

Black Women's Perceptions and Experiences of Cervical Screening.

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Abstract

Cervical cancer is the second most common cancer among South African women, and Black African women have the highest risk of developing this disease. Unfortunately, the majority of South African women do not adhere to recommended regular cervical screening. The purpose of this research is to explore the perceptions, experiences and knowledge relating to cervical cancer and preventative screening, amongst Black women residing in the Western Cape urban informal settlements of Red Hill and Masiphumelele. The Health Belief Model (HBM) provided a theoretical framework for this study. Four focus groups ($n=21$), with women between the ages of 21 and 53 years, were conducted using questions derived from the HBM, and thematic analysis was used to analyse the data. The analysis revealed an absence of knowledge as to the purpose of a Pap-smear to be a key barrier to treatment. Other structural barriers identified were time, age at which free screening is available and health education. Psychosocial barriers that emerged included fear of the procedure and fear of stigmatisation. Finally, the source of the women's information as well as the presence of physical symptoms, the perception that screening provides symptom relief, the presence of HIV and the desire to know one's physical health status were identified as facilitators of cervical screening adherence.

Keywords: adherence to screening; Black South African women; cervical cancer; Pap-smear testing; informal settlement

Background

Cervical cancer is the second most common cancer among South African women (World Health Organisation, 2010). Recent surveys indicate that 5743 South African women are diagnosed with cervical cancer annually. Despite readily available and effective treatment of early stage disease as well as the existence of reliable and accessible screening, using cervical cytology 3027, (53%) of these women will die from this disease each year (WHO, 2010). In South Africa, the risk of disease differs for different ethnic groups (Redelinghuys & Van Rensburg, 2004; Smith, Moodley, & Hoffman, 2003). Black African women have the greatest risk of developing cervical cancer with 1 in every 34 women developing this disease. (Redelinghuys & Van Rensburg, 2004).

Furthermore, the human papillomavirus (HPV) is recognised as being responsible for 62.8% of invasive cervical cancers (WHO, 2010). HPV is associated with a more rapid disease progression, reducing disease development to as brief a period as 20 months (Schneider, Sawada, Gissmann, & Shah, 1987). Alarmingly, approximately 21% of South African women are carrying this sexually transmitted infection (WHO, 2010).

The following review will outline cervical screening protocol and adherence behaviour as it stands within the South African context. In addition, it will provide an overview of the Health Belief model and its applicability to cancer treatment adherence. Finally, it will review previous research into the barriers, knowledge and attitudes towards cervical cancer screening.

Cancer Screening and Treatment

A 3-year period of successful cervical cytology, using Papanicolaou (Pap-smear) screening, is estimated to reduce cervical cancer incidence by 60% to 90% in populations which have previously never undergone screening (Suba, Murphy, Donnelly, Furia, Huynh, & Raab, 2006). This screening aims to reduce the mortality rate associated with this disease through the early detection and treatment of abnormalities in the cells lining the cervix (Kelaher, Gillespie, Allotey, Manderson, Potts, Sheldrake et al., 1999).

On receipt of abnormal Pap-smear results (i.e. results suggesting precancerous lesions) appropriate follow-up consists of repeat Pap-smears and, when necessary, repeat colposcopies together with biopsies of the abnormal areas (McKee, Lurio, Marantz, Burton, & Mulvihill, 1999; Miller, Siejak, Schroeder, Lerman, Hernandez, & Helm, 1997; Paskett, Carter, Chu, & White, 1990). In contrast to this relatively simple treatment plan, when lesions

are only detected once they have progressed to invasive cancer, far more drastic treatments are necessary. In most cases, invasive cervical cancer treatment includes a radical hysterectomy and/or radiation therapy (Marcus, Crane, Kaplan, Reading, Savage, Gunning et al., 1992).

It is widely accepted that the more advanced the cancer, the more costly the treatment and the poorer the prognosis. However, more concerning are the differences in survival projections between the various stages of cervical cancer (Lee, 2000; Marcus et al., 1992). With appropriate treatment, the 5-year survival rate for woman with invasive cervical cancer (i.e. stage I disease) is estimated to be between 80% and 90%. These rates decrease significantly, to between 50% and 60%, for women with stage II carcinomas and even more dramatically when moving to stage III and IV carcinomas, with survival rates of less than 30% and less than 15%, respectively (Marcus et al., 1992).

Critically linked to the above outline of cervical cancer development and treatment is the influence of HPV on disease onset and progression. HPV is an infection frequently located in the anogenital tract of women (Clifford, Franceschi, Diaz, Munoz, & Villa, 2006). Globally, more than 70% of all cervical cancer cases are attributed to HPV 16 and 18 (Clifford et al., 2006). In light of these statistics and the stigmatised nature of HPV, it is important to consider the possible influences that the above relationship between cervical cancer onset and HPV could have on screening adherence.

The above survival rates and treatment recommendations emphasise the importance of early detection and continued follow-up care in order to reduce avoidable morbidity and mortality in women suffering from cervical cancer (Thoms, Unger, Johnson, Spann, Hunter, Smith et al., 1995). Unfortunately, the majority of South African women do not adhere to recommended cervical screening practises. A survey conducted by the World Health Organisation for the 2001-2002 period, estimated that only 13.6% of South African women had received a Pap-smear in the previous three years (WHO, 2010).

The Health Belief Model (HBM)

The Health Belief Model (Kirscht, Don, Kegeles, & Rosenstock, 1966) is the theoretical model most frequently used to explain health behaviour (Gillam, 1991). The model includes six key constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy, which determine an individual's decision to take up a health behaviour (Johnson, Mues, Mayne, & Kiblawi, 2008). *Perceived susceptibility* is an individual's assessment of the probability of suffering from a negative health condition.. This feeling of vulnerability regarding the development of an undesirable

health condition motivates the individual to take preventative action. *Perceived severity* is an individual's perception of the seriousness of the effects of this condition. The more severely the condition is perceived, the greater the chance of the individual taking action against it. *Perceived benefit* is an individual's opinion of the effectiveness of the recommended health behaviour to reduce the risk, severity or impact of the condition, while *perceived barriers* are the costs, both psychological and tangible, which prevent the individual from carrying out the behaviour. Thus, what occurs is a cost-benefit analysis where the individual weighs the positive outcomes and effectiveness of the behaviour against the possible costs of the behaviour. The model defines experiences which encourage an individual to carry out the health behaviour as *cues to action*. Cues may be external or internal. Examples of external cues are radio and electronic media messages, while the perception of one's bodily state is an internal cue (Lee, 2000). Finally, *self-efficacy* is an individual's belief in his/her ability to carry out the desired behaviour successfully (Johnson et al., 2008).

The model was later revised to include several modifying variables which influence the aforementioned factors. These can be broadly categorised as social-psychological such as socio-economic-status (SES); demographic such as ethnicity; and structural such as knowledge about the condition (Gillam, 1991; Lee, 2000).

