pap smear, they do it only touches here [referring to cervix] and womb scraping it cleans this part [referring to the womb].”

FG1 P5: “Maybe they don’t really understand, but I know when they go for a Pap smear they just say: I’m going for a cleaning of the womb, just to make sure it’s clean.”

Studies in other developing countries, such as India and Botswana, have indicated the positive relationship between knowledge of what a Pap smear is and adherence to screening practices (McFarland, 2003; Roy & Tang, 2008). Women indicated that their limited knowledge of the Pap smear procedure was an obstacle in attending cervical screening (Roy & Tang, 2008). In order to attempt to increase cervical screening, all areas of uncertainty, including that of the Pap smear procedure, needs to be addressed.

In this study, participants identified that there may be a link between knowledge and behaviour around cervical cancer screening practices.

FG2 P1: “If you don’t know much about cancer, you won’t want to go for treatment.”

One of the greater barriers preventing cervical screening has been seen to be insufficient knowledge regarding cervical cancer and screening, as well as a lack of knowledge about the idea of prevention (Krombein & De Villiers, 2006; Nene et al., 2007). Many studies have indicated that the higher the education level the more likely a woman is to attend screening (Holroyd et al., 2004; Nene et al., 2007). It was identified that perhaps the lack in screening could be attributed to the possibility that if people did not know enough about cervical cancer, then they were less likely to actively seek treatment. Studies have shown that people who are less educated will more likely not partake in cervical screening (Bradley et al., 2004; Krombein & De Villiers, 2006; Nene et al., 2007; Sankaranarayanan et al., 2003).

A possible outcome of the lack of knowledge is that confusion also exists with regard to symptoms of disease. From the data it is seen that people also associate any signs of weight or hair loss as indicating a cancerous disease.

FG2 P6: “There are certain symptoms that people would naturally assume, or that assume it to be related to cancer or cervical cancer ... When you have cervical cancer and then you get sick and then you become so thin.”

FG2 P3: “... and also, if you have if you are losing your hair, then they just believe you have cancer.”

This is an area where it is important that communities understand what the symptoms of cervical cancer actually look like. Women often associate the absence of pain or symptoms as a sign of good health and therefore do not seek cervical screening (Lee et al., 2010). It has been found that women will wait until they find symptoms or feel discomfort before seeking medical help and screening (Roy & Tang, 2008). Usually, at this stage (the late stages of cancer, such as stage III), chances of survival are much lower, thus possibly creating for the perception that once diagnosed with cervical cancer, it can only result in death (Roy & Tang, 2008). Along with this confusion, women have also been reported not to seek cervical cancer screening once they perceived themselves old enough not to be at risk for cervical cancer (Holroyd et al., 2004; Nene et al., 2007). Women who are not aware of the risk factors for cervical cancer are less likely to present for screening, as they do not perceive they are at risk

of developing cervical cancer (Holroyd et al., 2004). With many developing countries not having organised structured screening the responsibility therefore is largely with women to seek out cervical cancer screening. Therefore a woman's understanding of cervical cancer is crucial as this is what encourages her to seek out cervical screening (Perkins, Langrish, Stern, & Simon, 2007).

Yet the data showed that, although in most cases cancer is thought about in general terms, there is an outcome where some specific associations are made with, particularly, cervical cancer. Across the focus groups, it emerged that there was an association between cervical cancer and certain causes. Some of the identified causes of cervical cancer that occurred across most focus groups were that of intercourse, sexual disease and young onset of sexual activity. To a large extent the causes identified by participants were correct even though exactly how the causes can produce cancer was not identified by participants.

FG1 P2: "What do you mean by cervical cancer? You were telling me you know something about the causes. Can you elaborate?"

FG1 P6: "I, actually, not like I know most ... but I have an idea that it has to do with the sexually, sexual diseases ... the deliveration [delivery] of the sexual diseases. If you have a sexual disease, then it transforms into something else as a result of it not being cured."

FG3 P4: "I'm not sure though but I think, uh, people do get a cervical cancer maybe during sexual intercourse, I'm not sure."

FG1 P2: "Do you just get it when you have sex at a young age?"

It was also identified that disadvantaged community members believe in other causes of cervical cancer. Some believe that, if you have not given birth by a certain age, have multiple sexual partners or do not keep yourself clean, you will be more likely to have cervical cancer. While some of the causes were correctly identified, namely, having multiple sexual partners, other causes such as not giving birth by a certain age or keeping yourself clean were not accurate causes of cervical cancer.

FG1 P7: "... about, uhm, if maybe you don't give birth, let's say maybe by the age of 50 whatever and you never give birth..."

FG1 R1: "So they believe that, if you don't give birth by the time of 50 then you might get cervical cancer?"

FG1 P7: “Yes, yes, exactly ... They believe is, you know, the people on the ground level they think that it is something to do with the like you not keeping yourself clean or maybe you sleeping around ...”

These findings are in agreement with previous research where associations of cervical cancer and sexually transmitted diseases were also present (De Abreu et al., 2013). Research by Byrd et al. (2007) has indicated that this knowledge is shared amongst disadvantaged women with regard to cervical cancer.

With regard to risk factors, participants identified risk factors to cervical cancer, such as being older in age, having more than three children and losing one’s virginity at a young age.

FG1 R1: “Is there anything that the community maybe identifies as particular people ... that are more at risk ... are there people that the community thinks are more likely to ...”

FG1 P5: “Most of them say if you have more children, more than three ... if you are a bit old ...”

FG1 P2: “If you like lost your virginity at a young age, then they say ...”

The findings concerning risk factors are consistent with other studies in which women have also identified risk factors to be inappropriate cleaning of self or partner, promiscuity, marriage (number of children) and youth (Holroyd et al., 2004). The importance of there being accurate knowledge around risk factors for cervical cancer is that women need to be aware of how to protect themselves from getting cervical cancer. Knowing that multiple sex partners and early onset of sexual activity can increase the risk of cervical cancer may discourage women from engaging in these behaviours.

Within the focus groups, it was identified that often women went for a Pap smear not to detect early signs of cervical cancer but rather to detect any STIs since becoming sexually active.

FG2 P7: “She [the student the MKI trainer trains] said, uhm, I’m 21 and I want to go for a Pap smear and, for her, it was like ... because she was like now the reason she went now was like: I’m now sexually active that’s why I went for Pap smear, you see, so for her it’s like: Now I’m sexually active, I went to check for the sort of STIs, things like it was not like really related to this [cervical cancer].”

Therefore, although it emerged that women are attending Pap smear screening, they are not doing so with an interest in the results of whether or not they have cervical cancer. These findings are consistent with previous research, which identified that many women fail to identify the Pap smear test's function (De Abreu et al., 2013). These findings also support the current research, which states that there is a lack of knowledge with regard to cervical screening within South Africa (Pillay, 2002).

The data indicated that fear was another factor, and possible outcome to lack of knowledge, in preventing women from gaining knowledge about their health status.

FG2: P3: "... and you must understand the women when you go to the clinic, they don't want to know their status. They say you can keep this and this and, they don't want to know their results, they say no you can keep it ..."

As earlier discussed, women holding beliefs that discussion of disease could result in the acquisition of disease, as well as the lack of conversation around cervical cancer amongst women and possible incorrect associations, or lack of knowledge about how the disease progresses and what treatment is available, could all contribute to the reason that this fear is present (Holroyd et al., 2004; Krombein & De Villiers, 2006). Even though at times fear of becoming ill may lead an individual to seek treatment, it has at numerous times been reported that the emotion of fear has been indicated to be a major barrier towards a woman's perception of her susceptibility to cancer, thus not increasing her adherence to cervical screening (Krombein & De Villiers, 2006; Thomas et al., 2005). In previous studies, it has been reported that the fear of being diagnosed with cervical cancer has been so strong that it has been seen to prevent women from attending screening (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Krombein & De Villiers, 2006; Lee, 2000; Lyttle & Stadelman, 2006; Ogedegbe et al., 2005; Taylor et al., 2004; Thomas et al., 2005). According to the Health Belief Model, susceptibility partly explains adherence to a health-related behaviour, thus if people do not perceive themselves as at risk for a disease then they would not adhere to a certain behaviour. Perhaps, in addition to susceptibility of disease affecting adherence behaviour is the fear of disease. Where normally fear of disease would result in behaviour to avoid disease, in this context, due to there being limited access to medical help, fear of disease does not act as a promoter to behaviour adherence (Burak & Meyer, 1997). Thus the level of fear is so great that it is often seen as the main barrier to obtaining cervical screening (Krombein & De Villiers, 2006). What emerged from the data is that, even if women arrived at a clinic to take a

Pap smear test, due to the level of fear still present they were often not interested in knowing their Pap smear result, resulting in a lack of knowledge.

It emerged from the data that, even when women attended clinics for a Pap smear, they do not always receive information relating to the topic of Pap smears.

FG2 P7: “What happens is that, when you go for a Pap smear, most specially I’ll talk about my case, that I said: Ok, I’m over forty and then I’m here for a Pap smear and like ... you know, they don’t actually educate you or give you information ...”

It was seen that even when some community members had some knowledge around cervical cancer, it was often incorrect information or not enough information to cause a response of seeking cervical cancer screening and treatment.

FG2 P8: “You see [the people in the community have a] lack of knowledge, wrongly informed.”

FG2 P7: “You know they [clinics] don’t actually educate you or give you information ...”

FG2 P7: “So it is a lot of misinformation or maybe her not having enough pack about information of exactly what is it.”

Again, this uncertainty surrounding Pap smear procedure contributes towards the major obstacles, including fear of the procedure, that women in developing countries have to face when deciding to attend a cervical screening or not (Roy & Tang, 2008). Nene et al. (2007) have also identified that, when women are less informed about procedures or what is expected of them, they are less likely to comply with cervical screening; thus highlighting the importance of women having the correct knowledge around cervical cancer and cervical screening procedures.

