Assessing perceptions – Addressing (mis)conceptions: An exploration of interventions to address the health needs of female teenagers affected by Bilharzia

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COLLEGE OF HUMANITIES

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I ... Duduzile Charol Zwane........declare that

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Acknowledgements

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Female Genital Schistosomiasis (FGS) commonly referred to as Female Bilharzia (FB) is caused by a waterborne parasite that is endemic in KwaZulu-Natal (KZN) South Africa. It has a prevalence of approximately 30% amongst females under the age of 20 years old in the Ugu District, KZN. Schistosomiasis causes morbidity and preliminary studies have suggested that there may be an increased risk of HIV amongst those infected. The Female Bilharzia Project has been proactive in combating the adverse effects of the disease through research amongst those affected in this area. This study seeks to unveil improvements to the project’s existing communication strategy, in order to address the health needs of the female teenage segment that it targets. The topic of FB is sensitive and the potential for increasing stigma is a concern. Furthermore, the issue of finding the balance between maintaining confidentiality whilst trying to communicate publicly about Schistosomiasis is a delicate one. To counter this, this study seeks to identify and discuss the value of the optimum communication channels (namely schools, peers and family) and modes of communication (such as print media, text messages to cell phones). Data gathered through the use of participant observation and face-to-face interviews was instrumental in suggesting strategic communication interventions suitable for teenage girls aged 16 years and older. In this way they can be given a voice and the impact of the disease on their lives can be established and addressed. Through a random selection of schools located in rural and semi-rural areas of the Ugu District areas, the study evaluates the current communication channels in order to suggest considerations for the way forward. Principles from the participatory development communication paradigm, lessons from health campaigns and Albert Bandura’s social learning theory provide the conceptual framework within which the Female Bilharzias’ communication approach is evaluated. It was discovered that more targeted communication was required in order to clear many of the young women’s misguided perceptions about Bilharzia. Although moderate success has been achieved in this regard, the social constraints impeding a clear understanding of this issue were outlined.
## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABC</td>
<td>Abstain, Be Faithful &amp; Condomise</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>BCC</td>
<td>Behaviour Change Communication</td>
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<tr>
<td>CCMS</td>
<td>Centre for Culture, Communication and Media Studies</td>
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<tr>
<td>CFPD</td>
<td>Communication for Participatory Development</td>
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<tr>
<td>DoE</td>
<td>Department of Education</td>
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<tr>
<td>DoH</td>
<td>Department of Health</td>
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<tr>
<td>DramAidE</td>
<td>Drama Aids Education</td>
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<tr>
<td>EE</td>
<td>Entertainment Education</td>
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<tr>
<td>FB</td>
<td>Female Bilharzia</td>
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<tr>
<td>FGS</td>
<td>Female Genital Schistosomiasis</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HTC</td>
<td>HIV Counselling and Testing</td>
</tr>
<tr>
<td>JHHESA</td>
<td>Johns Hopkins Health and Education in South Africa</td>
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<tr>
<td>IUD</td>
<td>Intra Uterine Device</td>
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<tr>
<td>KAP</td>
<td>Knowledge-Attitude and Practice</td>
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<td>MMC</td>
<td>Male Medical Circumcision</td>
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<td>NCS</td>
<td>National Communication Survey</td>
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<td>NGO</td>
<td>Nongovernmental Organisation</td>
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<tr>
<td>PAP Smear</td>
<td>Papanicolaou smear</td>
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<td>SCC</td>
<td>Social Change Communication</td>
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<td>STD</td>
<td>Sexually Transmitted Disease</td>
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<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>VT</td>
<td>Virginity Testing</td>
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<td>WHO</td>
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Chapter One: Introduction

Female Bilharzia communication: listening to the voices of the previously unheard

The world we inhabit is rife with diseases that effectively impede people’s quality of life. What makes this fact more distressing is that in many instances these diseases are easily preventable, manageable and treatable. An example of such a disease is Female Genital Schistosomiasis (FGS) commonly referred to as Female Bilharzia (FB). Aspects regarding the communication of the risks and treatment of FB as well as the perceptions of this disease will be explored in this dissertation. Exploring diverse ways of effectively communicating with a minority group of females who are extremely susceptible to FB is the primary goal of this study. Numerous studies have been dedicated to understanding the thought processes that influence young women’s attitudes towards their health. Scholars such as Kirby (2002) and Hindin and Fatusi (2009) have examined this subject extensively. However, evidence of studies that endeavour to actively listen to their viewpoints – and afford them the level of seriousness they are worth – is limited. This study is amongst the first to address this challenge. This chapter aims to convey the motivations behind the decision to conduct this research as well as provide a brief discussion of my role as the researcher.

In the past, many development projects have entered communities with predetermined notions of the community members’ needs (Dyll 2004). They neglected to understand two essential principles that need to be adhered to by any developmental initiative seeking to create change. They are “two way communication and cultural sensitivity” (Dyll 2004:8). These principles are the cornerstone of any successful developmental project (Dyll 2004). Therefore, as a researcher within such a project, the changes that may materialise following the completion of this dissertation will come as a result of mutual knowledge exchange between myself and the female participants. Being a researcher that has an understanding of FB does not translate into being an authority on the best way to communicate about it.

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1 FGS, FB, Bilharzia are terms that are used interchangeably throughout this dissertation.
2 “A culturally, ethnically, or racially distinct group that co-exists with, but is subordinate to a more dominant group. As the term is used in the social sciences, this subordinancy is the chief defining characteristic of a minority group” (EncyclopediaBritannica.com2008). Available at: www.britannica.com/EBchecked/topic/384500/minority Accessed: 15 October 2012
Therefore, listening to the suggestions of the affected group about the best way to go about this is vital. Succinctly put, I am a communications researcher deployed into the Female Bilharzia Project, in order to assess prevailing perceptions about Bilharzia\(^3\). Once they have been established, the responses received from participants will generate ideas that will be integrated into a public health campaign. It is anticipated that the campaign will simultaneously alter misconceptions around FB and address various communication needs. As the wider project in which my dissertation research is embedded is not from within the community, it is difficult for the project, at the outset, to fully understand the participating communities’ cultural norms. As this wider project addresses health issues that may be of a sensitive nature, it is essential that there is an effort to understand these norms in a culturally appropriate manner. It is thus crucial to collaborate with participants from the area where the project operates. It is only through participants’ guidance that the study’s objectives may be fulfilled. Therefore, like my predecessors in the development communication field, it is important to re-iterate that: “I do not aim to speak on the community members’ behalf, but rather to offer my interpretation of the knowledge I have gained of their circumstances made possible through a dialogue” (Dyll 2004: 6).

**Context of the Study**

This study is located in Ugu District, Port Shepstone, KwaZulu-Natal (See Appendix A). This is a coastal area that boasts a population of 704 028 people with females comprising 54% of this figure (Ugu 2010:1\(^4\)). Access to sanitation and water is poor and stands at 18.1% and 49.2% respectively (Ugu 2010:2). This is a possible explanation for the Bilharzia prevalence in the area. It is a place rooted in Zulu culture and tradition as demonstrated by the 18 traditional leaders in high ranking positions throughout the area (Ugu 2010:1). These traditional authorities occupy 3450 square kilometres of the land (Ugu 2010:1). Their strong presence may indicate the high regard in which the cultural values they represent are held. In fact the Ugu District demonstrates its pride in its culture by practicing customs that are perceived by many as outdated. An example of such a custom is the controversial virginity testing (VT) (Taylor *et al.*, 2007). It is a practice that is important to this study for reasons that will be elaborated on below.

\(^3\)Ethical Approval for this study was granted based on this objective (See Appendix B)

The locals are incredibly protective of VT as a result of it being an inherited practice that is under constant public criticism (Taylor et al., 2007). Critics believe that it is unsanitary, scientifically unsound and an encroachment on an individual’s human rights (Taylor et al., 2007). Furthermore they have stated that it subjects females to treatment that undermines “gender equity” (Reuters 2001 in Taylor et al., 2007:27). Despite this negative perception a study conducted in the Ugu District that involved 846 Zulu speaking females aged 16 years and older, revealed that 70.5% of them were in favour of it (Taylor et al., 2007). The young females and their parents alike were confident in VT’s ability to combat the growing HIV and AIDS crisis (Taylor et al., 2007). This is relevant because the participants that were part of this study needed to consent to a gynaecological exam in order to detect FB. Due to the similarity of the examination to VT, discovering the best way to manage any misunderstandings that might arise around this procedure was a further goal of this study. The previously mentioned statistics suggest that Ugu District is a conservative area that needs to be approached cautiously due to the ease with which this medical practice can be misinterpreted.