In terms of cervical screening behaviour, there has been considerable evidence to support the use of this model (Agurto, Bishops, Sanchez, Betancourt, & Robles, 2004; Byrd, Chavez, & Wilson, 2007; Fylan, 1998; Lee, 2000; Thomas, Saleem, & Abraham, 2005). Women's perceived susceptibility to cervical cancer, as well as their perceived barriers to screening, have been found to be predictors of screening behaviour (Hill, Gardner, & Rassaby, 1985). Furthermore, there is greater incidence of screening protocol adherence among individuals who exhibit a high 'health-locus-of-control' (i.e. those with greater self-efficacy), than among those individuals with a low 'health-locus-of-control' (Fylan, 1998).

Despite its widespread use as a psychosocial model to explain this health behaviour, the HBM has several noteworthy limitations (Johnson et al., 2008). Firstly, factors directly affecting access to health services, such as social support, and language barriers are not accounted for by this model (Johnson et al., 2008). Secondly, the abstract nature of the HBM leaves the model with little predictive power. Furthermore, the HBM does not account for the potential influence that a positive, longstanding relationship with a health care provider can have on an individual's decision to adopt a health behaviour. Therefore, when used as a theoretical basis for understanding and categorising cervical screening behaviour, and not as

a means of predicting this behaviour, the HBM has considerable value (Gillam, 1991; Johnson et al., 2008).

Barriers and Facilitators to Cervical Screening

Knowledge. Research has consistently shown misinformation and a lack of knowledge surrounding cervical cancer and preventative screening to be a major barrier to screening adherence (Byrd et al., 2007; Fylan, 1998; Lee, 2000; Markovic, Kesic, Topic, & Matejic, 2005; Ogedegbe, Cassells, Robinson, DuHamel, Tobin, Sax et al., 2005; Thomas et al., 2005). For example, a systematic review by Fylan (1998), found that a lack of awareness of the purpose, benefits and indications of Pap-smears was a key factor in diminishing screening adherence. Furthermore, this report highlighted an absence of knowledge about cervical cancer and its risk factors as being an important barrier to recommended screening practices (Fylan, 1998).

An important aspect of misinformation is women's inability to distinguish between cervical screening and diagnostic tests. Research has repeatedly shown that women are frequently unaware of the purpose and significance of a Pap-smear. Many women do not understand the importance of the Pap-smear as a preventative measure and believe that Pap-smears detect existing cancer (Fylan, 1998; Hislop, Clarke, Deschamps, Joseph, Band, Smith et al., 1996; Markovic et al., 2005). Accompanying this belief is the notion that a Pap-smear is performed when a woman is suffering from a reproductive health difficulty such as vaginal bleeding or discharge (Lee, 2000; Markovic et al., 2005). Consequently, women will often only undergo cervical screening once they are symptomatic (Agurto et al., 2004). As a result, their cancer is only detected at a more advanced disease stage which is associated with significantly lower survival rates and more costly and severe treatment plans.

An alarming pattern regarding the above lack of knowledge and misinformation is its relationship to age. Research indicates that older women have a higher level of knowledge regarding screening than their younger counterparts (Idestrom, Milsom, & Andersson-Ellstrom, 2002; Thomas et al., 2005). For instance, a study of the screening practices of black and minority ethnic groups in the United Kingdom found that the youngest members of the African Caribbean community had the lowest levels of knowledge regarding cancer screening (Thomas et al., 2005). Once again, the result of this is that the opportunity for early detection and straightforward treatment is foregone.

Finally, research by Pillay (2002) highlights the importance of this barrier within the South African context. This study investigated the degree of awareness held by rural and urban black South African women regarding cervical and breast cancer. The study found that

20% of the women had never heard of cervical cancer and more than 50% were unaware of cervical screening tests.

Language. Research repeatedly sites language as a key barrier to cervical screening adherence (Agurto et al., 2004; Fylan, 1998; Kelaheer et al., 1999; Lee, 2000; Thomas et al., 2005). A common feature of populations with low screening adherence is that the women do not have access to healthcare providers who speak their first language. The result of this is inadequate communication of the purpose and importance of cervical screening and what the procedure entails (Agurto et al., 2004; Fylan, 1998; Lee, 2000). Furthermore, media used to promote screening rarely caters for all language groups, and as a result, many women do not receive adequate information on cervical screening (Thomas et al., 2005).

Cultural beliefs and attitudes. Many studies have cited culture as a crucial barrier to cervical screening (Baldwin, 1996; Lee, 2000; Tung, Nguyen, & Tran, 2008). An important aspect of cultural beliefs and attitudes is the influence they exert on decision making practices. Research shows that treatments which are markedly different from a woman's traditional practices are often not followed. Amongst various low-income cultural groups, especially African groups, this decision involves the input of the whole family. If a woman's family decides that a treatment does not fit in with her cultural practices, she may be barred from seeking further treatment (Baldwin, 1996; Lee, 2000; Tung et al., 2008). A woman's culture shapes the manner in which she understands and experiences cervical cancer and cervical screening (Baldwin, 1996). It is therefore crucial to take the influence of culture into account when investigating cervical screening adherence within the culturally diverse and complex context of South Africa.

Health professional characteristics and influence. The vast majority of research into the barriers and facilitators of cervical screening adherence, indicate that women's experiences with service providers greatly influence their adherence decisions (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Lee, 2000; Markovic et al., 2005; O'Malley, 2002; Ogedegbe et al., 2005; Thomas et al., 2005). Women have reported that discourteous, insensitive providers with unhelpful attitudes are a major deterrent to undergoing screening (Agurto et al., 2004; Byrd et al., 2007; Thomas et al., 2005). In addition, healthcare provider gender has a significant effect on adherence. Women frequently cite a lack of female providers as the primary reason for not attending cervical screening (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Lee, 2000). Finally, a chief facilitator of cervical screening has been found to be a health professional's recommendation (Ogedegbe et al., 2005).

Fear and anxiety. Fear and anxiety surrounding ideas of pain, embarrassment and a potential cancer diagnosis, greatly contribute to a lack in 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, Yasui, Burke, Nguyen, Acorda, Thai et al., 2004; Thomas et al., 2005). Women frequently report a fear that the Pap-smear will be painful as well as a fear that they will experience pain or sustain internal injuries after the procedure (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). Fear of embarrassment from a loss of privacy as a result of having to expose their genitalia is another barrier repeatedly cited by women (Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Lee, 2000; Ogedegbe et al., 2005). Finally, a fear of receiving a cancer diagnosis has been identified as a key barrier to cervical screening. Many women have a fatalistic attitude to a cancer diagnosis and fear the potential treatment plans and associated costs and discomforts (Agurto et al., 2004; Byrd et al., 2007; Fylan, 1998; Hislop et al., 1996; Lee, 2000; Lyttle & Stadelman, 2006; Thomas et al., 2005). The above fears place women in high states of anxiety, and as a result, many women do not at adhere to recommended screening practices.