Although studies (Bradley et al., 2004; Nene et al., 2007; Sankaranarayanan et al., 2003) have shown that education has been seen to be a predictor of cervical screening adherence, this study showed there could be another element affecting screening adherence in spite of high education levels. Although these university attending community members were receiving a tertiary education, there was a lack of knowledge about cervical cancer-screening practices.

FG3 P8: “What do you know about cervical cancer?”

FG3 P1: “No clue ...”

This shows that knowledge provision alone cannot be responsible for the uptake of cervical screening services. Research in South Africa by Krombein and De Villiers

(2006) has indicated that the subject of cancer is not openly discussed amongst women and children in all cultures. Hence, even if children grow up to receive an education, they can remain uninformed about cancers. Thus, cancer becomes something that is unspoken of and therefore is seen as a taboo subject (Krombein & De Villiers, 2006). This experience then shapes not just the individual but also the community that the individual grows up to be a part of. Thus, without appropriate cultural and social educational intervention, the continued lack of screening adherence may continue. Therefore, it is important to highlight the value and need of a culturally relevant intervention strategy (Lee et al., 2010).

4.4.2 Desire for Knowledge

Desire for knowledge as a sub-theme is the longing for information regarding cervical cancer, Pap smears and health behaviours relating thereto in order to destigmatise cervical cancer and encourage change in health-seeking behaviours amongst current-peer generation and those younger generations. Desire for knowledge as a sub-theme can be seen as an outcome of the Lack of Knowledge that was identified.

What emerged from the data is that there was a desire to know more about cervical cancer and topics related to the disease, such as who was at risk and how it could be prevented.

FG1 P5: “Who’s at risk?”

FG1 P2: “Are there any ways of like preventing it?”

FG1 P6: “... but I would like to know if it can ... for example, the common causes, sexually or ...”

FG1 P6: “So, what I want to know is, can one have it without having any sexual ... does it have any connection with the sexual problems or something?”

FG1 P5: “Does it say you have unprotected sex with someone who has that cervical cancer. Does it do something to the guy?”

FG1 P8: “Symptoms.”

Participants also reported various sources of how they could acquire knowledge about cervical cancer.

FG2 P9: “People they get information from the clinic and the doctors...”

FG2 P5: “Health workers ... ja, and from TV and radios and all that stuff ... and there posters and stuff like that.”

FG2 P5: “Ja and a, when they chat to one another, that’s where the most information is.”

It has been seen that women exhibit a strong desire to gain knowledge about various factors relating to cervical cancer (Krombein & De Villiers, 2006). Some of these factors included topics such as prevention, risks, causes, symptoms and any link of cervical cancer to sexual intercourse; thus highlighting the women’s hunger for more knowledge. This is important to encourage as Lee et al. (2010) has shown knowledge and education to be significantly related to attending a Pap smear screening.

When people had a desire for knowledge, they reported receiving information from various sources. Knowledge is seen to come from media sources, such as television, radio and posters, as well as human interaction, such as with doctors, health workers and friends (Krombein & De Villiers, 2006). It is important to encourage this desire for knowledge acquisition as across research it has consistently been shown that one of the main barriers to screening adherence is insufficient knowledge (De Abreu et al., 2013; Krombein & De Villiers, 2006; Lee et al., 2010; Nene et al., 2007).

However, a strong desire was not just for knowledge, but also for knowledge distribution towards youth. Women have been reported to be motivated to reach out and help educate their communities once they have received knowledge about cervical cancer (Krombein & De Villiers, 2006). It emerged from the data that this creation of conversation around cervical cancer was important so that cervical cancer could become less of a stigmatising topic.

FG4 P5: “When I look at that picture you know what I see? I have a vision that tells me that they [kids] get bent while they are young. These are young children ... if ever we can get i-early education about these things ...”

FG4 P5: “... from from from the young ones can understand, if you get to our age, they can understand the cancer in the womb and that they can talk about it so that it wouldn’t be a secret.”

Despite only receiving health education about cervical cancer at a later age, many of the women, as seen in other studies, expressed the strong desire to disseminate knowledge around cervical cancer to both the youth and aged, male and female (Krombein & De Villiers, 2006). This is important, as one of the barriers to cervical screening is that very often a diagnosis of cancer is seen to be so stigmatising that it needs to be kept a secret amongst the diagnosed (Krombein & De Villiers, 2006).

Hence, the more people are informed regarding the disease the more discussion can be had and cervical cancer can become less stigmatising.

It is interesting to note that perhaps HIV has moved away from being taboo and stigmatising. This is indicated below while also highlighting that cervical cancer is highly stigmatising. From the data, it emerged that one of the possibilities to increase cervical screening was to attempt to normalise cervical cancer.

FG2 P5: “I agree with her, the more it’s out there, it’s public, you can just see it it’s in posters and just hear about it, then, when for instance HIV, first HIV, if you mention the word HIV, people would gawk, but now if you say HIV people it’s become normal, for some people like, they with HIV, it’s happened because they living with HIV.”

FG2 R2: “I like that word, make it become normal.”

FG2 R1: “Normalise it.”

Research has shown that there is already a lack of dialogue around a cancer diagnosis within certain South African communities (Krombein & De Villiers, 2006). The status of a diagnosis being a secret, or being stigmatising, as previously discussed does not facilitate discussion around cancer and screening. Research done by Delius and Glaser (2002) within a South African context highlights that it is not only cancer that is taboo within certain cultures, but also the topic of sex. Delius and Glaser (2002) revealed that children were often surrounded by sexual activities as they lived in small homes with little privacy where older siblings brought partners over, or the children’s beds were only separated from their parents’ bed by a curtain. Yet even though children were exposed to sex as a topic, it was extremely taboo and barely spoken about to them at home (Delius & Glaser, 2002).

This taboo in discussing sex, and therefore diseases relating to sex, contributes to this distancing from these specific illnesses. In conjunction with sex being taboo, cervical cancer is perceived to cause problems in having pleasurable sexual relationships whereas other chronic disease like HIV and diabetes do not directly carry that association (Summers, 1998). This highlights the importance placed on sexual function and perhaps why cancers, as opposed to other chronic diseases such as HIV or diabetes, are a more taboo subject to speak about or be associated with.

This lack of discussion about anything relating to cervical cancer adds to an already existing shameful and taboo of discussing such private areas of the body (Lee et al., 2010). The idea is to create a discussion around cervical cancer so that, as

a community, there can be greater knowledge amongst people of what having cervical cancer actually means. The identification of these desires for knowledge can become a starting point of dialogue, being able to inform communities with the knowledge to address the uncertainty that exists with regard to cervical cancer. Although knowledge is not purely formed from an individual's social-cultural setting, it can be however accepted or rejected based on what the individual's society deems acceptable. Therefore in order to increase adherence to cervical screening, there needs to be the ability to have a discussion of cervical cancer before change can be seen.

4.4.3 Misperceptions

The sub-theme of misperceptions identifies knowledge and facts about cervical cancer and Pap smears which individuals believe to be accurate but which are not so.

A problem, which was seen from acquiring information from friends and family, was that incorrect information would be passed from one person to another.

FG2 P5: "They would get from one another, maybe, they would get i i-false information, then maybe they would say it's sore or or it's whatever, they say then some would be reluctant to go and do the test."

FG2 P9: "Ok ... few people have a correct info about the cervical cancer."

Women reported often hearing of previous unpleasant experiences or stories of painful procedures that were relayed to them through friends.

FG2: P8: "The instrument they use, it is scary."

FG2: P7: "Yes, we just want to, you just look at them and you petrified ... you look at them because they [instruments] somewhere there in the bowl and then you open your legs and then you ..."

FG2 P8: "You shiver ..."

The process of a Pap smear can be made to sound extremely painful and, in combination with the anxiety in attempting to attend a screening, this causes some women to be reluctant to attend screening (Holroyd et al., 2004; Roy & Tang, 2008). Therefore, it is important that the correct experience of a Pap smear is disseminated to the public so that misperceptions may be decreased and screening may be encouraged.

It emerged from the data that the reason for women not wanting to know their Pap smear result was that women understood a cervical cancer diagnosis as a death sentence.

FG2 P6: "... there's belief that, if you have it, then it's a death sentence."

FG2 P3: “Because they don’t want to know, as as they were saying, that’s some of them they know about cancer but they don’t want to know ... because, if I know I’ve got cancer, it’s going to seriously, I’m going to go down and I’m going to die ...”

The belief that women had about cervical cancer being a death sentence is what is seen to create an outcome of fear, which in turn many studies (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Krombein & De Villiers, 2006; Lee, 2000; Lyttle & Stadelman, 2006; Ogedegbe et al., 2005; Taylor et al., 2004; Thomas et al., 2005) have indicated to act a barrier to screening.

The data also indicated that community members believed that, regardless of the stage of cancer, if you were diagnosed with cancer, the treatment and outcome would be that you would likely suffer death.

FG2: P4: “... others believe that, once you have cervical cancer, you can die ... uhm, and then others believe that when you have, is it called laser treatment? Is it called laser, laser treatment? ... Once you do that, you also at risk of death.”

FG2 P6: “There’s belief that, if you have it, then it’s a death sentence.”

FG2 Others: “Mmm.” [nodding]

FG2 R1: “Even if it’s at an early stage?”

FG2 P6: “Even if it’s at an early stage. So, just the news of cancer, cervical cancer, it’s it can scare the hell out of a person.”

Previous research, as well as has been highlighted above, has indicated that, when women receive a diagnosis of cancer, it is immediately seen as a death sentence (De Abreu et al., 2013; Summers, 1998). Regardless of the stage of disease, to some women the diagnosis of cervical cancer is taken as an automatic death sentence (Krombein & De Villiers, 2006). There is such a strong association of cancer and death that many women would rather not know they have cancer as they view death as the only one outcome if they are diagnosed.