Also important to note within the Ugu District is the gap between the rural and urban population. It is extremely wide since 84% of the locals inhabit the latter whilst a meagre 16% can be found in the former (Ugu 2010:1). The educational status of the locals is moderate with 64% of them not progressing further than Grade 12 (Ugu 2010). However, for the purposes of this study, the participants’ level of education is adequate because many of them are literate (Ugu 2010). Regarding their socio-economic status, many of the locals have “poor access to economic opportunities and social services (Ugu 2010:2). As a result a large number seek employment “in the agricultural and domestic sectors” (Ugu 2010:2). Amongst the main health issues in the district are tuberculosis (TB) and HIV and AIDS (KZN Department of Health 2012). Minor infectious diseases in the area include chicken pox (KZN Department of Health 2012).

**Background and Rationale for the Study**

In his 1976 evaluation of the communication field, scholar Everett Rogers predicted that in the years that would follow, communication research would “illuminate the new pathways to development” (Rogers 2006: 125). Thirty six years after his assertion was made research indicates that his foresight was accurate. This is evidenced by numerous communication studies and programmes that have led to major social change breakthroughs (Gumucio-
Dagron and Tufte (2006). This study aims to further demonstrate the accuracy of Rogers’s words by exploring the possible social change achievements that can be realised when the communication and bio-medical fields are combined. This will be done by interacting and researching with participants of the FB project and utilising their feedback in order to suggest communication considerations that can be factored into the construction of a public health communication campaign.

The FB project is an international research initiative that aspires to broaden its reach throughout South Africa and this study is initiated with their support. Its main aim is to heighten awareness about FB and thus prevent the incidence of gynaecological lesions. It is hoped that the findings obtained through this study will assist the FB project in its objective to raise mass consciousness about FB. The works of researchers, pioneering medical practitioners within the FB research field will be employed extensively during the introduction of FB and the discoveries made about it thus far. Due to their being at the forefront of FB research these experts’ work forms a critical component of this dissertation.

I am well positioned to conduct this study because my interest in health communication originates from prior exposure to the Communication for Participatory Development (CFPD) course at the University of KwaZulu-Natal (UKZN). The course is offered by the Centre for Culture, Communication and Media Studies (CCMS) which is respected internationally for its competence in establishing capable health communication researchers. The course demanded that the researcher be well versed in theories pertaining to CFPD and public health communication. The course assessment is based on an in-depth research project in this field. Undertaking the CFPD honours project equipped me with the tools necessary to cope with the demands of the research environment. Other reasons that support my claim of being well positioned include the fact that I am entrenched in a developmental/research project (that is the FB project) that forms part of wider projects. This then improves the level of access to many resources such as the proximity of experts on FB and gynaecology. Also, the groundwork done by the FB project improved the relations between the local authorities and the researchers affiliated with it.

As the title of this study indicates, getting to the core of misconceptions was a major motivation for embarking on this study. It was known that they existed because the FB

http://ccms.ukzn.ac.za/
project has been operational in the area for a period of three years. During its launch phase it encountered a slightly negative reception from the locals. It was believed that this negativity stemmed from their misunderstanding of its presence in the area. As mentioned earlier FB is a relatively unknown disease in many ways (Schall 1995). Therefore, people’s failure to comprehend the level of risk associated with it, combined with apprehension about the manner in which it is diagnosed, fuelled their negative reaction to the project. Having observed the unfavourable reception from community members, authorities within the FB project recognised the need for improved communication channels, hence their support of this study.

Although the intentions of the FB project were the main source of confusion, it was suspected that to many community members, even the term research was unfamiliar [my emphasis]. Therefore, the communication interventions that will be suggested as part of this study aim to stipulate how best to familiarise people with it. The title of the study does more than convey the issues under examination to the reader. This is evidenced by the unconventional manner in which the word “(mis) conception” is written. It is meant to indicate that by the end of the study existing conceptions of FB, the FB project are hoped to be understood. Once that has been done, communication interventions that address possible inaccurate notions will be suggested, based on the ideas the study generates.

**Partners supporting the study**

The opportunity for the FB Project to conduct its study in the area was made possible through the collaboration of several academic institutions. These universities partnered with local authorities in order to raise awareness, treat and in due course, eradicate the threat of FB. The local partners involved are the KwaZulu-Natal Department of Health (DoH) and the Department of Education (DoE). This particular study, within the wider FB project will focus on working with the female teenage portion of the Ugu District population that the project aims to include. They are crucial to the project’s success and improving channels of communication with them is the first step towards actualising the ultimate objective. This is because the project recognises that they are not passive receivers of information. They understand the challenges in the local context in terms of communication and resources for example, and can aid in finding possible solutions for improving the communication between the project and beneficiary community (Tufte 2003). Other health related reasons for targeting young women (16 years and older) will be elaborated on further in the study.
Research Objectives

The first objective is identifying the strengths and weaknesses of the Female Bilharzia Project’s existing communication strategy [my emphasis]. The FB project has been operational since 2009. Therefore, it is important to identify areas of success in their communication approach as well as those in need of improvement. In order to gain an in-depth understanding of the current communication strategy, I aimed to ascertain participants’ perceptions on the following: the project’s recruitment procedures, the interviews they undergo prior to receiving treatment, the clinical investigations they undergo, and the support (or lack thereof) they receive from the families and peers following their participation in the project. Understanding their motivations for consenting to participate is another issue of interest. The objective here is that the findings obtained from these questions will be integrated into written material. This material may then be distributed during a future health campaign initiated by the project.

The second objective is to ascertain whether or not the current communication strategy successfully addresses the needs of young females from two diverse geographical locations which are rural6 and peri-urban7. I have been embedded in the project since the 3rd of January 2012. Early in my research, I observed that the participants from the more rural areas tend to be more passive whereas those from peri-urban areas are inquisitive and require thorough information about the disease. This may be due to the diversity of their backgrounds and the fact that they may have been socialised differently. This then raises the question of the extent of their exposure to the media. It is important to not only meet their health needs, but to provide a platform where they can voice their perceptions, expectations and or appreciation of the project. Through this study young women can assert their status as active participants in the process of refining communication channels that are intended to help them understand Bilharzia better.

The third objective is to propose a way for the FB project to address stigma related to FB as well as some of the other health services it offers. The most significant of these being the free HIV counselling they provide to those who seek it. Further, researchers understand that due

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6 “Pertaining to less-populated, non-urban areas” - Available at: http://www.allwords.com/word-peri-urban.html. Accessed: 02 Feb 2012
7 “Immediately adjoining an urban area; between the suburbs and the countryside”- Available at: http://www.allwords.com/word-peri-urban.html Accessed: 02 Feb 2012
to the limited exposure the public has to FB, many of them regard it as an obscure disease (Helling-Giese et al, 1996). As a result the vast majority do not understand the possible connection of HIV to Bilharzia (Kjetland et al, 2012). Therefore, the challenge is to find the balance between communicating the possible ill effects of Bilharzia and HIV, without stigmatising those who may be diagnosed with it (Guttman and Salmon 2004). Nurit Guttman and Charles Salmon (2004:544) believe that a stigmatised individual may experience feelings of “self-blame and destruction” and on account of their age, participants may be more emotionally vulnerable. It is, therefore, important to understand whether the project has a communication approach that is tailored to address sensitive, and in some ways taboo issues in a manner that avoids inflicting emotional distress of any kind (Guttman and Salmon 2004).