Service accessibility and cost. Time forms a significant access barrier and includes factors such as a long waiting period at clinics, lengthy travelling times to clinics and inconvenient clinic operating hours (Agurto et al., 2004; Fylan, 1998; Lee, 2000; Ogedegbe et al., 2005).

Another access barrier which has consistently been shown to deter cervical screening adherence is the costs associated with screening (Agurto et al., 2004; Byrd et al., 2007; Lee, 2000; Lyttle & Stadelman, 2006; Ogedegbe et al., 2005). More specifically, research has shown that travel costs and procedural costs discourage women from undergoing screening. In contrast to this, the presence of health insurance or free cervical screening has been related to increased rates of adherence (Agurto et al., 2004; Byrd et al., 2007; Lee, 2000; Lyttle & Stadelman, 2006; Ogedegbe et al., 2005). By using a psychological proactive or preventative approach, health care providers can work towards more women adhering to cervical cancer screening (Miller et al., 1997).

Barriers and facilitators to cervical screening in the South African context. Historically, within South Africa there had been a severe shortage of research focussing on individuals of African heritage. This is most evident in the paucity of research involving black women. Currently, only two studies have investigated cervical cancer screening amongst South African women. The first was limited to the assessment of the degree of knowledge about cervical cancer and screening possessed by black women (Pillay, 2002). Similarly, the second study also assessed the level of knowledge

about cervical cancer and screening possessed by South African women from a variety of socio-economic backgrounds. In addition, this study assessed the utilization of screening facilities within these different groups (Wellensiek, Moodley, Moodley, & Nkwanyana, 2002). There is therefore a need to determine what barriers and facilitators exist which are specific to the black women living in underserved regions of South Africa. This is particularly important considering the socio-political disadvantages faced by these women.

Aim of the Research Project

The aim of this research project was to explore the perceptions and experiences of black women residing in South African urban informal settlements with regards to Pap-smear screening and cervical cancer. The authors hope that this research will contribute to the current understanding of the reasons for which women do not adhere to recommended screening practices. Furthermore, it is hoped that this knowledge will aid policy formation by highlighting the reasons for low cervical screening among these women.

The following research questions were asked: 'How do Black women residing in South African informal settlements perceive and experience their knowledge, barriers and facilitators to cervical screening; and how does this influence their adherence to recommended screening practices?'

Method and Design

Theoretical Framework

The Health Belief Model (HBM) provided a theoretical framework for this research. As previously discussed, this model has consistently shown to be effective when used as a theoretical basis for exploring women's cervical screening practices (Agurto et al., 2004; Byrd et al., 2007; Gillam, 1991; Johnson et al., 2008; Lee, 2000; Thomas et al., 2005)

A comparative examination of the research questions and the HBM reveals this model to be particularly appropriate for use in this study. The research questions ask how women's perceptions and experiences regarding their knowledge, barriers and facilitators to cervical screening influence their decisions to adhere to recommended screening practices. Therefore, the data generated by this research is the personal and subjective experiences of these women. Similarly, the HBM proposes that six factors, four of which are related to individual perceptions, influence an individual's decision to adopt a health behaviour. For this reason, the HBM's focus on perceptions, self-efficacy and cues to action/experiences provided a useful framework within which to structure and analyse the present research. In addition, the exploratory nature of this research and the extremely under-researched population it focussed

on further supported the use of a model which emphasises the importance of perceptions and experiences.

Participants and Sampling Procedure

Purposive, convenient sampling was used to recruit the participants. Members of two informal settlements located on the Southern Peninsula of Cape Town, namely, Red Hill and Masiphumelele, assisted the researchers in recruiting participants from their respective communities. In total, twenty-one black women between the ages of 22 and 49 years, residing in these informal settlements, participated in this study.

Masiphumelele was established in 1992 and is located on the boundary of the wetlands between Kommetjie and Noordhoek. Masiphumelele's initial settlers were predominantly migratory workers from the Eastern Cape. This was a result of the late apartheid and post-apartheid slackening of laws restricting labour migration which allowed many individuals who were categorised as 'African' under apartheid's population classification system, to migrate from rural to urban areas in the hope of finding employment and reuniting with family who were lost during forced segregation. These migratory patterns still exist today and as a result the majority of Masiphumelele's residents are black. Although Masiphumelele was originally established as a formal settlement, the influx of migrating workers and resultant lack of adequate housing has led to poor living conditions and overcrowding with most of the settlement's inhabitant residing in informal structures. As a consequence of this overcrowding and expansion of unsafe informal shelters, the incidence of fires and floods is high. Furthermore, life in this settlement is characterised by poverty, unemployment and poor service delivery as well as unsanitary living conditions. Regarding cervical screening services, there is a government clinic in Masiphumelele.

Founded in the 1980's and located between Scarborough and Simon's Town, Red Hill is a small settlement, with approximately 1000 residents and only informal housing. The settlement is more integrated than Masiphumelele with a mix of black and coloured residents. In addition, due to the recent influx of foreign migrants into South Africa, many of the black residents in Red Hill are not South African. In 2005, the municipality provided the majority of Red Hill's shelters with running water, and in 2007 the settlement was electrified. The combination of this increase in infrastructure and lower levels of overcrowding, have resulted in Red Hill's living conditions being significantly better than those in Masiphumelele. That being said, Red Hill is still characterised by poverty, unemployment, high fire risks and unsanitary living conditions. Red Hill does not have any schools and there is only a part-time

medical clinic; consequently service delivery in the area is poor. The above information provided a contextual backdrop for the analysis of the women's views.

Of the twenty-one women in our sample, all were black and between 21 and 53 years of age. With regards to nationality, eighteen of the women reported themselves as South African, one reported that she was Zimbabwean and three declined to answer. With regards to children, four of the women reported having one child, six reported having two children, six reported having three children, three reported having four children, one reported having five children and one declined to answer. Of the twenty-one women, eleven reported that they were single, ten reported that they were married and one declined to respond. With regards to employment status, ten of the women reported that they were unemployed, six reported having a job and five declined to answer. In addition, seven of the women reported their highest level of education to be that of primary school and fourteen reported a degree of secondary education.

Inclusion criteria. Only women of no younger than 21 years of age were included in this study. This is in accordance with the cervical cancer screening guidelines set by the American National Cancer Institute (2007) which recommend that women begin cervical screening within three years of their first experience of sexual intercourse, or at the age of 21, whichever comes first. This institution's guidelines were used as the South African Department of Health did not have a recommended age available.

A further inclusion criterion was that only women who resided in either Red Hill or Masiphumelele were included in this study. This was because these were the communities in which the researchers had established contacts as well as private, easily accessible venues.

A final inclusion criterion was that only women with a basic level of English proficiency were accepted into the study. The reason for this was that the researchers who ran the focus groups were English and as a result could not facilitate groups in other languages.