This overall fatalistic attitude about disease is important to note as this contributes to increased cancer mortality rates (Lee et al., 2010). This type of attitude enables women to avoid taking responsibility for seeking help with regard to their health, as all efforts are deemed futile within a fatalistic attitude. Therefore, in order to prevent this cycle of helplessness amongst women, it is important to permeate a perception that cervical cancer is preventable and treatable. This fatalistic perception

about disease has been seen to act as a barrier in cancer-screening behaviours (Lee et al., 2010). Hence it is important to provide comprehensive knowledge about cervical cancer. By so doing, the attitude of helplessness can be discouraged and instead women can be encouraged to take steps to see to their health status by adhering to appropriate health-screening behaviours.

A possible explanation of this fatalistic attitude is that most often a positive Pap smear is perceived as a cancer diagnosis, and the treatment following is ineffective and therefore the screening, and cancer diagnosis, just leads to pain and early death (Summers, 1998). A further explanation for this perception of ineffective treatment could be due to long waiting times at clinics between diagnosis and treatment, or late stage presentation of disease, in which there is less that can be done to treat the patient (Agurto et al., 2004; Markovic et al., 2005; Thomas et al., 1995). A sense of hopelessness is then generated, as cancer is strongly associated with death (Summers, 1998). If a woman faces the reality that she has cancer, sometimes it is also the emotions of this reality more than the actual disease process that a woman believes will be enough to be the end of her life (Krombein & De Villiers, 2006). This stems from the knowledge that some women in South African communities have been seen to have a fatalistic view of cervical cancer. Due to African beliefs that disease may be caused by ancestors or witchcraft, many African women may in turn have a fatalistic attitude towards disease (Pretorius, 2012). This fatalistic attitude results in the thinking that, if the cause is out of their control, then the treatment will be out of their control too.

The data indicated that, some women are so afraid of the diagnosis and the attached labelling; they would rather face death than be known to have the diagnosis of cervical cancer.

FG2: P8: “You see people they hear that, no man, cancer it’s a serious killer so he don’t want to go and test or, uh, do some x-rays and all that. That word say it’s a serious killer, so people they run away and they better die, because, if I can go and diagnose that I that I’ve got a cancer, I’m going to die, so I better keep quiet and I I never go to the doctor and do some check-ups, I better DIE, you see ... because you have been wrongly informed, you see.”

This finding is consistent with previous research that has shown that women would prefer not to know their status and face possibly imminent death than to go for a cervical screening (Krombein & De Villiers, 2006).

This distancing from even the possibility of illness is also seen amongst men when they are faced with the option of attending prostate cancer screening (Wray et al., 2009). The threat that having prostate cancer presents to them, possible sexual dysfunction, is enough to discourage men from attending screening. In conjunction with the discouragement from screening, research by Wray et al. (2009) also highlighted the reluctance of Black men to discuss cancer with family or friends as this topic was seen as very taboo (Wray et al., 2009).

4.4.4 Disease Social Identity

The sub-theme of disease social identity incorporates how individuals construct a social identity of a disease, which is influenced by what they believe as well as their knowledge.

A comparison between different communities, with regard to knowledge about disease, emerged from the data. A belief participants claimed, is that it is easier to know about cervical cancer in 'White' communities than in 'non-White' communities.

FG2 P6: "You see, unlike the White community where the disease is so ... uhm, how do I say people are aware, so they would obviously discover that they have the cancer and everything so that, that's why it's easy to know that a White person has it."

Perhaps what needs further classification is what is defined as a White community. Due to past social injustices in the apartheid system, "whiteness" is attached to superiority and desirability as the White community were seen to have a higher socio-economic status, more access to education and western medical care (Kincheloe & Steinber, 1998; Storrs, 1999). There is perhaps a construction of the White community as more knowledgeable or as having an awareness of disease etiology. Thus it is viewed that disease discussion and possible acceptance could take place resulting in dialogue existing around certain diseases. Perhaps it is this perceived characteristic of a White community that participants believed makes it easier to know about a disease such as cervical cancer in a White community.

One of the main characteristics shared amongst women at risk for cervical cancer is the lack of knowledge. When comparing developing and developed worlds it has been indicated that there is a lack of knowledge around cervical cancer in the developing world (Francis et al., 2010). Research has highlighted that this lack of knowledge often occurs amongst women living in rural areas (Pillay, 2002). A study

in Botswana indicated a pattern of a lack of knowledge amongst women with a low income (McFarland, 2003). This is further supported by Bradley et al. (2004) who conducted research in Khayelitsha, Cape Town amongst a fairly homogenous group of Black women. It was found that there were differences between those who did and did not attend cervical screening in that group. Amongst this fairly homogenous group the women not attending screening were seen to be those who were less educated and amongst other factors poorer and unemployed. This highlights the link between; on the one hand lack of knowledge and attending screening, and on the other hand a lower socio-economic status.

Cervical cancer has been shown to be a large burden of disease in Africa as it is a disease synonymous with poverty and poor women, which are big problems in Africa (Ali, Kuelker, & Wassie, 2012). Poverty has been shown to be a major barrier to gaining knowledge (education) and therefore preventing access to prevention, treatment and care. This highlights that a lack of knowledge is a factor that is not attributed to either a White or Black community, but rather a factor associated with a low socio-economic status. However in South Africa, due to past social inequalities during apartheid, there are large disparities seen, including that many Black South Africans have not always had optimal access to the best western medical services and thus not received knowledge about cervical cancer and the importance of screening (Francis et al., 2010; Moodley et al., 2006; Mosavel et al., 2005; Pillay, 2002). So although it is seen that a lack of knowledge is largely associated with lower income, in South Africa the group that are in the lower income tend to be, but are not exclusively, part of the same ethnic population. Perhaps what participants in the focus groups identified as White communities could be defined as a community that is perceived to have a higher socio-economic status and a different culture (perhaps not as concerned with privacy or the use of traditional healers), and therefore tends to have had greater access to knowledge and therefore awareness of cervical cancer.

Although the data highlighted that the communities are seen to be aware of cancer as a disease, it emerged that it was believed that cancer was a disease that affected more White people and thus was branded a 'White' disease.

FG2 P4: "... and Black people also believe that some diseases are also just for White people."

FG2 P6: "... ja, also this point that it is a White disease, it's a White disease so, in fact, not just cervical cancer, cancer in general."

FG2 P6: “As I can say: when you hear the name ‘cancer’ you think of White people.”

Although participants correctly indicated that certain people are more at risk than others, they incorrectly identified who was at a higher risk. It has been identified that in South Africa the risk of disease differs among the diverse ethnic populations (Redelinghuys & Van Rensburg, 2004; Smith et al., 2003). Black South African women experience cervical cancer as the most common form of cancer, while also having a higher risk of cervical cancer than people in the White population (Mosavel et al., 2009; Redelinghuys & Van Rensburg, 2004). Black South African women have a risk of one in 34, while White South African women have a risk of one in 93 (Redelinghuys & Van Rensburg, 2004). With these statistics in mind, it is even more pressing that this belief can be addressed in order to encourage more women to attend cervical screening. With research showing that approximately 60.5% of Black South African women have never been for a Pap smear, despite having a higher risk for cervical cancer, it is most pressing that psycho-education around screening and access to appropriate cervical screening be lobbied for (Peltzer, 2001).

The data indicated that participants believed that cervical cancer is more accepted as a chronic ill health condition in a White community than a Black community.

FG2 P6: “...in White communities a disease like this will be embraced [more] easily, the information or the diagnosis, then what happens in the African community”

Perhaps the stigma that came from being branded as having a disease, which is associated with a White community, contributes to how embracing people are of the disease. Research by Storrs (1999) reveals the anger that women experienced when they were passed as White, but whose identity was aligned with their non-white ancestry. Indicating that at times being seen as White can contradict an individual’s identity as non-white, thus creating an undesirable outcome. Women saw their identities spoiled by appearing too “White”, and not by their non-whiteness (Storrs, 1999). Thus, having a ‘white associated disease’ can carry the extra stigma of, even though involuntary, losing one’s identity and taking up another racial identity.

In conjunction to previously discussed factors that are associated with a White community, that is a higher socio-economic status and more accessibility to medical care, is perhaps the acceptance of cervical cancer amongst a social support network of

an individual. It has been reported that in many low socio-economic groups there are not high levels of education on cervical cancer, therefore it remains a health topic which is largely not prominent in the consciousness of the focus group participants (Mosavel et al., 2005). In higher socio-economic groups research has indicated that knowledge of disease is higher, therefore this may encourage more social support and therefore acceptance (Bradley et al., 2004; Francis et al., 2010). So perhaps what is spoken of as acceptance in the White versus Black communities is a role of social support that underlies the acceptance. Yet having stated that, research has indicated that female adolescents report high levels of support from friends and family (Mosavel et al., 2005). Thus maybe narrowing the focus of a lack of social support down to perhaps an older generation of women, and not an overall lack of acceptance of the disease cervical cancer.

An outcome to the above-discussed beliefs is that participants indicated that cervical cancer is not as feared in White communities as it is in Black communities.

FG2 P6: “And, also, community wise I think the disease is, uhm, is not feared in the White community the way it is in the Black community...”

Within South Africa it has been highlighted that the cytology-screening programme has been disproportionately utilised by White women (Bradley et al., 2004). Francis et al. (2010) indicates there is a limitation to access of medical care in non-urban areas in developing worlds. Due to South Africa’s history of past social inequalities during apartheid, people were relocated according to race, therefore resulting in limitation to access of screening facilities not only then but to a large extent today (Francis et al., 2010; Moodley et al., 2006; Pillay, 2002). When there are inadequate resources and screening is not accessible, feelings of being powerless and fear can ensue as death becomes imminent.