Structure of dissertation

The first chapter provides a concise context for the study. It has also introduced the study’s objectives and issues under investigation. Chapter Two consists of a review of the most pertinent literature about topics that are relevant to the study. These include previous and current articles about Bilharzia and HIV, expert opinions on the merits of combining communication and bio-medical fields (Scalway 2010), and different viewpoints about approaching teenage sexual and reproductive health (Hindin and Fatusi 2009). In order to contextualise my study, it also explores successful health campaigns, including several controversial ones. Chapter Three examines a range of potential solutions to the problems being examined that are grounded in theory. The theories include the social cognitive theory, particularly the concept of self-efficacy (Bandura 1995; 2004), and the possible measures that can be employed in order to cultivate and maintain it in the participants. Also, inculcating a mindset of empowerment (Servaes 1999) through the use of principles from prominent advocates of the participatory development communication/paradigm will be explored (Melkote and Steeves 2001). Chapter Four is the Methodology section which outlines the logic behind my selection of participants and the tools employed in order to obtain the final results. Further, this chapter explains the way in which the collected data will be analysed. Chapter Five presents the findings of the study and analyses them on the basis of the theories that frame it. Chapter Six contains the conclusions and suggested communication interventions that can be implemented into the project’s public communication campaign.
Chapter Two: Literature Review

This chapter aims to provide a critical appraisal of research conducted in different parts of the world about Female Bilharzia (FB). It will compare and contrast the conclusions drawn about it and then highlight the findings that can add value to the Female Bilharzia Project. Due to communication being central to this study, this section also examines different viewpoints on public health communication as a field and its relevance or connection to the biomedical field. Following that, literature on communicating with the youth about sensitive issues such as HIV and reproductive health will be reviewed. To conclude, various expert opinions on guidelines to follow during the development of a public health communication campaign will be explored.

Introducing Female Genital Bilharzia

Female Bilharzia is a disease that can be acquired following exposure to fresh water sources harbouring the *Schistosomahaematobium* parasite (Kjetland et al., 2012). Although its presence has been identified in other parts of the world, it is highly prevalent in Sub-Saharan Africa, with an estimated 33% to 75% of women being afflicted by it in highly endemic areas (Hotez et al., 2009:2). In the Ugu District where the FB project is based, preliminary results indicate that the prevalence is 30 % (Kjetland et al., 2012; Thomassen Morgas et al., 2010).

Despite these high figures Bilharzia does not obtain as much public coverage as other diseases such as perhaps Malaria (Hotez et al., 2009). The little knowledge that exists about it appears to be based on unsubstantiated stereotypes as opposed to concrete medical facts. Research conducted in Brazil, for example, shows it is accepted as a condition that is “restricted to populations of the less affluent classes [and] is related to poor life conditions [and] to areas lacking basic services” (Schall 1995:229). As a result, it is ignored instead of being acknowledged as a serious medical problem (Kjetland et al., 2012).

Studies also indicate that FB was initially discovered in the early 1950s yet the medical community fully understood its severity during the “last two decades” (Hotez et al., 2009:3). This further emphasises its reputation as a “neglected disease entity” (Helling-Giese et al., 1996:225). According to Helling-Giese et al (1996), FB manifests itself in different ways in the human body. It is associated with problematic menstrual cycles, sexual intercourse complications, severe abdominal pains and symptoms that resemble those of STDs and...

**FB and its possible connection to HIV**

The FB parasite’s preferred areas of habitation in the body are the urinary tract, genitals, with the cervix, fallopian tubes and vagina as the most common sites (Hotez et al, 2009; Kjetland et al, 2012). Recently, scientists have identified chronic lesions in these parts that they have termed “sandy patches” due to their resemblance to actual sand (Feldmeier 2001:33). These so called sandy patches are problematic due to the belief that they provide an “entry point for the HIV virus” (Kjetland et al, 2012:61). This may be due to the fact that they are essentially deep wounds in the cervix which become a passage way for HIV to filter through.

A study of a rural community in Zimbabwe corroborates findings on the heightened vulnerability to HIV in women with FB related lesions (Hotez et al, 2009; Kjetland et al, 2008). The study found that “women aged 20 to 49 with FB exhibit a threefold risk of having HIV relative to women without FGS” (Kjetland et al 2006: 741). Furthermore, due to the lesions being prone to bleeding upon contact, there is a probability of HIV entering the body via the bloodstream (Hotez et al, 2009; Kjetland et al, 2012).

Helling-Giese et al (1996) state that: “it is impossible to differentiate FGS of the cervix from the cancer lesions by microscopic appearance alone”. This suggests that the possibility of being misdiagnosed for FB, or for it to remain undetected, is high because in an African setting, access to sophisticated medical equipment is limited. This assertion is corroborated by Feldmeier et al (2001:31) when they state that “so far the only reliable means to diagnose genital schistosomiasis in women is through a biopsy of the cervix”. Yet this method is “wholly inappropriate in a primary health care facility and difficult even in an out-patient setting” (Feldmeier et al, 2001:31). This is because it may carry an increased risk of HIV acquisition until the wound has healed.

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8The FB project does not campaign to inform teenagers that they are susceptible to HIV via schistosomiasis as this direct link is still being researched. However, the likelihood of this relationship has been noted (Kjetland et al, 2006-2012).
These statements were made following the results of research that was conducted in a public hospital in Malawi in order to ascertain the efficacy of PAP smears in detecting FB. This is the only gynaecological diagnostic test available to the general public and it is not satisfactory for Bilharzia diagnosis (Feldmeier et al, 2001). Fifty one local women of child bearing age consented to participating in the study after their urine tested positive for *S.haematobium* (Feldmeier et al, 2001). Following meticulous examination the results revealed “a disappointingly low sensitivity of endo/ecto cervical PAP smears to diagnose women with cervical schistosomiasis” (Feldmeier *et al*, 2001:32). From this we can gather that FB is a disease that can be silently destructive because of the difficulty associated with its identification. As a result of this it may become crucially important to alert young women to the importance of early diagnosis in order to avoid the possible combined HIV and FB risks. With regards to HIV, it is common knowledge that early detection can significantly expand an infected individual’s life span. Since the Female Bilharzia Project recently began offering HIV counselling, this study hopes to investigate the level of awareness women have about the connection of HIV to FB. The findings will be helpful during the process of creating a communication strategy. The sample can assess young women’s attitude towards HIV counselling, whether or not there is stigma\(^9\) attached to it and whether they believe it is a worthwhile service.

*FB treatment*

Treating FB may be easier if it has been detected before the damage has become severe (Hotez *et al*, 2009; Kjetland *et al*, 2012). Thus far the World Health Organisation (WHO) approved drug Praziquantel is prescribed for the treatment of most strains of Bilharzia (WHO 2011; Kjetland *et al*, 2012). Praziquantel is almost unrivalled in its position as the preferred drug for treating Bilharzia because it is “both a highly effective and low cost anti-schistosomal therapy” (Hotez *et al*, 2009:4). Although Praziquantel eradicates existing Bilharzia worms in the body following repeated dosages and prevents the development of new schistosomiasis eggs, it will not heal the lesions that have already developed (Kjetland *et al*, 2012). Kjetland *et al* (2012) indicates that the lesions remain open thus making the affected individual susceptible to re-infection and HIV despite repeated rounds of Praziquantel.

\(^9\)Erving Goffman (1963:5) suggests that the modern concept of stigma is a feature that “acts as an undesired differentness”. This concept will be discussed more fully further in the dissertation.
Optimum treatment results are dependent on several factors. These include the age of the individual, the advancement of the disease prior to treatment, and its location in the body (Kjetland et al, 2012). Most significant about Kjetland et al’s (2012:63) study is their work indicates that “in younger patients...lesions are more responsive to treatment”. The accuracy of their hypothesis was demonstrated in Burkina Faso where a single dose of Praziquantel was found to reduce the prevalence of S. haematobium by 84% in young girls (Hotez et al, 2009). In other parts of sub-Saharan Africa similar rates of success were achieved (Hotez et al, 2009).

Hotez et al (2009) then argue that treating young girls early should be prioritised in order to curb the progression of the disease into aggressive FB. Furthermore, they argue that early treatment presents “an innovative AIDS prevention strategy in areas of HIV and S. haematobium” (Hotez 2009:4).Hotez et al (2009:5) substantiates their argument by revealing that in Zimbabwe women who had been treated with Praziquantel before “the age of 20 exhibited an absence of sandy patches and contact bleeding”. The FB project is trying to explore this prospectively. It targets young girls for treatment because FB may be easier to treat in the young (Kjetland et al, 2012; Kallestrup et al, 2005). Based on these findings developing an effective communication strategy is then necessary because it would inform young women of the options available to them, such as seeking early medical attention. Through identifying the strengths and weaknesses of the project’s current communication strategy, this study can then recommend understandable and relatable ways in which to communicate their likely vulnerability to HIV.