Data Collection

The data collection method used was that of focus groups. Focus groups are a widely utilised method in qualitative research and have found particular popularity within health psychology (Wilkinson, 2008; Willig, 2001). Focus groups offer an alternative to semi-structured interviews. The most notable difference between focus groups and semi-structured interviews is the attention focus group's pay to the interactions between individuals. The power of focus groups is found in the way in which they encourage participants to interact, and therefore respond, to each other's opinions. This creates an environment where

statements can be challenged and elaborated in a manner which provides a far deeper source of data for the researcher (Wilkinson, 2008; Willig, 2001).

The nature of focus group data creates an opportunity for the researcher to explore questions about how attitudes are formed or altered. Focus groups also allow for the simultaneous collection of a diverse number of opinions (Frith, 2000). In addition, focus groups give the researcher the opportunity to investigate the ways in which the participants co-construct the meanings attached to a specific phenomenon (Willig, 2001). For this reason, focus groups are suited to research which is concerned with eliciting the participants' own understandings, perspectives and opinions of a phenomenon (Wilkinson, 2008).

There are several noteworthy advantages of focus groups. First, focus groups are a 'naturalistic' form of data collection (Wilkinson, 2008). This allows participants to feel more at ease and encourages the interaction characteristic of this data collection method.

Second, focus groups are ideal for exploring topics about which little is known (Frith, 2000). This is because the fairly unstructured nature of focus groups allows the participants to guide the discussion towards areas of personal concern. The result of this is that the participants are allowed to 'introduce their own themes and concerns' (Espin, 1995: 228). In addition, by allowing the participants this freedom, unexpected insights are often revealed to the researcher giving him/her a fuller and more accurate understanding of the phenomenon (Frith, 2000).

Third, the group setting of focus groups shifts the power balance in favour of the participants. This reduces the researcher's influence and prioritises participants' opinions (Wilkinson, 1998).

There is considerable evidence to support the appropriateness of focus groups as a data collection method when researching sensitive topics. A number of studies have found that this type of group environment promotes personal disclosure (Överlien, Aronsson, & Hydén, 2005; Wilkinson, 2008).

Focus groups are an appropriate method of data collection for the current research project for the following reasons:

- The research was exploratory in nature and focused on exploring the knowledge, perspectives, experiences, understandings and opinions of the participants.
- The research topic is sensitive.

- To date, there has been limited research into this area and therefore it was important that the participants were given the opportunity to highlight areas which are of greatest personal concern.
- Finally, the sensitive nature of the research topic means that in order for the participants to have felt comfortable enough to disclose their experiences, the power balance between the researcher and participants needed to be addressed.

Procedure

This research involved a total of four focus groups. Two of the focus groups were conducted with women who had undergone cervical screening and two were conducted with women who had never undergone cervical screening. The researchers decided to divide the women according to their screening status so as to avoid the women who did not adhere to screening feeling embarrassed or intimidated by their adhering counterparts. Each participant was contacted by a member of their community who was working with the researchers. The recruiters briefly outlined the research and obtained permission from each participant for their information to be given to the researchers, as well as informed the participants of the date, time and venue of each focus group.

The focus groups were held in the recruiters' homes in Red Hill and Masiphumelele. These locations were private and in a familiar setting and therefore served to reduce participant anxiety and encourage open discussion. Tea and biscuits were provided as refreshments to facilitate group interaction. All the focus groups followed the same procedure.

Before each focus group discussion commenced, the researchers introduced themselves and explained the purpose of the focus group to the participants, along with how it would be conducted. The researcher leading the focus group then went through the information sheet (Appendix A), answering any questions that the participants had, before asking them to sign the consent forms (Appendix B). Furthermore, as the focus groups were tape recorded, the researcher explained why the tape recorder was being used as well as how it worked.

Thereafter, the focus group was led by the lead researcher through a series of questions (Appendix C). At this stage, the co-researcher took notes on the non-verbal communication that would not be detectable in the tape-recordings.

The focus group closed with a debriefing by the lead researcher. The participants were asked to complete a demographics questionnaire (Appendix D) and were provided with

resources on cervical screening along with a R50 Shoprite Checkers voucher as a token of appreciation for their contribution to the research.

Once the focus groups had been conducted, the researchers transcribed the recordings. As the researchers were interested in the participants' experiences and perceptions regarding cervical screening, the manner in which the participants expressed themselves when referring to these experiences was of interest. For this reason, the transcriptions included details on the ways in which certain statements and questions were expressed. For instance, if a participant was defensive or confrontational when discussing a particular experience, this was recorded.

Additional ethical considerations. This research project adhered to the University of Cape Town's guidelines for research with human subjects. Additionally, the research met the ethical requirements specified by the Research Ethics Department of the Department of Psychology.

Risks and benefits for participants. This research did not pose any great risk to the participants. However, there was a chance that the participants may have become distressed if the discussion led them to conclude that their health was at serious risk due to their lack of screening adherence. In order to account for this, the researchers provided each individual with the contact information of a counselor working from Victoria Hospital. This is a government hospital and therefore counseling services are free. Consequently, cost would not be a barrier to seeking further support.

This research does not provide any direct benefits to the participants. However, the women were provided with resources on cervical cancer, encouraging them to seek screening. In addition, an information session within each of the communities has been co-ordinated. This meeting will be attended by a cytopathologist from Groote Schuur hospital who will briefly discuss cervical cancer and cervical screening, thereafter the women will be given the opportunity to ask any questions that they may have regarding cervical cancer, screening and treatment.

Data Analysis

The data generated by this research was analysed using thematic analysis. Thematic analysis is a theoretically flexible way in which data, and therefore themes, are identified, organised, analysed, and reported (Braun & Clarke, 2006). Thematic analysis allows for a rich overall description of the data set. This was useful in investigating our research question in its particular context as an under-researched area where the participants' views are unknown. Thematic analysis is a recursive process in that there needs to be a constant backwards and forwards movement between the data sets. Through the different phases in the

analysis the researchers moved back and forth between the different coded extracts of data, the whole data set, and the overall analysis that was being produced. Writing is a key part of analysis and starts in the first phase of analysis with the writing down of possible coding schemes and ideas (Braun & Clarke, 2006). These processes helped to make sure that the themes produced were relevant to the research question.

Thematic analysis contains six phases (Braun & Clarke, 2006). The first phase involved the researchers familiarizing themselves with the data. This was done by transcription, reading and re-reading data. During this phase the researchers jotted down any ideas for coding which were relevant to the research question. The second phase consisted of the initial construction of codes from the data. In a systematic fashion any interesting features of the data was coded, and relevant data was collated for each code.

During the third phase, the researchers searched for themes. All the different codes of what the participants were expressing were grouped into potential themes, and the relevant data extracts for each code were collated within the different themes. The data was then organised within each theme.

The themes were reviewed in the fourth phase. This phase began with the researchers checking to see if the collated codes for each theme formed a coherent pattern. Then they checked if the themes related to one another across the entire data set.

Phase five is where the themes were defined and named. The specifics of each theme and what the overall description of the analysis revealed, were also refined during this phase.

The final phase involved producing a concise and coherent description of what the data brought forth. This was done by the utilisation of the extracted themes to make an argument in relation to the research question. In this way experiences and barriers to screening behaviour were identified.