4.5 Stigma

Stigma is defined as a mark of shame or disgrace that is associated with a person because of their personal circumstance. This theme includes the associations of stigma with cervical cancer and the diseases screening behaviour.

The communities that these disadvantaged women live in were identified as being judgemental towards their own community members.

FG4 P8: “And then a stigma is the big one the guy said stigma neh because of too judgemental you know that there and when you sitting like this at the

clinic, I look at you I see ok blue eyes that someone hit you, you understand I don't even think that maybe it's an accident.”

From the data, it was identified that the community at large could be quick to make judgements about a person's health.

FG2 P6: “When you have cervical cancer and then you get sick and then you become so thin they will label your sickness. They will assume your sickness to be any other thing, maybe you got, uhm, HIV or maybe you got TB rather than looking at it that it might be that you are suffering from a cancer.”

It emerged that merely attending a clinic may result in the woman being stigmatised.

FG4 P5: “... so people are not really keen to go to the clinics because they, because of the stigma, people say say all these things about you when you at the clinic.”

This is supported by research which indicates that being seen at a clinic for cervical screening results in the potential of being labelled as sick (Summers, 1998). A person with any symptom of illness will automatically be judged and labelled as having one of the more commonly spoken about illnesses, such as HIV or tuberculosis. With HIV and tuberculosis being highly stigmatised, people are afraid to become ill and then get too thin for fear of being labelled by the community (Nam et al., 2008).

It emerged from the data that, not only would a woman be stigmatised if seen at a clinic, but there would be the possibility that a woman's status would be spread around her community.

FG4 P5: “We worried about stigma, we worried about stigma. When people see you standing on a queue in the health facility they tend to make assumptions, you know, and sometimes people think but because you are standing in the clinic they will make assumptions but when you get to the townships if you we saw that person at the clinic they have something on the outside of the body [disease], you're positive, we saw them at a particular clinic, he was there; he's positive. So people are not really keen to go to the clinics because they, because of the stigma, people say say all these things about you when you at the clinic.”

FG4 P3: “Secondly, some people don't like to be sent around, walk around, when they at the clinic, they afraid, that someone is going to see.”

As indicated earlier, regardless of if a woman is married or unmarried, there is still the high possibility that a woman may be stigmatised for her attending a clinic for cervical screening (Thomas et al., 2005).

What came across strongly in the focus groups was that there seems to be a lack in community support when it comes to sickness. It emerged that there was a belief that, when a person shared the burden of their medical status with a presumed friend, it could often lead to their entire community knowing about their status.

FG2 P8: “Your status is a secret. So, if I tell my friend, yeah, I’ve got this problem ... he’s going to spread it ... [agreeing giggles from others in group] all over Khayelitsha, within a minute each and everyone will know that whooo whooo [laughter from others and nodding in agreement] so and so have got this, you see ...”

With research highlighting the importance of social support in influencing low-income women to seek cervical screening, this lack of support from the community could be a major barrier to women deciding whether or not to seek cervical screening (Chigbu et al., 2013; Markovic et al., 2005).

As discussed previously under the theme Disease Social Identity, stigma could result from women being associated with a “White” disease such as cervical cancer. As previously discussed, this results in women losing a part of their identities as a “non-White” individual. The data also highlighted another manner of how women were stigmatised if it was found out that they had cervical cancer. This was that community members would behave differently to them once they knew they had cervical cancer. The community would respond to the diagnosed woman with such fragility and as if the woman was on the edge of dying.

FG2 P6: “Everyone else would even show a sign, you can see even from the way people will behave towards you if you are diagnosed with the disease, then they would just believe that your time to live is, uh ... ja, is expired ...”

As some of the expectant roles that a woman has are to look after her children and family and to sexually pleasure their partners, this rendering her as ‘expired’ not only highlights her possibly imminent death but also her failure in fulfilling her culturally expectant roles (Agurto et al., 2004; Chigbu & Aniebue, 2012; Holroyd et al., 2004; Mosavel et al., 2009).

The data indicated that the power of stigma is so strong that women would rather it is known that they have been bewitched than that they have cervical cancer.

FG1 P3: “But sometimes they do know the word ‘cervical cancer’, they don’t want to believe they have the cancer. Then they believe they have been bewitched.”

It emerged that the stigma was so powerful that women would prefer to die than be stigmatised for having a serious disease.

FG2 P6: “We have a serious stigma problem. [Others nodding] The problem of stigma is just so huge that sometimes a person would prefer to die with their secret, because the moment you, the moment your neighbours know that you’ve got some serious disease, what happens is that, that’s their weapon to to bring down your spirit to make it spread around.”

These findings are consistent with what other research has presented, that the power of stigma acts as a barrier towards adherence to cervical screening behaviours (Holroyd et al., 2004; Nene et al., 2007; Thomas et al., 2005). The intensity of social stigma associated with health reproductive problems is so strong that, for many women, it is often the main barrier as to why they do not comply with cervical screening practices (Holroyd et al., 2004; Nene et al., 2007; Thomas et al., 2005).

Another issue are the assumptions that come with attending a cervical screening. There is the assumption that if there is a need for a cervical screening then either the woman or her partner has been promiscuous (Summers, 1998).

FG4 P5: “And and a there’s this tendency amongst our people, which is a Black people, if you have a private a private problem in a private part, that that there’s an assumption that maybe you’ve been going around, you know ...”

It emerged that being labelled as having cervical cancer is so stigmatising that women do not even want to say the words ‘cervical cancer’.

FG1 P6: “Because, even though it is a cancer, even though maybe some of them will take their time going to the gynaecologist ... to bring the result that it is cancer, they don’t really want to say it.”

Some of this stigma is felt more by women involved in religious activities, which can be explained by the direct link that an abnormal smear is seen to have, that is being linked to sexual activity and promiscuity, with promiscuity being frowned upon within religion (McCaffery, Waller, Nazroo, & Wardle, 2006). Yet even without religion, many women feel the stigmatising nature of a cervical cancer diagnosis primarily due to the sexually transmitted nature of HPV, which causes cervical cancer (McCaffery et al., 2006).

Often attendance for cervical screening can be seen as an indicator of sexual activity, which for unmarried individuals may be too intrusive (McCaffery et al., 2006). This indicator of sexual status stems from the belief, which the data indicated to be that community members believed a cause of cervical cancer may be a woman having multiple sex partners

FG1 P7: "... the people on the ground level, they think that it is something to do with the like you not keeping yourself clean or maybe you sleeping around ..."

FG1 P2: "Hygiene, hygiene, it's about hygiene. It's about believing that, uhm, the second one is about believing that keeping yourself clean that you don't sleep around."

These associations have been previously found by other research and are important to focus on because, as discussed, there is already a sense of shame and taboo around discussing private body parts and, in particular, cervical cancer (Byrd et al., 2007; Lee et al., 2010; Thomas et al., 2005).

As there are often strong perceptions held that only married women should be sexually active, this discourages unmarried women from attending cervical screening (Roy & Tang, 2008; Thomas et al., 2005). With such a strong association between cervical cancer and sexual causation emerging from the data, it is easy to see why there is hesitation to attend a screening that would essentially indicate a woman has been sexually active. As problematic as this association may be, it is still imperative to generate awareness around HPV's transmission in sexual activity. This is in order to prevent the spread of HPV, which can play a role in the causation and progression of cervical cancer (WHO, 2010).

In addition, there emerged also a strong belief amongst men specifically that promiscuous women are diagnosed with cervical cancer, therefore strengthening the association of cervical cancer and promiscuity.

FG2 P6: "And also there is a beliefs for mens, on the side of mens that women, women who who are promiscuous are more likely to have such a disease."

This belief could be another stigmatising factor that women face, regardless of whether it was her or her partner who had been engaging in promiscuous behaviour.

Within the focus groups, it was reported that women refuse to believe that they can contract cervical cancer.

FG2 P4: “Others are in denial; they just don’t want to believe that they can get cervical cancer ...”

These findings support previous research which indicates that women have been stigmatised if it is known that they have been diagnosed with cervical cancer (Thomas et al., 2005). The reason for stigmatisation is that a cervical cancer diagnosis is associated with promiscuity and a sexually transmitted disease. Therefore, any woman undergoing a cervical screening is seen as having had sexual relations (Nene et al., 2007; Thomas et al., 2005). Thus, if a woman is diagnosed with cervical cancer, she is viewed as promiscuous and irresponsible. If a woman is unmarried, this is even more stigmatising as sexual relations outside of marriage are frowned upon (Thomas et al., 2005). If the woman is married, it is still stigmatising as it means that either her or her partner have been promiscuous. Therefore, to avoid stigmatisation, women would choose to avoid a behaviour, that is cervical screening, which may lead to them being viewed as promiscuous and deserving of the disease as a just punishment (Thomas et al., 2005).

4.6 Summary

From the data there emerged many potential themes relating to the cervical cancer screening experience that women in underprivileged communities face. However, the themes that most strongly answered the research question which sought to understand how *socio-cultural* factors affect cervical screening were Gender, Spiritual and Religious Beliefs, Home Remedies, Knowledge and Stigma. Some of these themes, namely, Knowledge and Stigma, have previously been found by other research studies (De Abreu et al., 2013; Krombein & De Villiers, 2006). However this study identified the greater role that Gender, Spiritual and Religious, and Home Remedies play in influencing cervical screening behaviour. Within the theme Spiritual and Religious Beliefs the two main themes which strongly emerged across the entire data was that of the role of Traditional Healers and Religion. This study is one of the first studies to focus upon how influential these factors, Traditional Healers and Religion, are on a woman’s decision to adhere to cervical screening within the South African and sub-Saharan Africa context. Even though factors promoting western clinics were searched for, it emerged from the data how Knowledge (a lack thereof), Gender, Spiritual and Religious, and Stigma acted largely as barriers to cervical screening adherence.