“Dissecting” Public Health Communication

FB is a valid public health issue and the project was initiated to combat it and minimise its effects on young women who are an important segment of the public. Like any other organisation that seeks to alleviate a public health concern, the project is aware of how vital communication is to the attainment of this goal. At the most basic level, communication can be understood as the sharing of information. Studies reveal the massive evolution of communication from being a one dimensional process into an integrative one that is capable of instigating rapid changes (Bernhardt 2004; Albert et al, 2008).This proliferation of information has solidified the rise of communication into a fully-fledged discipline that is applicable to almost every field, particularly public health (Bernhardt 2004).
Public health communication is a process that is intended to intensify the impact of public health initiatives (Bernhardt 2004). Early public health practitioners claimed that efficient communication was “the backbone of health promotion and disease prevention” (Plimpton and Root 1994:86). During the development of public health communication strategies it is important to differentiate between behaviour change communication (BCC) and social change communication (SCC). Behaviour change communication is “results oriented, science based, project oriented, client centred, cost effective...[and],tries to encourage people to make informed choices” (Deane 2002:1). Conversely, social change communication is based on the belief that people are:

Agents of their own change... [It] emphasises community empowerment, creates an environment of change, is process oriented, provides a voice for communities and opportunities for dialogue and...is based on a belief that behaviour change is dependent on social change and is a long term process(Deane 2002:1).

Given that the FB project aspires to work together with young women to raise individual awareness about Bilharzia and equip them with correct information with the hope that it will promote informed decision making, it may be advantageous to draw from both these fields. Being a science or biomedical driven project where number-based results are considered an indication of success or failure, integrating BCC and SCC may be the best way to get these results. Using guidelines that were developed around SCC may also be beneficial because the young women included in the project are inextricably linked to their communities. Therefore, providing them with knowledge about Bilharzia may translate into them passing on correct information to other women in the community who may be uninformed about it. In this way an entire community may eventually be empowered in their awareness of its causes and prevention.

This study subscribes to the concept of empowerment that is promoted by communication scholars such as Jan Servaes (2008) who describes empowerment as an approach that emphasises the involvement of people in the management of their wellbeing. This conception of empowerment is appropriate for this study because it complements the long term vision the project has for young women, which is to foster a spirit of responsibility in them towards their health. This is evidenced by their eagerness to involve them and enlist their help in the planning of an effective communication strategy. The role of empowerment will be discussed in greater detail further in the study.
Applying behaviour change communication to public health

The success of social change interventions is determined by altering behaviour at an individual level first (Parker 2004). This section of the literature review addresses the execution of behaviour change campaigns. Communication experts unanimously agree that “behaviour communication is notoriously difficult to initiate and sustain” (Panter-Brick et al, 2006:2810). This difficulty is encountered in almost all health interventions (Panter-Brick et al 2006). Whether it is attempts to persuade the public to quit smoking, adopt an active lifestyle, or practice safer sex, it remains a challenge. The reasons behind the difficulty are still under investigation (Panter-Brick et al, 2006). However, it has been established that there needs to be a “compelling element inherent in every campaign [in order to] mobilise communities wholesale, rather than effecting behaviour change in piece-meal fashion with the hope of trickle-down or trickle-up effects” (Panter-Brick et al, 2006:2811).

This means that every health intervention needs to contain a key element that is powerful enough to motivate its intended audience in its entirety to adopt the behaviour change it promotes. It needs to refrain from selecting a portion of the audience to address, with the hope that if their behaviour changes, the other people in the population will follow suit. Based on this logic, the project’s communication strategy needs to be tailored to have an impact on all the young women it treats as opposed to a select few.

This “helps address the crux of disappointment...namely gaps between the awareness of risk, the intention to change behaviour and actual behaviour change” (Panter-Brick et al, 2006:2811). If a health message is designed to be understood by everyone they will have ideally, equal amounts of knowledge and understand the consequences of not adhering to health recommendations. Also the discrepancy between the unfulfilled desire to change and actually changing can be addressed. If this democratic approach to behaviour change were to be adopted by the project, it would increase the possibility of all the young women being equally educated about the risks posed by Bilharzia.

Other literature on BCC recommends refraining from adopting a top down approach when addressing the target audience (Parker 2004). This is an authoritative and impersonal approach to communication where the decision makers adopt an omniscient attitude towards their targets. Instead, experts working within the participatory approach believe that any behaviour change strategy needs to take into consideration factors such as social and physical context, which may hinder behaviour change (Parker 2004). These factors are beyond an
individual’s control. In order to demonstrate the importance of social and physical factors on the adoption of behaviour changes, Panter-Brick et al (2006) make reference to a communication intervention in The Gambia, the smallest country on mainland Africa. It was intended to persuade locals to make use of mosquito nets in order to minimise the risk of contracting Malaria. To an outsider, the prevention of Malaria infection in this area was a matter of simply making use of the nets because it seemed like an uncomplicated method (Panter-Brick et al, 2006).

However, upon investigation the researchers discovered that in a rural setting such as The Gambia a mosquito net held a lot of cultural significance. As a result, encouraging what seemed like responsible behaviour would mean forcing people to drastically modify their way of life. For instance, in the area the practice of polygamy is accepted and a net is used to signify different matters such as a wife’s ranking in a household (Panter-Brick et al, 2006). Also, it was used to denote the power dynamics within the community because the men of the households were given first priority when it came to the allocation of the nets (Panter-Brick et al, 2006).

Furthermore, purchasing mosquito nets was expensive as they were regarded as a commodity (Panter-Brick et al, 2006). Through this intervention, the researchers realised that by promoting the use of mosquito nets, to a large degree they were failing to understand all these external elements and were infringing on the community’s way of life. They came to the conclusion that for health initiatives to attain success they: “should build on existing practices, skills and priorities, recognise the constraints on human behaviour... and engage local communities and nestle within social and ecological landscapes”(Panter-Brick et al, 2006:2812).

If the lessons learnt from this study were to be applied to the FB project, the challenge would be to build on the general, albeit sparse information the young women have about Bilharzia (Scalway 2010). Furthermore, the project would have to understand how high Bilharzia rates on their list of priorities in order for them to commit to either its prevention or treatment. In addition, it would be important to understand the external issues that would prevent them from adopting any other behaviour changes they propose (Kincaid and Figueroa 2009). Most importantly, any strategy that the project initiates with the intention being to truly resonate with these young women must be sensitive to their way of life.
Despite the strides that public health communication has made towards asserting its status as an important discipline it does not always receive the credence it deserves (Popay and Williams 1996). Public health scholars have observed that it is still “perceived as more skill than science” [and] until recently [it has] operated at the periphery of public health” (Bernhardt 2004:2051). The field has been overshadowed (by amongst other hindrances) medical scientists who regard communication practitioners as “untrained amateurs” (Popay and Williams 1996:759). However, there are several voices who strive to emphasise the virtues of public health communication in spite of the frequent disregard it receives from the science field. A scholar who makes a compelling case for communication in his work is Thomas Scalway (2010). He makes several points that underscore the interconnectedness of public health communication and science.

In his argument Scalway (2010) explains how combining communication with medicine has led to several victories in the fight against HIV/AIDS. Firstly, he highlights how most HIV/AIDS communication interventions are either having their budgets reduced or have not received any funding at all and even their usefulness is under scrutiny (Scalway 2010). This is a grave injustice according to him because even when compared with their international counterparts who operate on larger budgets, local interventions still manage to attain “measurable results” (Scalway 2010:16). For instance between the years 2008 and 2009 it was suggested that “701,494 South Africans would have been infected with HIV if they had not practiced any HIV prevention behaviour” (Scalway 2010:3). Furthermore Scalway (2010:3) reports that even in other countries “condom use is shown to be 18% higher among those exposed to mass-media interventions”. Although these figures could be higher, they indicate that despite severely limited resources, communication manages to make an impact. The figures also make one consider the depth of impact it could have if more funding was available.

In addition, in the biomedical paradigm the “concept of disease is... [understood] as something that can be treated objectively, separate from the individual’s experiences of the material reality of their everyday lives” (Popay and Williams 1996:760). However, public health communication research reveals that a disease cannot be treated as an entity that is separate from the afflicted individual. There are other factors that can either exacerbate or limit its impact despite the availability of medication. Scalway (2010) lists other important
elements that may have a bearing on the successful treatment of disease in an individual outside of medication. They include: “knowledge, motivation, attitudes, norms (or ideational factors) or behaviours...” (Scalway 2010:3). To illustrate this point clearly, if for instance an HIV positive person had sufficient information communicated to them on how to manage the disease, this may, ideally, motivate them to commit to adopting a healthier lifestyle. This decision would indicate a positive attitude and to a large degree attitude influences people decision making. This is the argument made through a number of health communication theories.