Reflexivity

Our sociocultural position as white, English-speaking, young middle-class females, with a starkly different culture from that of our participants, affected the type of information they felt comfortable sharing with us. As the focus groups progressed it became apparent that the participants assumed we were associated with a hospital or medical system as they often asked for medical explanations and information. In addition, we remained separate from what was occurring within the focus groups and became intensely aware of our status as ‘outsiders’. This was only exacerbated by our inability to effectively communicate with the women in their own language- isiXhosa. In addition, there was a mutual understanding and manner of relating amongst the women which was not extended to us. At times, this made us

feel uncomfortable and uneasy. This discomfort was due to a heightened awareness of our outsider status and consequently feeling as though we were being scrutinised. Witnessing this uneasiness in us, may have adversely affected the women's feelings of comfort and safety, thereby inhibiting their ability to comfortably and openly express themselves.

As we anticipated the women associating us with medical institutions and therefore as authority figures in this respect as well as because we were aware of our vastly different cultural backgrounds, our decision to conduct the research in the homes of the two recruiters, who resided in Masiphumelele and Red Hill, was an attempt to create a comfortable environment where the women would feel more empowered. However, despite the benefits of this setting, our socio-cultural position and perceived affiliation with medical institutions still had an impact on what was said.

As our cultural background prioritises and places importance on Westernised medical care, it was important for us to be mindful of this while working with the data. Constant reflection on our perceptions of 'normal' health adherence behaviour was necessary, in order to conduct and interpret the research and data without imposing our personal views on the meanings that emerged. Although our aim was not to control or interfere with the research process, we acknowledge that who we are, where we are from and what we believe, did impact the research.

Analysis and Discussion

The thematic analysis of began with one of the researchers and a bilingual research assistant transcribing the focus group discussion. The transcribed data was then reviewed and analysed following the process outlined above. The analysed data was reviewed independently by the second researcher, and after a discussion to clarify themes and ensure agreement, the transcripts were coded according to the themes. Three main themes; barriers, facilitators, and knowledge, were identified.

Barriers to Screening Service

A number of themes emerged in the analysis of the data relating to barriers to screening service. Barriers were defined as the negative outcomes and impediments to undertaking health behaviours. Two sub-themes of barriers were identified; structural barriers and psychosociocultural barriers.

Structural barriers. Structural barriers were factors which affected the accessibility of healthcare services to the women. The structural barriers that appeared in this research were that of time, age, and health education. The following participant identified time as a barrier:

Participant 4: I have never get the chance to get to the clinic because I'm always working.

A lack of time due to long working hours appears to prevent women from attempting to attend screening. This is a particularly important barrier when viewing these women within the context of post-apartheid South Africa. Black women living within informal settlements are subjected to the gross inequalities of contemporary South African society, and the resultant experience of economic pressure and consequent long working hours is an aspect of this.

Age emerged as another structural barrier which inhibited women from attending a Pap-smear. A participant described her willingness to attend a Pap-smear, but how due to her age she was not allowed:

Researcher: Ok why did you decide not to go for a Pap-smear? When you heard about it at the clinic, why didn't you...

Participant 1: I did, but they said I am underage. They said you must have a 30. Women who had the time and did attempt to go for a Pap-smear were frequently denied screening as they were not yet at the age at which free Pap-smear tests are administered. This was a government policy which the researchers were unaware of prior to commencing the research (City Health, 2011). As a result of limited resources, only women who are older than 30 years are eligible for free cervical screening. An exception to this is that women younger than 30 years who are HIV positive are also eligible. This is because women living with HIV have an increased risk of developing cervical cancer (Maiman, Fruchter, Guy, Cuthill, Levine, & Serur, 1993; Serraino, Carrieri, Pradier, Bidoli, Dorrucchi, Ghetti et al., 1999). Once again, the disadvantaged position of these women, within a society marked by inequality, is highlighted by this information.

A lack of availability of information about cervical cancer and preventative screening emerged as a key barrier preventing women from attending Pap-smears:

Participant 16: I think that that it's information, that info we don't know, and myself I don't realise that it's starting probably, that information doesn't really go to especially, we most of the women, we not really well educated or educated can you say, so there's no one who goes and give us that information that you have to go.

The barrier of formal education again refers to the disadvantaged position of these women. Consequently, many of these women have never and may never be given the opportunity to be educated on their health and illness prevention options. The women identified not being

exposed to information regarding cervical cancer and screening as a reason for not attending Pap-smears.

Psychosociocultural barriers. Psychosociocultural barriers are factors which relate to the socialization and background of the women interviewed in the present research (Lee, 2000). Psychosociocultural barriers were identified as the fears, thoughts, and feelings that the women had around clinic attendance and test procedure.

Women reported that fear relating to undergoing such an invasive procedure deterred them from attending a Pap-smear. Associated with fear were feelings of uncertainty and confusion.

Women were unsure about why they were undergoing the test:

Participant 9: I don't think they really explain to people what it is... (silence) so u just do it because the nurse told you to do it, you don't really understand what it is

Women related their fear of feeling uncomfortable and not knowing enough about the procedure as is demonstrated in a conversation between two of the women:

Participant 1: I am feeling, uhm uh uncomfortable

Participant 12: we not sure because don't know anything

In addition, the women were worried about what stigma would be attached to them if they attended a clinic for Pap-smear screening. Women mentioned that other community members may speak about them in a negative manner if they were seen going for a Pap-smear. To some women this was a concern, while to others it was a barrier which they could overcome.

Participant 1: yes, peoples going to say about you when you go there...

Participant 4: (slight laughter) I feel fine cos I don't care what they say

Participant 6: it's a secret between you and that person that is actually doing the Pap-smear

This concern may have been related to negative associations with Pap-smear testing. For instance, the fact that only HIV positive women who are younger than 30 years are eligible for Pap screenings, may deter younger women from undergoing screening for fear of revealing their positive status' (Carr & Gramling, 2004; Taylor, 2001).

Across all the focus groups it emerged that there was an effect of both personal and social barriers which influenced cervical screening behaviour in women. Fear was strongly evident as a barrier across all focus groups. This finding is consistent with previous research which has identified fear surrounding the process of Pap-smear testing as contributing to a lack of 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). Factors such as health education and time, which were identified across

all focus groups, have also been cited by other studies as barriers to cervical screening adherence (Byrd et al., 2007; Fylan, 1998; Lee, 2000; Markovic et al., 2005; Ogedegbe et al., 2005; Thomas et al., 2005). A significant contributor to the development and perpetuation of these barriers is knowledge. This is because inaccurate knowledge regarding cervical cancer and screening prevents women from making accurate evaluations of their risk as well as contributes to their screening related fears. The above structural and psychosociocultural factors which inhibited screening adherence are in agreement with the barrier factor that the HBM identifies as affecting behaviour change (Strecher & Rosenstock, 1997). In addition to the above structural and psychosociocultural factors, several facilitators of screening adherence were identified.