Chapter 5

Conclusions and Recommendations

5.1 Summary of Findings

The findings of this research revealed how cultural and social factors affect previously disadvantaged Black South African women's decision to adhere to cervical screening. This study identified five broad themes which influence a woman's decision to adhere to cervical cancer screening. Broadly these themes are *gender*, *spiritual and religious beliefs*, *home remedies*, *knowledge* and *stigma*. These influences, which could function as either barriers or facilitators to cervical screening, come from factors identified within the literature, namely, socio-cultural norms, beliefs, knowledge, and gender factors.

Some influences identified in this study, namely, *knowledge* and *stigma* have previously been identified by other research studies done within currently disadvantaged communities in the Western Cape, South Africa (De Abreu et al., 2013; Krombein & De Villiers, 2006). Although these previous studies share some of the same factors, this current research went into more depth in examining these factors. In addition to these shared influencing factors, other factors emerged in this study that have not been extensively focused on in previous research within a disadvantaged South African community. These factors not previously identified or focused on are *spiritual and religious beliefs*, which include *traditional healers*, *religion* and *balancing paradigms*, as well as the theme *home remedies* and *gender*, which includes *loss of womanhood*, *male's role*, *practitioner gender* and *privacy*.

With regard to the main theme of *knowledge*, this research identified four sub-themes: *lack of knowledge*, *desire for knowledge*, *misperceptions* and *disease social identity* to best explain the theme. With other developing countries having identified the positive relationship between knowledge and screening adherence, it is imperative to investigate at a deeper level what specifically about knowledge affects adherence (McFarland, 2003; Roy & Tang, 2008). This study indicated that one of the most powerful barriers regarding knowledge of cervical cancer was the lack thereof, as well as misperceptions that women and the community at large had about the Pap smear procedure and cervical cancer disease. The theoretical model used in this study, the combination of the HBM and TRA, helps to explain the role of this theme in the behaviour choice of individuals. While *lack of knowledge* affects an individual's

attitude which in turn effects their intention and then behaviour to screen, the *misperception of knowledge* and *disease social identity*, can be directly seen to affect an individual's susceptibility and severity view of disease, thus effecting their intention and behaviour towards screening. With the previously indicated lack of dialogue around cervical cancer in South African communities, it was encouraging to observe that the theme *desire for knowledge* was strongly expressed across all of the focus groups. This desire for knowledge can be viewed as a cue to action in terms of the HBM and TRA combination model, resulting in individuals having the intention to know more and thus seek out and change their behaviour around cervical cancer screening.

With regards to subjective norm, there are not many research studies that have identified or focused enough on what role normative beliefs can play in a woman's decision to adhere to cervical screening. This study is one of the first to highlight how the pressures of a woman to act or not act in a certain way, that is their normative beliefs, can influence a woman's intention and behaviour decision around cervical screening. What this study identified as largely shaping a woman's normative beliefs is, amongst others, the sub-theme of knowledge, *disease social identity*. The participants in the focus group strongly claimed that there is a perception that is being regarded as truth amongst their community members, which is that cervical cancer, and cancer as a whole, is seen to be more of a White person's disease. This belief was strongly evident across all focus groups in the study. This is of great concern as statistics indicate that currently Black South African women are more at risk for cervical cancer than any other ethnic population group of women in South Africa (Redelinghuys & Van Rensburg, 2004). In addition to the risk rates being higher for Black South African women is the stigma of having a so-called White disease. Thus together this provides support towards the lobbying for a socio-culturally sensitive psycho-education programme around cervical cancer to be disseminated amongst women, and specifically amongst those at the highest risk of contracting cervical cancer.

The other factor that was identified as contributing towards a woman's subjective norm was the main theme of *gender* that existed within a woman's specific community and culture. What strongly emerged from all the focus groups was that a woman would be considered as less of a woman without her womb. The community as a whole, but especially men, expressed this belief. Not only was it indicated that a

woman lost her womanhood, but it was also perceived that she would lose her sexuality. This is problematic as then cervical cancer becomes associated not only with possible death but also with the loss of a woman's place in a society. This loss is within a society and culture that defines womanhood as the ability to produce children and sexually satisfy a partner. In the context of South African society, where women are perceived as inferior to men and gender equality remains an on-going battle through the twenty-first century, these gender beliefs play a role in sustaining the gender oppressive conditions that many of these women live under (Hutson, 2007). This highlights further the need for a psycho-education programme around cervical cancer to be disseminated to the communities at large. If it were known that early detection results in easier treatment not necessarily requiring a hysterectomy, then perhaps a woman would not be seen as less of a woman if she had cervical cancer, as it would be known that cervical cancer does not equal automatic womb removal. Women have to make a decision to attend screening taking into account the physical health benefits on the one hand, and then on the other hand, knowing they might dissatisfy their partner and therefore lose their partner. This weighing up of outcomes creates tension and pressure that a woman faces when deciding to adhere to screening behaviour or not, and can lead to poor adherence. Furthermore by providing correct knowledge, beliefs held by men that women will lose their ability to be sexually pleasurable can also be countered, thus perhaps some of the tension and pressure that women feel when needing to decide to adhere to screening will be alleviated. If a conversation can be started around cervical cancer and what it actually entails, perhaps not only will men not want to leave their partners but they may also start to be more supportive. Thus a woman's perceptions of what her spouse or partner will expect her to do lines up with the possibility of early cervical screening. According to the HBM and TRA combination model, by addressing gender beliefs (normative beliefs) that so deeply affect a woman's sense of who she is, a woman's subjective norm and thus intention to screening behaviour may be affected and encouragement of screening behaviour may be seen.

Another influential theme that this study identified which largely affects a woman's normative beliefs is that of *spiritual and religious beliefs*. The theme is composed of the sub-themes *traditional healers*, *religion* and *balancing paradigms*. The sub-themes that affect a woman's normative belief, *traditional healers* and *religion*, were seen to be closely associated to each other as well as being strongly

expressed across the focus groups. What was evident across all focus groups was the sub-theme of *traditional healers*. The HBM and TRA combination model suggests how a woman's support for traditional African spiritualism and medical practices could affect her adherence to cervical screening. Very often what an individual believes to be true or not, affects their overall attitude towards their intention to screen for cervical cancer. The strongest belief was that of a traditional healer being the first point of call when an illness is believed to be present. Several reasons were offered for this, the most important being that traditional healers were the most accessible to community members, that is geographically, financially, and with regard to cultural and social perspectives. Another reason that traditional healers are sought out first is that within the African cultural beliefs, treatment should be sought out in accordance with the cause, and for many diseases (cancer included) the cause is interpreted as being supernatural forces. Then it depends what is defined as a supernatural cause by an individual. If the supernatural cause is seen as the ancestors then an individual will seek out traditional healing. If the supernatural cause is seen to be God then many community members choose to seek healing from their religious source, believing this to be the only possibility of cure. At times, only when these options do not work do individuals seek out a western clinic, often when the disease has progressed into a more aggressive stage. These beliefs directly affect an individual's attitude and thus their health-seeking intention and screening adherence behaviours.

While it is important to allow for an individual to have all options of healthcare, it is imperative that when a disease is beyond a specific profession's scope the patient be re-directed towards an alternative healthcare option which can successfully see to the patient. This highlights the importance of there being a dialogue and relationship built between traditional healthcare and western medicine. Although currently traditional healers are recognised via the Traditional Health Practitioners Act, Act 35 of 2004, as South African medical fraternity members, the integration of their practice is still largely fragmented (Learmonth, Jansen Van Vuuren, & De Abreu, in press, 2014). Only once a conversation and dialogue is established can there be a working together of the different disciplines. This is essential in order for the patient, in this study women at risk for cervical cancer, to have all her healthcare outcomes maximised knowing she is able to seek the best possible healthcare suited and available to her.

At times westernised clinics can themselves act as a barrier in women's intention to attend cervical screening. The barriers that a western clinic presented included the costs, lack of privacy at clinic, and gender of service provider. Very often women need to travel far distances to reach the clinic and must spend the entire day waiting to be seen. This is costly in that this is time they are not able to work or take care of their family. In addition, western medicine costs more with regard to money. Mosavel et al. (2009) points out that the South African National Department of Health has a screening policy in which clinics offer free Pap smear screening every ten years for women thirty years and older. Despite this, monetary cost still exists in terms of paying for transport to clinics that are often not closely situated to people's homes. Other monetary costs is that often when attending a government western clinic the travelling to and from as well as waiting to be assisted at the clinics takes so long that people often need to take the whole day off from work (Oscarsson, Wijma, & Benzein, 2008). If a person isn't able to go to work for the day then they do not get paid for that day, hence another monetary cost is incurred.

In addition to the cost barrier is the lack of privacy experienced at clinics. A woman, who already faces the anxiety of whether the service provider will be her preferred choice of being female, in addition is exposed to other waiting patients' curiosity as to why this woman is attending the clinic. This is due to the structure of the clinics, which have previously been discussed as providing a lack of privacy to their patients. This occurs as there are often different sections at the clinic for specific illnesses, example one area for HIV, or one area of rooms only for gynaecology. Therefore when a woman leaves the general waiting room where all patients wait and heads to a specific area or room, it allows for easy identification of what illness a woman has when visiting a clinic. However, the greatest violation of privacy was reported occurring through the case of confidential information of a patient being disseminated to the community via a health practitioner who worked and lived within the community. This creates a deep sense of distrust towards a setting, the westernised clinic, where private information about oneself may be revealed to one's community. It is interesting to note that this distrust was not perceived or reported as a problem with sangomas or herbalists (traditional healers). This being despite that most traditional healers are situated within the community that they serve. Therefore implying that the community members trust traditional healers.