Airhihenbuwa and Obregon (2000) identify a few of these theories. They first refer to the theory of reasoned action (TRA) which was developed and popularised by Fishbein and Azjen in 1975. They define it as a “linear progression from attitude to action [through which] a given behaviour will be determined by an individual’s intention” (Airhihenbuwa and Obregon 2000:8). This model theorises that people’s attitudes influence their rationale when they make decisions. It suggests that attitude (as opposed to other factors) plays a significant role in determining the choices people make regarding many issues including their health.

Albert Bandura’s social learning theories (which will be drawn upon further in the study) also suggest that people’s behaviour is influenced by factors such as the environment they inhabit, the manner in which they process information (cognition) as well as physiology (Bandura 1995). This implies that behaviour is not dependent upon a single factor, but rather a combination of them [my emphasis]. Due to this variety of factors that act upon behaviour changes, Scalway’s (2010) interdisciplinary approach appears to be a natural progression in the fight against disease management. These examples highlight the fact that scientific measures alone cannot cure illness. There are other considerations that when enhanced by communication, result in the successful management of illness or cure in non-HIV cases.

Communication is a tool that can be used to not only encourage people to adopt healthy behaviour, it also helps them to maintain it which is conducive to disease prevention [my emphasis] (Scalway 2010). In the FB project this would entail avoiding risk water contact if they can. This is done through constant re-enforcement of messages through the media and it is an important public service because where disease is concerned prevention is genuinely better than cure (Singhal and Rogers 1999; Scalway 2010). Using the example of HIV again, despite the fact that it is an “entirely preventable” disease, by the end of 2010 it was estimated that 25 million people had died from it (Scalway 2010:4). However, following
exposure to public health messages that advocate behaviour change Scalway (2010) shows that the incidence of infection has been reduced.

In order to further highlight the unacknowledged importance of communication to the science field, Scalway (2010) explains that biomedical HIV prevention interventions (advances in medical male circumcision and post exposure prophylaxis for example) are a vital part of the efforts to stop new infections. However, the notion that they can be scaled up in isolation from social and behavioural change communication is misguided. “The reach of mass media communication on HIV is around 90% in countries like South Africa and 90% of the population is exposed to at least one mass media HIV intervention”(Scalway 2010:5). Evidence in national studies such as the National Communication Survey (NCS) suggests that a high dosage of media exposure over a sustained period of time (in combination with interpersonal and community based communication) can produce significant results (Scalway2010).

*Making the case for Communication and its Theories*

There have been a number of different criticisms levelled at social and behaviour communication (SBC) from the scientific community. These include questioning whether it is effective or not because its impact is not immediately quantifiable (Albert et al, 2008). In response to this Scalway explains that it is unreasonable to suggest that communication does not work when “there is not a single country where it can be said to have been fully tested”(Scalway 2010:5). Communication has never been given the opportunity to obtain the type of results its advocates believe it is capable of obtaining.

In order to further explore this point, (Scalway 2010) again uses the example of male medical circumcision (MMC) which has been shown to reduce HIV infection in men. He argues that it is only through employing communication that the public can be made to understand that MMC does not immunise men from the virus, but merely reduces the risk. Furthermore, it is only through communication that important information about disease can be re-enforced (Bandura 1995; 2004). Were this not the case, the public would have to cope with the burden of disease due to only having minimal health information (Parker 2004). To support this point, Scalway discusses how in South Africa it is assumed that everyone has the correct information on how HIV is transmitted. The disappointing reality is that only a meagre:
“30% in both sexes and across all ages [have] accurate knowledge of HIV [i.e.] correct knowledge of sexual transmission of HIV and rejection of major misconceptions of HIV transmission among adults” (Scalway 2010:6).

Further, the public is at a disadvantage because “there is only partial coverage of interpersonal communication, community based communication and other more targeted methods” (Scalway 2010:5). This is despite the above figure indicating that there is a great need. Scalway (2010:6) firmly believes that “sustained communication through a number of channels is required for meaningful impact on...prevention”. This means that in order to get information firmly imprinted into the minds of people, it needs to be constantly re-enforced from various avenues.

Other communication practitioners who understand the value of repetition in health communication are Arvind Singhal and Everett Rogers (1999). They discovered its power during an evaluation of a communication strategy known as Entertainment Education or “Edutainment” (EE) (Singhal and Rogers 1999). Like their colleague Servaes (2008), they believe that the repetition of educational information within entertainment education increases its educational impact. This means that constant repetition of EE messages with lessons embedded heightens people’s understanding of them. In this way the likelihood of their application to their lives increases. EE “combines the attraction of entertainment with educational messages to help educate, inform and encourage behaviour change to achieve development and social progress” (Servaes 2008:207). Essentially it is a method of reaching out to the public by incorporating entertainment elements into serious health messages. In this way the audience is simultaneously educated and entertained.

Advocates of EE support its usage in public health because it has been instrumental in “promoting healthy choices, practices and lifestyles” (Durden and Nduhura 2005:3). According to Durden and Nduhura (2005:3) there are several factors that are responsible for the success of EE: Firstly, it is pervasive and its reach transcends socio-economic circumstances and geographic locations. Even in places where there are no “cinemas or the Internet; we find songs, drama and storytelling” (Durden and Nduhura 2005:3). Secondly it is popular due to the need for entertainment being shared by everyone irrespective of their background (Durden and Nduhura 2005). It is also personal in the sense that when a story is being told or a play is being acted out, individuals select characters that they relate to and the reasons behind that emotional resonance differ with each person (Durden and Nduhura 2005).
EE can be participatory because when presented at a grassroots level, the audience is encouraged to actively participate during the performance by “following the experiences of the characters and discuss[ing] them with families, colleagues, and community members” (Durden and Nduhura 2005:3). This participation allows for the diffusion of health messages. EE can be passionate because of the emotions it elicits (Durden and Nduhura 2005). When emotions are evoked people are more likely to recall the reasons behind that. If for instance there was a drama or song about Bilharzia and it triggered an emotional reaction in an individual, when they think back to the reason behind that emotional state, Bilharzia is likely to be the first thing they recall. In their work Durden and Nduhura (2005) make reference to EE relying on role models to perpetuate exemplary behaviour worthy of imitation. Bandura (1995) whose work also focuses on role models and imitation highlights their significance. Bandura (1995:4) states that through their portrayal of desirable behaviour they “transmit knowledge and teach observers effective skills and strategies for managing...demands”. Durden and Nduhura (2005:1) believe that it is this impassioned emotional involvement that “may lead to behaviour change”. If a play was performed with the intention of discouraging behaviour that would increase women’s susceptibility to FB or HIV, the audience would “see for themselves the consequences” of ignoring that recommendation (Durden and Nduhura 2005:3).

EE is an “approach [that can also] employ traditional or indigenous media such as puppet shows, music and dance to promote issues in health care” (Durden and Nduhura 2005:3). With that being said, Singhal and Rogers (1999) believe that the key to locating a tool that can effectively entertain and educate lies in understanding the target audience. Due to their age, participants in the FB project may not be responsive to puppet shows for example. Therefore, Servaes (2008:207) suggests using “mediums that are produced locally to appeal to the local audience” [and then combining them] with “electronic media such as radio, television, video and audio cassettes”.

Addressing teenage sexual and reproductive health

In order to detect the presence of Bilharzia young women have to consent to a gynaecological examination. Although this can be invasive undergoing it can be a young woman’s first awakening to the importance of reproductive health. However, communicating about it is a difficult task because it is a sensitive matter. What further complicates it is that parents who are meant to be strong role models that can be relied on to impart information to their
children struggle to do so openly about it with them. This is because many of them “were not taught about sexual and reproductive health by their own parents” (Hindin and Fatusi 2009:58). As a result their understanding of these issues is limited.

Furthermore, conservative social settings like Africa prohibit parents from candidly discussing matters they considered as “taboo” and reproductive health falls into that category (Hindin and Fatusi 2009:58). Faced with these facts, the project needs to tread carefully when communicating with young women about these topics. The goal is to provide correct information without violating any social codes. Literature on how to approach this had the following guidelines: Firstly, information relating to sexual and reproductive health in teenagers needs to be accurate and applicable even in a “changing world context” (Hindin and Fatusi 2009:60). This means that even countries as traditional as South Africa, need to overcome the reservations they have about communicating about these issues and accept the inescapable reality that times are changing.