Facilitators to Screening Service

Facilitators can be defined as environmental or bodily events which encourage women to attend cervical screening. This theme can be divided into two subcategories, namely, information sources and physical state.

Information sources. Women received their information about cancer and Pap-smears from informal as well as formal sources. Formal sources included information gained via radio and television broadcasts as well as information gained at a clinic. These formal sources were focussed on providing information which was specific to cervical cancer and cervical screening and created a desire in the women to either attend screening or to seek more information on cervical cancer and screening. Information received from a clinic was the most frequently cited of these sources.

Participant 8: they always talking about the cancer at the clinic, and about the Pap-smear...if you go to the clinic they will tell you about, and there is the signs there they say talking about the Pap-smear

Participant 5: I go to the clinic because I hear to the radio cervical cancer and the breast cancer all the women they must wake up and go to the clinic in order to check

However, radio and television were often cited as sources of information regarding cervical screening:

Participant 5: I don't understand cervical cancer...I want to know about it, ja, I hearing it on the radio, on or TV, at the clinic, whatever, but I don't know about it, I want to know about it

Participant 11: I've never heard about it ever, the only time I heard about it was on the radio, and that's the only time

Informal sources, which are sources not supplied by the media or clinics, included the experiences of a family member with cancer and the observation of individuals with cancer in their work environments. Many women spoke about their experiences of witnessing an employer being diagnosed and treated for cancer. It is noteworthy that when relating their experiences and perceptions gained from informal sources the women in the focus groups rarely spoke about cervical cancer, only one woman did so, but rather they spoke about cancer in general. These sources contributed to a general awareness about cancer among the women.

Participant 8: I heard the cancer in 1994 when my mother she start getting sick, and my father he taking to the doctor in East London and they didn't do the Pap-smear, at that time, it was 1995,4, 1995, and she passed away 1995...

Participant 5: my cousin's sister had the breast cancer, and she is still alive, they cut my sister's breast and she's still got a hole on her breast...My boss, she had made the, the operation on May for the breast, is taken off the breast, yes is still alive

The above findings showing the importance of small media as sources of information on cervical cancer and preventative screening are consistent with previous research. It has repeatedly been shown that small media are frequently cited as primary sources of formal information in this regard. In addition, effective interventions to increase screening adherence have been shown to use small media to some degree (Baron, Rimer, Breslow, Coates, Kerner, Melillo et al., 2008; Forte, 1995; Markovic et al., 2005; Pasick, Hiatt, & Paskett, 2004). Furthermore, the source of the information about cervical cancer and screening that women receive has been shown to have a significant effect on their adherence to cervical screening. Most notably, a health provider recommendation has repeatedly been found to be a key motivator, especially within underserved populations (Hislop et al., 1996; Kelaher et al., 1999; Ogedegbe et al., 2005; Taylor et al., 2004).

This is particularly significant when considering the context from which our participants came. During informal discussions with the women it was discovered that within many informal settlements medical service provision is poor and women frequently do not have adequate access to medical clinics. In light of this, it is very concerning that the clinics were the most frequently cited sources of formal information as well as they appear to be the most effective in motivating behaviour change, as a large majority of the women in informal settlements may not have the opportunity to receive information from clinics.

Physical state. The women referred to four main facilitators of cervical screening regarding their physical state: the presence of symptoms, the relief of symptoms, the presence

of another physical illness and the desire to know that one is healthy. The following woman spoke of physical symptoms as encouraging screening adherence:

Participant 5: when you are feeling different maybe you got the pains, the abdominal pains, and you go to the doctor and check, to make a check up

A commonly cited facilitator of cervical screening was the relief of undesirable physical symptoms:

Participant 7: I often got stomach pains as well, but it all stopped after Pap-smears

Participant 14: because I always had this discharge but then I did the Pap-smear and then it stopped...

Participant 8: you check if you have the pains and after you don't have it

With regards to the presence of another physical illness, this woman spoke of her HIV diagnosis as a facilitator to screening:

Participant 8: uhm I'm going to tell you the truth...I'm going to the clinic...in 2002, because they was talking about the HIV. And I went to the clinic in Sunvalley, it was 2002 in October. I went to test for HIV ...they find out that I am positive, that is fine. Now I went to test for Pap-smear.

Finally, many women expressed a desire to know their physical health status and reported that this acted as a facilitator to undergoing screening.

Participant 15: me, to check my womb, to see if it's still perfect in the right place, position, no infection

Participant 14: so for me it works because when I do get the results back I get to see whether I have cancer or anything wrong with my womb

Participant 2: I want to know I'm safe

The findings that the presence of physical symptoms and a desire to know one's health status are facilitators to cervical screening adherence are consistent with previous research (Agurto et al., 2004; Byrd et al., 2007; Lee, 2000; Markovic et al., 2005). The tendency for women to only seek cervical screening once they are experiencing symptoms has been well documented. Research has shown that women frequently believe Pap-smears to be a test for existing cancer (Fylan, 1998; Hislop et al., 1996; Markovic et al., 2005). As a result women will frequently only undergo screening once they are suffering from a reproductive health difficulty such as vaginal bleeding or discharge (Lee, 2000; Markovic et al., 2005). This finding further emphasises the importance of information as a barrier to cervical screening behaviour among women living in informal settlements, as a lack of

awareness as to the preventative nature of cervical screening is at the root of this tendency to only seek treatment once physical symptoms are experienced.

The findings that the experience of symptom relief subsequent to having a Pap-smear and the presence of another physical illness were important facilitators were unique to this research. It has not been found in previous research that women report the relief of undesirable physical symptoms as a facilitator of cervical screening. Additionally, this finding is of particular interest because Pap-smears are for screening purposes only and are not used for treatment and symptom relief. A possible explanation for the negative symptom relief experienced by these women is that health providers may be identifying and treating infections without adequately informing the patients about what is taking place.

All references to the presence of another illness as a facilitator to screening are related to a positive HIV status. Taking South Africa's current battle with the HIV epidemic into account, it is not surprising that this has become a facilitator. HIV is associated with an increased risk for the development of cervical cancer, a more advanced and aggressive disease presentation as well as a poorer prognosis (Maiman et al., 1993; Serraino et al., 1999). For this reason, clinics have prioritised this high-risk population.

Knowledge

An overarching theme which emerged in the data across all four focus groups was poor knowledge about cervical cancer and screening behaviours. If women have inadequate knowledge about prevention and cervical cancer they are not likely to present for screening (Markovic et al., 2005). Three sub-themes emerged from the data; knowledge about disease risk, view of cervical cancer, and knowledge about Pap-smears.