Women reported that after losing confidence in western healthcare they would often then seek out home remedies. This would often give them a high sense of control and self-efficacy as they viewed themselves taking responsibility for their health. However, this needs to be cautioned against as very often home remedies are not beneficial in treatment of cervical cancer, despite the higher internal locus of control it gives a patient. These mentioned barriers highlight the critical need for clinics to respond to their patients in both an ethically and culturally relevant way in order to achieve an intention to attend cervical screening and thus behaviour change.

The sub-theme of *balancing paradigms* highlights how an individual's beliefs and norms experienced can create a sense of confusion if these beliefs conflict with each other. If an individual is lacking scientific knowledge or is not familiar with western medicine this can then be related to an individual's reliance on traditional and spiritual sources of help. The confusion comes about when an individual has one foot in the modernity of western medicine and then one foot in their cultural traditional practice. Therefore there needs to be an acknowledgement of these various beliefs as the outcome of the intersection of these different beliefs in an individual may affect their decision to attend screening. This calls for culturally sensitive education for healthcare practitioners, nurses and doctors, with regard to cervical cancer screening programmes (Holroyd et al., 2004). Therefore when addressing cervical screening programmes a community-based effort should be looked towards. This effort should not just target community members at risk for cervical cancer, but also their male counterparts and health providers, whether that is a westernised doctor, or a traditional or religious healer. In this way there is a more holistic targeting of a woman's source of normative beliefs and thus her subjective norm.

Related to the barriers experienced at western clinics was the outcome of varying emotions across the themes. Emotions, namely, fear, confusion, and embarrassment were often found in response to an experience of seeking health at a clinic. The fear women experienced in relation to cervical cancer was identified largely as fearing a death sentence with cervical cancer diagnosis, as well as the dreaded possibility of being abandoned by their partner. There was also however, fear of the Pap smear process, including being physically exposed to another male who was not their sexual partner. Linked to the fear around treatment and screening was the feeling of confusion if too many treatment options were present. This confusion was seen to decrease women's adherence to any one particular screening and

treatment plan. Referring back to a woman's experience at a western clinic, there are often feelings of high embarrassment associated with cervical cancer. This is due to the unease women reported feeling in having a male practitioner see to them as well as the other patients in the clinic guessing as to why they have come to the clinic.

Yet one of the most often found and strongest barriers that research identifies is that of stigma. Cervical cancer was identified as being so stigmatising that not even the words 'cervical cancer' would be spoken about within the community. Women would also rather be told their illness is due to bewitchment than be told they have cervical cancer. It seems that a cervical cancer diagnosis is perceived as highly stigmatising in the communities where this study took place. The strength of stigma as a barrier to cervical screening is illustrated by the participant who reported that she would rather die from cervical cancer, than let it be discovered she was seeking screening for cervical cancer and then be stigmatised and brought down by the community in which she lives.

All these mentioned emotions and stigma factors are shown to affect the likelihood that an individual will perform a specific behaviour. In terms of the HBM and TRA combination model, these factors are seen impacting behaviour beliefs, which in turn shape the individual's attitude and then intention towards performing the desired health behaviour. Should these types of barriers not be addressed, the population within South Africa most at risk, Black women, will continue to be most susceptible to one of the most easily preventable cancers. In addition to the high mortality rates, the low adherence to cervical screening is adding to the burden of disease within a country that already has an understaffed and overused healthcare system. Therefore, providers of screening services should be trained to improve patient-provider interactions. It is critical to decrease patients' experience of embarrassment, fear and stigma around cervical cancer screening in order to increase adherence to cervical cancer screening and treatment.

5.2 Reflexivity

With regard to personal values and beliefs, the researcher acknowledged and was aware of the differences that there may have been between the researcher and the participants. Coming from a culture that prioritises western medical care, the researcher took a step back and reflected on the perceptions of what she considered normal adherence behaviour and health beliefs. The researcher had to be aware, as

was made evident through the focus groups, that not all families and cultures consider western medicine in the same light.

Another factor was that the researcher was part of a culture in which cancers, including cervical cancer, were openly spoken about and this was not the situation with all the participants. Therefore this could have been a reason that participants discussed the 'white' nature of cervical cancer. Even though the participants have been exposed to having other non-white members present in their groups, perhaps the researcher's presence was made more obvious in that it was disclosed to participants that the researcher would be in the room. The researcher also had to be aware of the beliefs that she held which the participants may not have shared. Such a belief was that the researcher believed that women should have the right to decide for themselves which healthcare option to choose, without suffering the consequences of family or society members. This belief was not the reality that many of the participants faced: many participants needed their husbands' and families' approval before embarking upon a treatment course.

Other factors that may have influenced the manner in which the questions were answered were the researcher's subjectivity and chosen data collection method. Although during the second phase of data collection when the researcher was not playing a principal role, (not conducting the focus groups) the position of the researcher as a white, English-speaking, middle-class female, with a different culture from that of the participants, may have affected the manner and content of what was shared in the sessions. Although the researcher had been aware and reflexive of the above-mentioned differences, there was not ever an atmosphere where the researcher felt uncomfortable.

5.3 Limitations

A methodological limitation, which may be drawn from this study, is with regard to generalisation. This research was based on a relatively small qualitative sample consisting of members from only one disadvantaged community in the Greater Cape Town region. Thus, the results from this study cannot be generalised to the entire population of disadvantaged Black South Africans. In addition, these findings, from a disadvantaged setting based in the Greater Cape Town region, may differ to that of disadvantaged settings based in other surrounding African countries such as Zambia or Botswana. Thus, generalisation between these contexts would be inappropriate. However, within the focus groups there was to a certain degree a

heterogeneous sample of participants. There were male and female participants as well as ethno linguistic groups: mostly isiXhosa, one Sotho, one Zulu. It is believed that the results of this study would most likely hold true to other disadvantaged communities within South Africa. Even though there is no reason to believe that the results would be different, future research needs to be done to establish whether similar findings are found in other disadvantaged community groups.

Additionally a limitation of this study is that two of the focus groups consisted of participants that were trainers (informed community members) from the Medical Knowledge Institute. Although the trainers were from the community, they often spoke about the community as 'other', referring to how the community holds certain practices and beliefs as opposed to they themselves. In their talk they created a distance between themselves and their community members. Thus perhaps to a certain degree a third party reporting took place. Third party reporting occurred in this research when participants in the first two focus groups spoke about beliefs and practices held within their communities, but did not include themselves as part of the community despite living in those communities. Thus participants reported as an external third party with regard to some of the beliefs and practices of their community. Yet, despite this, the other focus group participants, the non-MKI trainers, supported the views and beliefs that these trainer participant focus groups shared. Even though there might have been some third party reporting, the data indicated that the beliefs were in fact shared, so perhaps the third party reporting could have also been formed from some of the trainers' personal beliefs.

Another possible methodological limitation in this study could have occurred in the data analysis phase of research. As stipulated in the methodology chapter, focus groups were used for data collection, which includes the subjective nature of the researcher carrying out the focus groups. If a researcher is subject to their own interpretations then it could affect the data. This is why it is necessary for the researcher to be able to acknowledge their active role in data collection and analysis, thus allowing the researcher to understand that preconceived ideas held may influence the results. During this study the researcher was aware of and documented what preconceived ideas she held with regard to the research topic and beyond which may have differed from that of the sample group (refer to reflexivity in chapter 5). This, in combination with the researcher having had a trusted rapport with the MKI trainers, served to lessen the subjective bias which may have occurred. However, it is

important to take note that even though there are limitations, they do not overshadow the contribution this study has made towards gaining a clearer image of how socio-cultural factors can affect a woman's decision to adhere to cervical screening.

5.4 Recommendations for Future Research

In line with the first limitation mentioned, a recommendation for future research would be to carry out an investigation exploring the same questions around the influence of socio-cultural factors, but to explore this in a different disadvantaged community across South Africa. This would allow for a greater perception and generalisability of the findings of the two types of studies.

In addition, as was highlighted by the study, a community-driven culturally appropriate psycho-education programme is an effective mechanism to deliver information to community members. The data from this study should be used and considered when building upon, or developing, educational materials to be used around cervical cancer teaching. These materials can be developed to be able to be utilised by lay community health workers. Materials should incorporate words that women in the community use to describe cervical cancer, as well as misperceptions and specific situations that the women have described as being unique to them. Possible seminars with a question and answer format could be looked into, where male and female seminar groups were run separately. Concurrently nurses and doctors should be made knowledgeable around both the social and cultural norms of population groups in which they play a central figure in promoting health and screening services. Thus with a mutual understanding as a foundation, community members needing health care and health care workers themselves are able to improve cervical screening rates.

This study highlighted that western clinics are often distrusted with regard to staff and keeping information private. However, it was implied that this was not a problem with regard to traditional healers, despite that traditional healers live in the heart of the communities they serve. Therefore another future recommendation could be to explore the trusted regard of traditional healers.

Future studies need to take into account the cultural context of the research sample group in determining the researcher's method. This is important as the socio-cultural context of an individual, including their language, plays a critical role in the meaning making of their lived experiences. The depth and richness from this study's data generated from focus group discussion provides evidence of the value of

interactive qualitative methods. Thus, more qualitative scholarly studies need to be done in similar and comparable settings in order to confirm, or disconfirm, this study and thus strengthen its findings.

5.5 Conclusion

This study highlights the complex nature of factors that influence a woman's decision to adhere to cervical screening. Although this study highlights many barriers that women in disadvantaged communities face with regard to cervical screening, it identifies factors which if addressed could improve adherence. Knowledge dissemination (educational programmes) at a younger age, as well as to the older generation, needs to be culturally and socially relevant in order for people to integrate their beliefs and thus act out behaviour that will be both culturally accepted and beneficial to the individual. The current community education programmes that exist are either not accessible, understood or culturally acceptable to women in disadvantaged communities. Additionally, these educational programmes need to be targeted towards male significant others in order for there to be more social support available for women seeking cervical screening.