Following a review of patterns of sexual and reproductive health communication in developing countries, Hindin and Fatusi (2009) discovered that exposure to health communication programs resulted in favourable changes in the youth. For example, in Taiwan, the rates of unmarried youth who embraced contraception increased. Their second recommendation is that health interventions need to refrain from adopting a linear approach in their communication because “in sexual and reproductive health-currently...other STI’s and pregnancy prevention are conspicuously absent”(Hindin and Fatusi 2009:60). Therefore, communication about these matters needs to be all encompassing and avoid focusing on select aspects. To a certain degree the project has adhered to this suggestion because despite FB being their chief concern, they also offer treatment for STIs as well as guidance to young women who require contraception. However, based on the literature, if the goal is to refine the communication structures already in place more, changes may need to be implemented which is what this study worked towards.

In a South African context this is especially important because most sexual and reproductive health programs avoid addressing these topics outright. Instead, they allow them to be overshadowed by one sexually transmitted disease which is HIV. A prime example of this that Hindin and Fatusi (2009:60) refer to is the “ABC” strategy that urged the masses to abstain, be faithful and make use of condoms in order to manage the HIV crisis. Despite this campaign receiving lots of funding and coverage it failed to achieve the anticipated outcomes.
(Hindin and Fatusi 2009). Scholars speculate that amongst the reasons for this was its one dimensional messages that neglected other areas such as promoting what Hindin and Fatusi (2009:59) have termed “modern contraception”\(^\text{10}\) perhaps. This indicates that campaigns need to aim for wide ranging communication approach. An important benefit of such an approach is that it helps to facilitate dialogue and inspire lasting behaviour changes (Hindin and Fatusi 2009) by informing people of the different contraception options available to them and the ease with which they can be used.

Completely changing young women’s sexual behaviours is an ambitious undertaking. However, changing attitudes about the importance of regular gynaecological examinations is vital because it may ensure that they enter adulthood aware of its relevance to their health. Thus far, “no single educational or communication programme appears to lead to lasting behaviour change” (Hindin and Fatusi 2009:60). The project could be the first to achieve this feat if it designs its communication strategy with the intention to equip its participants with “tools to make informed and healthy choices concerning their sexual and reproductive health” (Hindin and Fatusi 2009:60). Success in this regard can be attained if a form of the above-mentioned intersectoral integration can be achieved, allowing a holistic communication approach to emerge that acknowledges: social determinants, local values, treatment protocol and biomedical procedures.

Also important to note when designing effective communication messages for adolescents is cultural uniqueness. Hindin and Fatusi (2009:58) discovered that in many countries particularly African ones “women’s gender identities and social status are tied to motherhood and childlessness is highly stigmatised”. In order for women to assert their status as women they need to demonstrate that they are fertile from as early as adolescence (Hindin and Fatusi 2009). Based on this alleged pressure to conform to societal norms, the resistance to contraception is understandable. To summarise Hindin and Fatusi’s (2009) work, messages around adolescent reproductive health needed to find the balance between being imposing and advocating responsibility.

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\(^{10}\)The researcher assumes this is an umbrella term referring to methods such as diaphragms, contraceptive pills, Intra-Uterine Devices (IUDs) etc.
**Understanding societal barriers to teenage sexual and reproductive health communication**

Other studies suggest that the most pervasive barrier to communication with teenagers about their sexual and reproductive health is society’s mental attitude towards teenagers/adolescents (Aggleton and Campbell 2000; Kirby 2002). Communication programs designed to address these issues are sometimes perceived as an exercise designed to instil an attitude of reckless promiscuity in them (Aggleton and Campbell 2000). Therefore, supporting their open discussion would be equivalent to condoning such behaviour in people’s minds. For instance after an assessment of school-based programs which were initiated to determine their effects on “adolescent sexual behaviour” Kirby (2002:288) agrees that:

> Effective programs include activities that some parents and communities oppose because they fear that they will sanction and encourage sexual activity...

> [Furthermore] many teachers and school districts do not realize that some sex-and HIV-education programs have strong evidence for their success.

However, according to Aggleton and Campbell (2000) the biggest obstacle hindering open communication about sexual and reproductive health is the condescension shown towards the youth by society. Disregard for teenage opinion is demonstrated firstly by the mere usage of the word “adolescence” which is used to describe a period characterised by hormonal and emotional changes (Aggleton and Campbell 2000:283). The problem, according to Aggleton and Campbell (2000:286), is the fact that adults dramatise this time in a young person’s life by assuming it to be turbulent to the point of rendering them “irrational”. As such their “perspectives on events... [are not] taken as equal to those of the older generations” (Aggleton and Campbell 2000:285).

When young people are not being “vilified” and “pathologised”, they are portrayed as unwitting victims who are at the mercy of biological and psychological changes beyond their control (Aggleton and Campbell 2000:286). They believe that these views of young people are misguided and deny them the right to be understood “on their own terms... [and not] on those of an essentially adult logic” (Aggleton and Campbell 2000:286). Due to their strong belief that it is the responsibility of practitioners in the communication field to be cognisant of young people’s perspectives on these matters, Aggleton and Campbell (2000) offer suggestions on how to approach this:

Like Hindin and Fatusi (2009) they also acknowledge that the starting point is to furnish young people with correct information about sexuality and reproduction. They then assert
that true understanding of these issues goes beyond being well informed. It becomes about being equipped with a combination of skills on how to navigate one’s way through sexual and reproductive matters and “the attitudes which make the adoption of certain behaviours seem worthwhile” (Aggleton and Campbell 2000:289). Like Panter-Brick (2006) they recognise that the latter is more of a challenge hence their suggestion of programmes of “youth friendly services [that aim to boost their] “confidence, self-esteem” (Aggleton and Campbell 2000:289). Kirby (2002) discovered that community structures such as school based clinics which offered what may be regarded as “youth friendly services” such as medical care and counselling services showed consistently positive results (Aggleton and Campbell 2000:289).

Lynn Dalrymple (2006) recommends EE for the task of inculcating a sense of self belief in people and enhancing their motivation to follow behaviour change recommendations. Dalrymple makes reference to the success DramAidE an organisation based at the University of KwaZuluNatal, has achieved doing this. DramAidE embarks on community projects which focus on “educational drama and theatre” with the end goal being to develop “a sense of self-worth, particularly in the contexts of different forms of oppression” (Dalrymple 2006:205). Paulo Freire (1960) stated that in order for genuine knowledge acquisition to occur people needed to be informed. If that did not happen then that was a form of oppression. For instance, if young women have limited information about Bilharzia and the project used EE as a strategy to enlighten them, then according to Freire (1985;1990), genuine, emancipating learning would have occurred. Essentially it ceases to be a matter of individuals being informed, but rather that they enter into the dialogue. Also the sense of self-efficacy which Dalrymple (2006:212) describes as feeling like “I can cope” [with FB or recommendations made] will have been instilled in them. This state of awareness is known as critical consciousness and it will also be discussed in depth further in the study (Freire 1985; 1990). In sum, the consensus amongst most scholars about sexual and reproductive health is that they are topics that need to be approached carefully because of their potential to spark controversy. In order to have an impact on behaviour, dialogue with young people about these matters needs to be accurate and executed creatively such as through EE perhaps.

**Communication guidelines for public health strategy development**

The development of a public health campaign that aims to touch the lives of the public is an undertaking of great importance. This is because it is possible to inflict more harm than good
unintentionally. The key to avoiding this is through meticulous planning so that it easier to predict potential conflicts and outcomes. Communication experts who understand the science behind creating effective communication approaches offer guidelines on how to do this. The first essential principle that needs to be integrated into any public health campaign according to Matthew Wynia (2007) is trust.

*The issue of Trust*

Trust is the foundation upon which successful health endeavours are built. Wynia (2007:6) believes that it is in the best interests of any health intervention to gain trust because a “lack of it will breed both fear and non-adherence”. During the time spent collecting data in the schools apprehension was the first reaction we received from them. This is a fair expectation because it is human nature to question that which seems foreign to us at first. If the role of trust is underestimated there is a high likelihood that health initiatives may fail. The messenger of any health message needs to be credible and prepared to support the information they circulate with “rock solid scientific facts” (Wynia 2007:6). Being new in the area in which they are embedded the project needs to ensure that they are in control of their public image. Being a primarily science based project, finding information to verify their recommendations is not a difficult task. However, conveying the scientific facts to young women whose level of education is not advanced is more difficult. Wendy Quarry and Ricardo Ramirez (2009) advice that a good starting point would be to find out who the community trusts and the media channels that are already in use. In so doing their preferred media channels, gateways to information, as well as the gatekeepers who determine access to it can be identified (Quarry and Ramirez 2009).