Knowledge about disease risk. Knowledge about disease risk was defined as the actions that the women believed to place them at risk of developing cervical cancer. Women identified being HIV positive and sleeping with multiple partners along with smoking, heavy drinking, unhealthy eating and being above the age of thirty as factors placing them at risk for the development of this disease. Women in this focus group discussed what the factors which they thought placed woman at risk for contracting cervical cancer:

Participant 1: but I heard that when you are HIV positive, but I heard at the clinic when you are HIV positive you have to check your Pap-smear after you have delivered the baby

Participant 5: I think cervical cancer sometimes is the transmission of the disease, is going to sleep with another... a lady is roaming about, the ladies is sometimes has got the infection, not to go the clinic I thinks can make the cancer

Women in another focus group believed the following behaviours to place a woman at risk for cervical cancer:

Participant 6: like smoking

Participant 5: drinking too much...or eat, you not eat like healthy food

Participant 9: it's common in ... mostly in women above the age of 30

Although most of the knowledge the women had was accurate, the knowledge that the women conveyed tended to relate to their conceptions of healthy behaviour in a general sense. There was an absence of an accurate and detailed understanding of cervical cancer. This theme has support from the HBM and is directly related to the HBM's perceived susceptibility factor. Perceived susceptibility is defined as an individual's assessment of the probability of suffering from a condition which would negatively affect his/her health (Strecher & Rosenstock, 1997). In relation to the current research, it is only logical that a woman's knowledge regarding cervical cancer risk factors would influence her perception of her own personal risk of developing this disease.

View of cervical cancer. Views of cervical cancer are the women's subjective perceptions and feelings about contracting this disease and the seriousness of not being treated. Women felt that death was an inevitable outcome of cancer as there is no cure for cancer. Additionally, when asked about cervical cancer, women associated vaginal discharge and sexually transmitted diseases (STIs) with the illness:

Participant 6: if they do find it in any part of the body, there's no cure for it, you die when they have found the cure too late

Participant 7: she died and it was too late to get a cure

Researcher: Just cancer, do you think about anything else with the Pap-smear?

Participant 3: discharge

Participant 1: STIs

The severity of the disease was considered very high amongst all focus groups and the women identified death as the outcome of being diagnosed with cervical cancer. The theme identified can be seen to influence behaviour decisions in the same way as the factor of perceived severity in the HBM.

Knowledge about Pap-smears. Some of the women had accurate knowledge of the Pap-smear test procedure, but the majority failed to correctly identify the test's function. The women believed that Pap-smears are a means of reducing bodily pains and discharge, as well as something necessary before sterilisation. Women attributed this knowledge in relation to having experienced a type of pain which post the test disappeared:

Participant 6: I've stopped having hip pains after doing Pap-smears

Participant 7: I often got stomach pains as well, but it all stopped after Pap-smears

Participant 8: you check if you have the pains and after you don't have it

Participant 14: because I always had this discharge but then I did the Pap-smear and then it stopped...

Many of the women believed that a Pap-smear test was a positive test which would benefit them:

Participant 6: Pap-smear makes everything right

Participant 15: me, to check my womb, to see if it's still perfect in the right place, position, no infection...

Participant 5: your result is abnormal, you find out you've got it, you've got the cervical cancer, if the result is normal you've got the normal, you are healthy

Many women had inaccurate knowledge regarding the function and benefits of a Pap-smear test. In addition, the women cited many benefits that they could receive from undergoing screening. In this way, knowledge acted as a facilitator of screening adherence. This finding is consistent with previous research which has identified a lack of awareness of screening benefits as a barrier to screening adherence (Fylan, 1998). Moreover, these findings further support the already existing research which highlights a lack of knowledge as a key barrier to cervical screening in South Africa (Pillay, 2002). This further emphasises the importance of awareness and knowledge of cervical screening tests as a means of improving adherence among black women living in South African informal settlements.

Limitations and Recommendations for Future Research

As language constructs and shapes rather than describes an individual's reality and experiences, a limitation of this research was its reliance on language (Willig, 2001). In the proposed research the researchers' stipulation that the focus groups be conducted in English inhibited the extent to which the women could comprehensively relate their experiences. Many of the participants' English proficiency was limited, for this reason, the experiences conveyed to the researchers were constrained as were the researchers' abilities to appropriately respond and reflect when the women expressed themselves in isiXhosa. This being said, the researchers are aware that the accounts they received were only interpretations and representations of what the women actually experienced.

A further limitation of this research is that the researchers were unaware of what the participants were being told about the meeting by the recruiter. This may have influenced the

participants' perceptions of what the purpose of the focus group was and therefore affected the type of data that was produced.

Finally, the use of the Health Belief Model as the theoretical framework underlying this research has several limitations. Firstly, this is a Western model that was developed from and based upon the experiences of Western populations. Consequently, our use of this model as a basis for our focus group questions forced a Western conceptualisation of health behaviour change onto the underserved, black, African women which took part in our study. The reasons for adopting a behaviour change may be very different for women living in this vastly dissimilar context. This is supported by research showing that although the HBM is a useful framework within which to investigate women's health beliefs, it only accounts for 15% of women's screening behaviour variance and 11% of their intentions to screen (Burak & Meyer, 1997). Secondly, the fact that the focus group questions were derived from this model may have inhibited the kinds of things that the women were given the opportunity to say and as a result, important information about the perceptions and experiences of these women may have gone undetected by the researchers. This being said, the researchers feel that the use of focus groups as a method of data collection mitigated these limitations to some degree. Although the questions were derived from the HBM, the informal discursive nature of the focus groups did provide the women with the opportunity to relate experiences, thoughts and beliefs which were not directly addressed by the question schedule.

In light of these limitations as well as by taking into account the difficulties that the researchers faced in creating a comfortable, safe and open environment for the participants to express themselves, the following recommendations for further research are made. Firstly, in order to create greater community buy-in, there is a need to establish connections with various important community members and stakeholders before the research commences. This will allow for the community to become comfortable with the researchers' presence while giving the researchers credibility. Secondly, the use of co-researchers who are members of the communities and who would be trained as group facilitators, to assist by conducting the focus groups, would be an ideal solution to the problems of language and researcher 'outsider' status. If this is not possible, the focus groups facilitators must be proficient in the African language predominantly spoken by their sample. Finally, a less structured theoretical framework would allow the women more flexibility to discuss topics and express concerns and beliefs which are of most importance to them.

Conclusion

This research revealed several interesting findings regarding the experiences of black women residing in South African informal settlements regarding cervical cancer and preventative screening. Three broad factors, namely, barriers, facilitators and knowledge, were found to influence a woman's decision to adhere or not.