These future educational programmes need to be focused within areas of communities that have the greatest concentration of marginalised women. This group, of underserved and marginalised women, tend to be the poorer, less educated women in the community and thus there is a need for innovative and peer education to increase the knowledge dissemination amongst women. In this manner stigma reduction, as well as a reduction in fear, confusion and embarrassment can be worked towards in order to create a change in an individual's attitude towards cervical cancer and thus promote behaviour of cervical screening. Messages that are being disseminated to the community need to be holistic in focusing on a woman's physical need as well as her emotional and mental health.

Training for health providers to increase their awareness of patient concerns should also be provided. The health providers training needs to include both the social and cultural information about various population groups as well as improving health provider skills. It should be emphasised that health providers need to play a more proactive role in educating and encouraging cervical screening. Perhaps changes in health policy to change the set-up of clinics and medical provision need to be looked at in order to complement the information being provided to the health providers.

Focusing alone on the structural barriers to behaviour change would not be sufficient. This needs to be considered with an account of a community's resilience and capacity to change. The knowledge and explanation of an illness (cervical cancer) needs to be embedded not just at an individual level but also at a macro social level, namely, through religious and traditional healthcare systems. Information seen to be disseminated through pastors or traditional healers appears to be highly valued and thus influences an individual's health-screening behaviour. Therefore the overall management and advocacy for an increase in cervical screening needs to include a holistic intervention taking into account the social-cultural, medical, psychological and religious systems that each individual identifies with.

The researcher is encouraged by the findings of the study to believe that a community-based education programme which takes into account the gender, socio-cultural, and socio-economic factors in conjunction with education levels would greatly contribute towards the increase of cervical screening adherence within disadvantaged communities within South Africa.

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Appendix 1A

Take Home Information Sheet

You are being invited to take part in a research study. Please take time to read the following information carefully and discuss it with others if you would like to. Ask (contact details supplied below) if there is anything that is not clear to you or if you feel you would like more information. Take time to decide whether or not you wish to take part.

This research project is about the knowledge, understanding, beliefs and experiences of cervical cancer. It aims to discover what the views and understandings of cervical cancer are, along with how this affects adherence to screening and treatment. The information you give me will be used to further develop an educational programme and then write a report to contribute to the understanding of what can be done to increase adherence to screening for cervical cancer. If you decide to take part in this research you will be required to partake in a group meeting. The group discussions will be tape-recorded and transcribed.

All information that is collected about you during the course of the research will be kept strictly confidential. Any data presented in research reports will also be completely anonymous – there will be no details (no names) included by which any of the participants in this study can be identified. Any University of Cape Town staff that review the data collected will also adhere to confidentiality.

I am from the University of Cape Town. I am not connected to or working for any hospital or service delivery program. I will not be giving any personal details that you give to me about your experience to any doctors or care delivers who work at the clinics. You are free to withdraw from the study at any time. Participating in this research will not affect your ability to receive any other treatment at the various clinics or hospitals. If you do not want to participate in this group session there will be another information session arranged that you can attend that will not be recorded or monitored.

I cannot promise the study will help you personally, but the information I get will be used to further develop educational materials which you can have access to via MKI. Once the study is completed, you can also arrange for a copy of these findings to be mailed to you (by post or e-mail) by using the contact details below.

Benefits

The benefit of participating in this research is that you will be educated on the topic of cervical cancer and be given the chance to raise any questions around the procedure or beliefs surrounding cervical cancer. Your information will form part of the researcher's understanding of cervical cancer screening.

Risks

There are no major risks to participating in this research. All information will remain strictly confidential from the side of the researcher. However, the researcher cannot ensure that the other people participating in the group discussions will maintain confidentiality.

When you have read this information sheet and signed the consent form you can take the duplicate copy of this information sheet to keep.

If you have any question about the study or decide that you would not like to be included in the study, you can contact me on 082 560 8920 or my research supervisor Dr. Despina Learmonth on 021 650 3420.

If you would like to contact a counselor to talk further about your experiences, you can contact Miss Salie from Victoria Hospital on 021 799 1160. If you would like to enquire about a Pap smear you can visit Khayelitsha (Site B) Clinic or call them on 021 361 6438 / 9. If you have any questions or wish to speak to the chair of the ethics committee please contact Rosalind Adams on 021 650 3417.

Thank you, Chantelle De Abreu

Thank you very much for taking part in this study.

Appendix 1B

Take Home Information Sheet (isiXhosa)

Uya Menywa Kuvavanywa

‘Iwesi fundo. Ndicela utathe ixhesha ufunde kakushe lemiteto uxhoxhe nabanye ukuba uyafuna. Bhuza (onke amana ase zantsi) ukuba khukho into engavakile fonela lama nane. Thatha ixhesa lwakho ukhucinga ukhuba uya funa ha kwesifundo ukha ba kwesifundo na.

Isi fundo sisifundo soku kwazisa ne nkolelo se cervical cancer. Injongo sesifundo khukwazisa wena imibono nukukwazi xha iqalakiyo i cervical cancer, noku bonisa ukhuba unga ncedakhala njani. Imphendulo yakho izokusinceda ukhu khulisa infundo ne program yokhu bhala ireport yokhu vakalisa nokhuba khungenzwa ntonina ukhukhulisa isifundiso se cervical cancer. Ukhuba uyavuma uku ngenela esifundo kuzo funekha udibone nabanye abantu. Nizo dibane okwe group. Nizo recodwa kwi tape xhanyi xhoxhayo. Yonke into enizokuyitha ayizoku izoku cinywa ekhukuseleki. Akusayi kubakho zinchukaca (amagama omntu) zomntu othe wavuma ukungenela ezi zifundo eziyakuthi zidandalaziswe ngumcwaningi. Nawuphina umsebenzi waledyunivesiti oyakuthi ahlole uqokelelo lwengxelo akasayi kuze aveze iziphumo Ndisuka kwidyunivesiti yase Kapa. Andisebenzeli nasiphina isibhedleleokanye naliphi isebe lezophuhliso. Inchukaca ondinike zona andisayi kuzinika nawuphi na ugrira okanye umntu osebenzela icandelo lezempilo.

Uvumelekile ukuba uroxhe nangaliphi ixesha ufuna kwesi sifundo.

Ukungenelela kwakho ezizifundo akusayi kukuthintela ukuba uxilongwe okanye ufumane amayeza esibhedlele okanye ekliniki. Ukuba akufuni ukuthabatha inxaxheba kwisininzi sabantu uyakulungiselelwa ukuba uthatyathwe wedwa inchukacha ezingazokubhalwa okanye zishiceleklwe ndawo.

Andikuthembisi ukuba ezizifundo zingakunceda wena ncakasana, kodwa ulwazi endilifumeneyo lingasetyenziswa ukuphucula banzi izixhobo zemfundo ongafikelela kuzo nge MKI.

Xa izifundo zigqityiwe ungacela ukuba nawe uthunyelelwe ngeposi okanye i-email ukuba unayo.

Inzuzo

Into emnandi xa uthe wangenela ezizifundo kukuba uzuze ithuba lokuba ufundiswe ngomhlaza wesibekeko, ubuze nayiphina imibuzo ongayiqondiyo ngomhlaza. Loo nto iyakuthi incede nomcwaningi ukuba abe nolwazi olunzulu ngomhlaza ngokuba uyakuthi aphande nzulu ngesifo somhlaza.

Imingcipheko

Akukho mingcipheko mikhulu ngokuthabatha inxaxheba kolucwaningo. Zonke inchukacha ziyakuhlala zifihlakele qwaba ngakwicala lomcwaningi.

Kodwa ke umcwaningi akanakuqinisekisa ukuba abanye abantu abantu abathabatha inxaxheba kwiqela lengxoxo bayakuyigcina imfihlo. Xa uthe walifunda iphepha lengcaciso waza watyikitya iphepha lesivumelwano, ungathabatha ikopi yephepha lengcaciso ulugcine.

Ukuba unombuzo malunga nesifundo okanye ugqibe ekubeni akungethandi ukufakwa kwisifundo unganxulumelana nam ku 0825608920 okanye umcwaningi wam oyintloko ugqira Despina Learmonth ku 021 650 3420. Ukuba uyathanda hlangana nomthuthuzeli (councilor) nithethe banzi malunga malunga namava akho. Lowo ke ngunkosazana Salie ofumaneka kwisibhedlele iVictoria 021 799 1160. Ukuba uyathanda ukubuza malunga nencindi yesibekeko uingatyelela eKhayelitsha (site B) ekliniki okanye utsalele umnxeba ku 021 361 6438/9. Ukuba unombuzo okanye unqwenela ukuthetha nomphathi wekomiti ye (ethics) nceda unxulumane noRosalind Adams ku021 650 3417.

Enkosi Chantelle

Ndiyabulele kakhulu ngokuthataha kwakho inxaxheba kwesi sifundo.