Wynia (2007) suggests consistent repetition of the same information in order to fully convey health messages. This “provides a necessary foundation, especially in making controversial recommendations” (Wynia 2007:6). This means that the project needs to be conscious of the content of the messages they broadcast to the public because they influence the decisions women make about their health when faced with societal judgement. For example, in an African setting encouraging young women to take preventative measures to avoid future reproductive problems may be viewed negatively. However, if the facts remain constant, over time they may trust in the content and be empowered to follow recommendations despite people being against it. Therefore, the constancy of a message connotes its reliability and it affects people’s motivation to be in control of their health.
An important step in the process of gaining the public’s trust is to avoid “conflicts of interest” (Wynia 2007:6). To illustrate this point Wynia makes reference to an internationally successful pharmaceutical organisation that collapsed after their image was tarnished irrevocably to the public. The events leading up to this involve the company promoting their products relentlessly and amassing a sizeable profit for itself and its stakeholders (Wynia 2007). The public then lost faith that this company prioritised their welfare and began to believe that making a profit at their expense was the goal (Wynia 2007). The lesson to be learnt from this case is that deception of the public has harsh consequences. Transparency with regards to profits made and the involvement of stakeholders is crucial. Therefore, the project needs to develop public trust which is dependent on people being made to feel that their health genuinely matters.

Lessons on authenticity in public health communication

In every society the public is bombarded with messages that compete for their attention. In public health it is imperative that the messages circulated rise above this racket to make an impression on people. Joseph Petraglia (2009:176) identified “authenticity” as an important factor that succeeds not only in ensuring that health messages are imprinted in the public’s minds, but motivates them to “translate knowledge into action”. Petraglia (2009) acknowledges that it is a concept that has not been sufficiently explored in the communication field; however, it does have behaviour changing potential:

Authenticity...is an appraisal made by a member of the public who is persuaded to view the information as especially relevant to his or her health behaviour and consonant with his or her prior experiences (Petraglia 2009: 176).

This means that following exposure to a message an individual will assess it and only take heed of it if it applies to their lives in some way. This evaluation of significance to people’s lives is what authenticity is about and Petraglia argues that there are different ways of improving it in order to encourage permanent behaviour changes in the public. Petraglia (2009:178) identified what he referred to as the “KAP-gap” (Knowledge-Attitude and Practice) which refers to the reluctance to apply what one has learnt to one’s life. Many health initiatives have failed to bridge this gap and one of the key reasons for this is their inability to connect on an individual level with people. Therefore, messages alerting them to health issues are reduced to “a droning buzz in the background that only occasionally reaches consciousness” (Petraglia 2009:176).
Using FB as an example, as mentioned previously it does not receive the same amount of public attention as other diseases (Hotez et al, 2009). Hypothetically speaking and according to Petraglia (2009), if young women were cautioned on the hazards of the disease without the impact it may have on them, the information is likely to fade into obscurity. If authenticity were incorporated into the communication of the same information, however, it may resonate differently. Young women would “understand, emotionally as well as cognitively, how [this] information can relate to their everyday existence” (Petraglia 2009:176). Petraglia (2009:177) identifies “persuasion, narration and dialogue” as three concepts that he believes may enhance the authenticity of health messages.

In public health thus far, the role of persuasion has been neglected mainly out of fear that it may be interpreted as an aggressive tactic to convince people to think in a particular way (Petraglia 2009). This is often the case within the dominant development communication approaches that are often critiqued for being insensitive to a community’s context and needs in their authoritative top down bias (Kincaid and Figueroa 2009; Morris 2003). McGuire (1960 in Flay, DiTecco, and Schlegel 1980:129) developed what he termed the “persuasion matrix” in order to explain how aspects of communication such as: “message design, source and channel, audience characteristics” can influence behaviour (McGuire 1960 in Flay, DiTecco and Schlegel 1980:127). The model has also been used in advertising. However, due to the level of power it wields over attitude and therefore behaviour, it has raised moral concerns (Barry 1987).

Most practitioners in the field tend to adopt a “facts speak for themselves (and thus persuasion is unnecessary) philosophy” (Petraglia 2009:179). Petraglia (2009:179) challenges this by suggesting that persuasion is intrinsically linked to authenticity, not by logic but by practical rationality, emotion and inference” (Petraglia 2009:179). This suggests that presenting an individual with facts only may not have the intended impact on them. They need to feel that information has implications for their lives. To illustrate this point, it would not be enough for the project to simply present women with medical facts about FB. They would have to feel that the information conveyed to them about it could have a bearing on their health. A tactic that Green and Witte (2009:245) recommend for alerting people to the health risks inherent in everyday activities is known as the “fear appeal”. Green and Witte (2009:245) discovered that although fear based campaigns are open to criticism, in an African setting they have had a substantial impact on behaviour change. They will also be discussed at length further in the study.
Ensuring that a health message is viewed as authentic is critically important in a field such as public health communication where people are expected to change their behaviour. This altering of behaviour often requires commitment on the part of the individual and one’s natural instincts seldom allow for the discomfort associated with change (Petraglia 2009). What further complicates behaviour changes is that generally this is tied to three factors which are: “history, emotional resonance, links to social identity and extensive connections within memory” (Petraglia 2009:180). For instance, expecting women from an area where FB is rife to avoid going to the river to do their laundry could be hard because it could be an inherited practice from their parents. Going to the river could also be a recreational activity that women in the area bond over or they could have fond memories of visiting the river as children. Therefore, asking them to stop going there would be equivalent to asking them to give up a part of who they perceive themselves to be.

Guttman (2009:165) believes that for health campaigns to preach discontinuing a behaviour that puts ones health at risky, is unfair because in this way “…the less privileged [are denied] pleasures they can afford”. In the areas where the study is conducted most people live below the poverty line (Ugu 2010). Therefore if visiting the river is one of the limited forms of recreation they have encouraging them to quit without suggesting alternatives compromises their “quality of life” (Guttman 2009:549). A plan that Petraglia (2009:180) suggests for strengthening a health messages recommendations without imposing it is “…perhaps, a narrative strategy that contextualises information in the form of stories, anecdotes and cases”. Conversely:

Non narrative (i.e., propositional) techniques are useful in attracting attention and delivering information, and may even prompt reflection, but they do not offer the opportunity for people to engage with the message and consider all the ways in which the information functions in real life (Petraglia 2009:180).

From this we can gather that if the FB project utilised stories and case studies to convey the seriousness of Bilharzia this may be more effective than a presentation of facts. This is because stories allow for consideration of consequences from every angle. Perhaps if a young woman was exposed to a short story about FB with health lessons inherent in it, it may prompt her to think more clearly and to weigh her options more carefully. This is due to the fact that the use of stories creates the “psychological space individuals need to integrate new information about new behaviours into an existing web of associations, cause–effect relationships, and experiences” (Petraglia 2009:180). Petraglia’s (2009) finding about self-
reflection that is induced by short stories is yet another example of the power of EE in action (Singhal and Rogers 1999; Durden and Nduhura 2005). If the project were to adopt Petraglia’s ideas of employing short stories to enhance communication with young women, the chances of achieving that outcome are high because it is a highly effective EE tool (Singhal and Rogers 1999, Durden and Nduhura 2005). Young women’s stories could then be acted thus making it easier to vocalise their issues (Tufte 2003).

The most important part of authenticating public health messages is the use of dialogue (Petraglia, 2009). Simply put dialogue can be understood as the act of verbally sharing information. However, scholars such as Petraglia emphasise the fact that “dialogue is not merely a mechanism of communication but the means by which Selves come into existence” (2009:181). Through the use of dialogue public health practitioners can get to the core of individuals and genuinely understand how they think as opposed to the superficial understanding that occurs when “individual agency and mental representation” are ignored (Petraglia 2009:179). Other scholars who speak extensively in their work about the virtues of dialogue are Kincaid and Figueroa (2009). The core of their argument is that it should be a mutual process of listening and sharing without one party emerging as the dominant voice (Kincaid and Figueroa 2009). In so doing decisions can be made as a group (Kincaid and Figueroa 2009). Petraglia (2009:181) distinguishes the two key theories of dialogue: Firstly, there are the descriptive theories which are concerned with conveying the “facts”. Secondly, there are prescriptive theories which change communication into “a self-actualizing process that creates the conditions for happiness, dignity, and justice” (Petraglia 2009:181). Petraglia (2009) believes that during the formation of public health communication approaches, practitioners in the field should aim for the latter.