The barriers identified were divided into two groups; structural and psychosociocultural. Structural barriers included time, age, and health education. Psychosociocultural barriers included the fears, thoughts, and feelings experienced by women that were associated with clinic attendance. A crucial structural barrier which is specific to the South African context is that as a result of limited clinic resources, only women who are HIV positive or older than 30 years of age are eligible for free cervical screening. Related to this structural barrier was the psychosociocultural barrier of fear. Two fears associated with clinic attendance emerged. The first was a fear of undergoing an invasive examination and the second was a fear of being stigmatised by one's community. As mentioned, currently in South Africa, a woman who is under 30 years old may only receive free Pap-smear testing if she is HIV positive and therefore, for these women, attending screening amounts to disclosing their status. For this reason, changes in health policy to lower the age at which free screening is available is essential to increasing screening adherence amongst this population. Furthermore, by allowing younger women access to preventative screening, many cancer cases will be identified at earlier stages. Consequently, prognoses will improve and treatments will become more cost-effective

A factor which emerged across all four focus groups as influencing screening adherence was knowledge. A particularly worrying aspect of this factor was a widespread lack of awareness as to the purpose of the Pap-smear test. An absence of health education emerged as a key source of this lack of awareness. What knowledge the women did have was predominantly gleaned through formal sources such as clinics and small media. These formal forms of information delivery emerged as the most effective and interventions aimed at improving adherence among these populations should focus on utilising these. In addition, the risks, benefits and purpose of screening should be thoroughly explained to all women attending clinics. In this manner, when the women are allowed access to Pap-smear testing, they will be more willing to adhere.

In addition to the source of information, several other facilitators relating to the women's physical state emerged. Women related that the presence of physical symptoms, the relief of symptoms, the presence of another physical illness and the desire to know one's physical health status, were all facilitators of screening adherence. The first two of these

further emphasise a lack of knowledge to be a key barrier to screening within this population, as underlying both of these facilitators is inaccurate information as to the purpose of a Pap-smear. Therefore, in order to improve screening adherence this absence of knowledge will need to be addressed. Furthermore, the benefits of screening such as knowing one's physical health status as well as the risk factors of cervical cancer such as the presence of HIV, will need to be highlighted.

In summary, although this study has highlighted the many obstacles to cervical screening, it has identified several factors which are crucial for improving adherence. The researchers believe that health education which is culturally specific will be most effective way of increasing the cervical screening adherence of black women residing in urban informal settlements.

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Appendix A

Information Sheet

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us (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 and experiences of women with regards to Pap-smear testing. It aims to discover what women's views and understandings of this test are, along with how this affects their adherence to screening and treatment recommendations. The information you give us will be used to write a report and 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 join a group discussion with 5 other women, lasting no longer than 60min. This discussion will be tape-recorded and transcribed.

All information which 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 included by which any of the participants in this study can be identified. The data may also be looked at by authorised medical professionals to ensure that the study is being carried out correctly. All these individuals will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research team.

We are students from the University of Cape Town. We are not connected to or working for any hospital or service delivery programme. We will not be giving any personal details that you give to us 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.

The results of this study will be analysed by members of the research team (listed below) and be used to understand the barriers to adherence of screening for cervical cancer. We cannot

promise the study will help you personally, but the information we get might help improve future medical screening. Once the study is completed, you can also arrange for a copy of these findings to be mailed to you (by post or electronically) by contacting one of the researchers listed below.

Benefits

The benefit of participating in this research is that you will be given a chance to voice your experiences and tell the researchers about parts of the medical service that you are satisfied or dissatisfied with. Your information will form part of the researchers' understanding of cervical cancer screening. You will not be paid money for your participation but a Shoprite Checkers voucher and tea and biscuits will be provided.

Risks

There are no major foreseeable risks to participating in this research. All information will remain strictly confidential from the side of the researchers. However, the researchers cannot ensure that the confidentiality will be maintained by the other women participating in the focus group.

When you have read this information sheet, and if you sign the consent form, you can take the duplicate copy of this information sheet along with the duplicate copy of your signed consent form 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 us on 082 560 8920/082 940 8053 or our research supervisor Dr. Despina Learmonth on 021 650 3420.

If you would like to contact a counsellor to talk further about your experiences, you can contact Miss Salie from Victoria Hospital on 021 799 1160.

Thank you.

Chantelle De Abreu and Hannah Horsfall

Thank you very much for taking part in this study.

Appendix B

Consent Form

Please tick box

- | | | |
|----|---|--------------------------|
| 1. | I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. | 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. | <input type="checkbox"/> |
| 3. | 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. | <input type="checkbox"/> |
| 4. | 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. | <input type="checkbox"/> |
| 5. | I agree to take part in the above study. | <input type="checkbox"/> |

| | | |
|---------------------|------|-----------|
| | | |
| Name of Participant | Date | Signature |
| | | |
| Researcher 1 | Date | Signature |
| | | |

Researcher 2

Date

Signature

Appendix C
Focus Group Protocol

Women who have Undergone Screening

1. What does it mean if someone is healthy?
2. What or who do you think controls one's health and illness? What makes someone healthy?
3. What do you know about cervical cancer?
4. What does your family think about cervical cancer and having a Pap smear? Did you tell them that you were having a Pap-smear?
5. Do you think that some people get cervical cancer more easily than others?
6. Do you know anyone with cervical cancer?
7. What do you think it is like to live with cervical cancer?
8. Do you think cervical cancer can be prevented?
 - If yes- how?
 - If no- why?
9. Do you think that you will know if you have cervical cancer?
10. Why do you think many women have not had a Pap smear?
11. What do you think a Pap smear is/does?
 - What does an abnormal result mean?
12. Why did you decide to go for a Pap smear?
13. What was it like to get a Pap smear?
14. Would you go again?
15. How did you feel about the clinic and the sister?
16. Did anybody tell you about Pap-smears?
17. What do you think will help more women to have Pap smears?

Women who have not Undergone Screening

1. What does it mean if someone is healthy?
2. What or who do you think controls one's health and illness?
3. What do you know about cervical cancer?
4. What does your family think about cervical cancer and having a Pap smear?
5. Do you think that some people get cervical cancer more easily than others?
6. Do you know anyone with cervical cancer?
7. What do you think it is like to live with cervical cancer?
8. Do you think cervical cancer can be prevented?
 - If yes- how?
 - If no- why?
9. Do you think that you will know if you have cervical cancer?
10. What do you think a Pap smear is/does?
 - What does an abnormal result mean?
11. Why didn't you go for a Pap smear?
12. Has anybody ever told you about Pap-smears?
13. What do you think will help more women to have Pap smears?

Appendix D**Arrival Questionnaire**

Name: _____

Surname: _____

Age: _____

Nationality: _____

Telephone number: _____

Marital status: __ Single __ Married __ Widowed
 __ Living together

Number of children: _____

Number of people living in home: _____

Highest education: __ Primary School __ High School __ College
 __ University __ Other

Employment: __ Employed __ Unemployed

PLAGIARISM DECLARATION

Plagiarism – this means that you present substantial portions or elements of another’s work, ideas or data as your own, even if the original author is cited occasionally. A singed photocopy or other copy of the Declaration below must accompany every piece of work that you hand in.

DECLARATION

1. I know that Plagiarism is wrong; Plagiarism is to use another’s work and pretend that it is one’s own.
2. Each significant contribution to, and quotation in, this essay/report/project from the work or works of other people has been attributed, cited and referenced.
3. This essay/report/project is my own work.
4. I have not allowed, and will not allow anyone to copy my work with the intention of passing it off as his or her own work.

NAME: Chantelle De Abreu and Hannah Horsfall

SIGNATURE:

STUDENT NUMBER: DBRCHA002 and MCCHAN001