Appendix 2A

Informed Consent Form

Please tick box

1. I confirm that I have read and understand the information sheet for the above study.
2. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I understand and consent to the fact that the sessions I am taking part in will be recorded.
5. I understand that relevant sections of any of the data collected during the study, may be looked at by a suitably qualified researcher from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.
6. I understand that my anonymity and confidentiality will be maintained throughout the study. No personal information, which could be used to identify me, will be used in the writing up or reporting of this research.
7. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher 1	Date	Signature
_____	_____	_____
Researcher 2	Date	Signature

Appendix 2B

Ifomu yemvume eyazisiweyo

Marka Apha

1. Ndiya vhuma ukhuba ndiyi funde yonkhe imithetho
2. Ndingisisile nda bhuza imibhuzo nda phendula ngokwenkoliso yam
3. Ndiyayazi ukhuba ndisenza isifundo ngo kuvuma kham, ukhuba andi safuni ukubulapha ndinga vele ndiyekha ngabahle khokhunika isizathu, nanini na
4. Ndinolwasi ukhuba ndizo rekodwa
5. Ndiyayiqonda ukuba, ku luhlu lwinzinto ezikhannkanyiweyo kolu phando, ezinye zezinto zinakho uku phononogwa li gqiza elithethekileyo le zomthetho. Apho ifunekayo inxhaso yam koluphando ndakulivumela igqiza elo lingene koluphando.
6. Ndiya qonda ukhuba yanke into endiyi phendulayo apha izokhuba yinfihlakalo. Akhukonto ezo vezwa ngami kwile report.
7. Ndiya vuma ukhu ngenela esifundo

Igama lomthathi nxaxheba

Umhla

Utyikityo

Umphandi 1

Umhla

Utyikityo

Umphandi 2

Umhla

Utyikityo

Appendix 3

Focus Group Interview Guide

Introduction Questions

What is the community knowledge around cervical cancer?

What do you know about cancer of the cervix?

What would you like to know about cervical cancer?

Teaching Segment on Cervical Cancer

Cells and cancer overview

Prevalence, incidence, and mortality statistics

Symptoms and risk factors for cervical cancer

Questions Asked Throughout Teaching Segment

What is cervical cancer?

What are the symptoms of cervical cancer?

What are the risk factors for cervical cancer?

What types of barriers prevent community from accessing screening for cervical cancer at clinics?

Discussion of:

Beliefs

Access to clinic services

Culture (social and gender factors)

Knowledge

Concluding Questions

How is cervical cancer affecting our communities?

Why is cervical cancer affecting our communities?

Can you think of any possible solutions to the barriers discussed?

Appendix 4

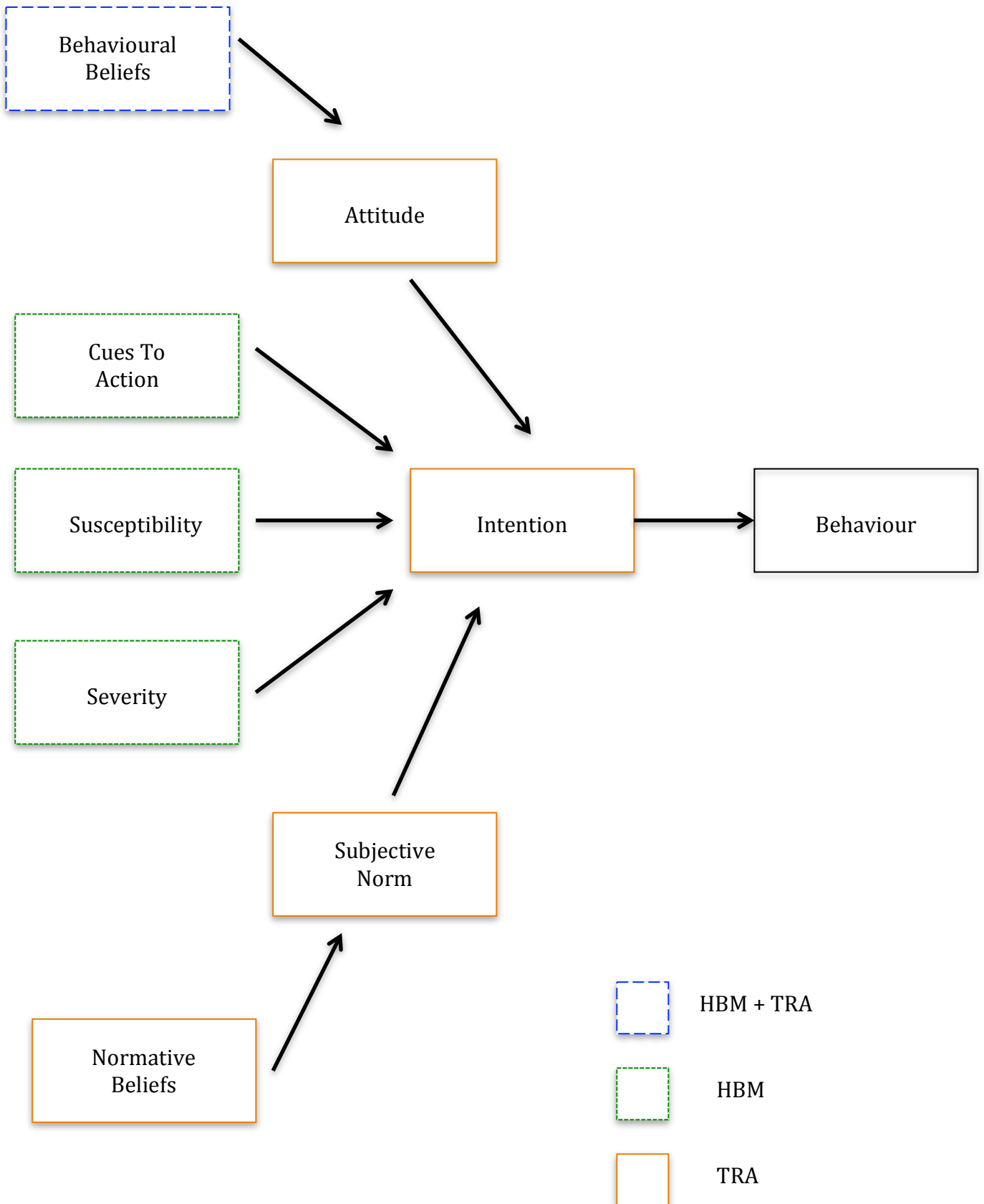


Diagram 1. Combination of HBM and TRA model

Appendix 5

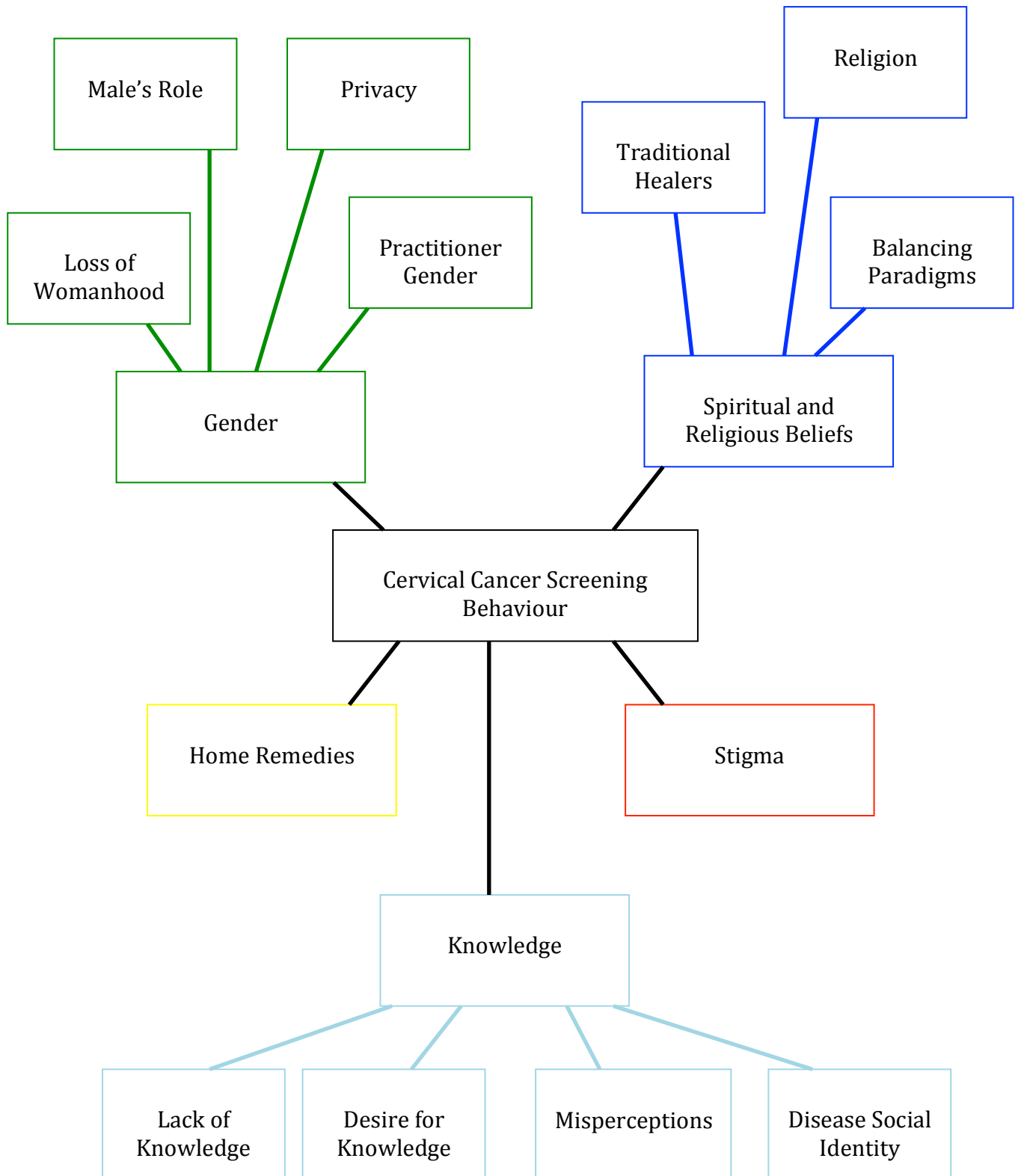


Diagram 2. Flow diagram of themes