Reducing stigma in public health campaigns

The construction of public health communication campaigns entails a lot of decision making in order to ensure that they are well-received by the public. The potential to make mistakes is a concern because the consequences can be catastrophic. In some instances communication oversights “actually elicit the opposite behaviour that the health message was trying to instil” (Guttman and Salmon 2004:547). For example some anti-drug campaigns have intensified the curiosity about drugs which resulted in increased experimentation by young people (Guttman and Salmon 2004). In the case of the project, inciting reckless behaviour amongst the young women is a possibility (Guttman and Salmon 2004). For example, instead of abiding by the
safe sexual and reproductive health recommendations made, they may become more irresponsible because of the availability of free treatment etc. This highlights the level of fastidiousness required when designing messages to be included in the communication campaign. Following a review of literature about inadvertent communication blunders that have been made by practitioners in the field, the issue of stigma reduction was identified as the most common and damaging one (Guttman and Salmon 2004).

Based on Guttman and Salmon’s (2004) findings one of the key reasons behind the repetition of this communication oversight is that it is hard to construct messages that convey the seriousness of a disease without portraying those who have it in a negative light. They believe that this is the “essence of the stigmatising effect” (Guttman and Salmon 2004:547). Using the example of HIV and AIDS they relate how very often in the media it is difficult to figure out if those affected by it are portrayed “as victims or as empowered” (Guttman and Salmon 2004:547). Within the project the best way to communicate about the connection of FB to HIV must still be determined because of the possibility of stigmatising the young women. According to Guttman and Salmon (2004:547):

> Once stereotypes and stigmas are established, they can result in individuals being feared, avoided, regarded as deviant, and even blamed for engaging in the immoral behaviours that must have elicited the ‘punishment’ of their affliction

This means that instead of being received with compassion and understanding stigma leads to the ostracism of affected individuals. Stereotypes are really unsubstantiated beliefs that are born out of ignorance which then breeds fear. That fear then shifts the focus from educating one’s self about a disease and supporting those suffering from it, to conditioning ourselves to believe that it is the penalty those who have it need to pay for making poor choices. In their explanation of how the fear appeal model works Green and Witte (2006), echo these sentiments. They state that “a perceived threat (causing fear arousal motivates) action” (Green and Witte 2006:244). However, it is one’s level of self-efficacy that determines whether a person behaves positively or negatively to people who have an illness that they perceive as threatening. This rejection by society “can be devastating to members of vulnerable populations who suffer from stigmatised medical conditions since it can result the internalisation of self-blame and destruction of self-esteem” (Guttman and Salmon 2004:547). The young women who participate in the project can be classified as “vulnerable” because of their age and background amongst other things (Guttman and Salmon 2006:549). As a result it is important to protect them from any possible negativity.
It would also tarnish the image of the project if the link between FB and HIV was misinterpreted and the participants who seek their help were negatively viewed by the community. However, Guttman and Salmon (2004) suggest several ways to reduce these adverse effects of stigma. First, they suggest being vigilant about the images that are selected to accompany messages that convey the effects of disease. This is because images can also accelerate the perpetuation of stereotypes. Using the example of HIV again, they describe how in Israel, in order to clear the misconception that it is a class disease, a picture of two women was used. One of them was dressed conservatively, the other was scantily clad. To further emphasise their point, the picture was accompanied by a caption that read: “AIDS hits [people] without making any distinctions” (Guttman and Salmon 2006:548). This example demonstrates the amount of power is inherent in an image and how it can be used to alter mindsets.

The second is to painstakingly select the vocabulary used to describe a condition and its effects because that too influences the rate of stigma it generates (Guttman and Salmon 2004). An example they refer to when explaining this point is an advert in the United States that was criticised due to the choice of words accompanying it. Advertisers stated that “sexually active teenage girls are often dumped by their boyfriends and wind up feeling ‘dirty and cheap’” (Guttman and Salmon 2004:549). Many felt that although promoting abstinence should be applauded, “the harshness of using “dirty and cheap” is unhelpful, especially for adolescents who may already be feeling stigmatized” (Guttman and Salmon 2004:549). The lesson here for the project is to be very cautious of how they describe the adverse effects of FB. This is because there are those who may already be feeling self-conscious about having it. In sum tackling the stigma issue requires for organisations to find the middle-ground between raising awareness and inadvertently turning people into outcasts in their own community. Based on the above findings the best way to accomplish this is to be sensitive in the manner in which information is conveyed.

Conclusion

This chapter has presented a range of literature pertaining to the issues under investigation in this study. Articles about FB presented the disease’s background, current research findings regarding its treatment, as well as their relevance to this dissertation. Other literary works examined the debate around the merits of merging communication with science. The possibilities inherent in deciding to join the two disciplines were also explored. Due to the
study’s main focus being communication about women’s health, studies of a similar nature were integral. They revealed the errors and successes earlier communication practitioners encountered in this regard. The latter sections of this chapter unveiled communication strategies that have been utilised by organisations during public campaigns. One of the ultimate goals following the conclusion of this study is to produce suggestions that can be considered during a prospective public campaign by the project. Therefore, works that could contribute to this was central to the study. In sum all the articles examined in this section aided in delineating the way forward for the FB project’s communication.
Chapter Three: Canvassing Theoretically Driven Options

This chapter aims to provide possible theoretically based options for the project to explore in order to address some of its current communication issues being investigated in this study. This will be done by synthesising the theories of various researchers in the behaviour change communication, social change communication and biomedical fields. The theories also guide the study as a conceptual framework in drawing comparisons between expert findings and the realities that have confronted me as a researcher embedded in the Female Bilharzia Project. The theories presented here will assist in “making sense” of empirical data collected in the field. They include the participatory/another Development paradigm (Servaes 1999, White 2004), Albert Bandura’s (1995, 2004) social cognitive theory, particularly his concept of self-efficacy, Paulo Freire’s (1990) work on critical consciousness and Kim Witte’s (1992) Extended Parallel Process Model (EPPM).

The participatory paradigm

The participatory/another development paradigm was initiated as a reaction to the top-down developmental communication approach of the modernisation paradigm (Lerner, 1958, Rogers, 1962, Rostow, 1960) as well as the Dependency paradigms (Gunder-Frank, 1967, Baran, 1967). Approaches within these paradigms were criticised for their inadequacy in earnestly understanding and meeting “beneficiary” communities’ communication and development needs (Dyll-Myklebust 2011:110). Modernisation which had been extremely popular in the 1950s recognised the importance of communication, particularly via mass media (Dyll-Myklebust 2011). However, it failed to make provisions for community members’ feedback (Dyll-Myklebust 2011). Further, no efforts were made to encourage endogenous participation. Attitudinal behavioural and value changes among traditional individuals were pre-requisites for modernity (Lerner, 1958; Rogers 1962).

Eventually it became apparent that developmental problems were not only due to what the proponents of the modernisation paradigm saw as the “backwardness” and “superstition” of many Third World people (Dyll-Myklebust 2011:36). The external constraints to development also played a role and the poor communication between external experts and locals was the main challenge that needed to be overcome before there could be any possibility of resolving them. Advocates of the modernisation paradigm attributed the lack of development mainly to what they termed “in the head psychological constraints”
(Melkote and Steeves 2001: 60) believed to be inherent in people as a result of their traditionalist thinking. Therefore, they were confident that the application of behaviour change programs was the route to modernity and thus development. In the years that would follow, such conceptions of solutions to development would give birth to models such as the Theory of Reasoned Action (TRA) (Fishbein and Azjen 1975) and the Health Belief Model (HBM) (Becker 1974). These models are used to support the notion that “rational” thinking as opposed to thinking that is deeply entrenched in traditional beliefs etc. overcomes developmental barriers (Airhihenbuwa and Obregon, 2000:7).

In the 1970’s the dependency/disassociation paradigm reacted against exogenously-initiated development and countries in the Third World or global south sought to disassociate itself from the West, or global North (Dyll-Myklebust 2011). Many countries thus focused their attention on nationalism and attempted to resist foreign aid (Dyll-Myklebust 2011). Communication strategies were developed on the premise that communication was a linear process where the state would pass down messages to the masses. Models such as the diffusion of innovations theory (1962, 1983) and the stimulus-response theory (1975) controlled the communication patterns between the public and government despite the fact that they did not accommodate public opinion (Melkote and Steeves 2001). Major state institutions such as the church and labour unions assembled themselves into a bureaucracy responsible for decision making on behalf of the masses (Dyll-Myklebust 2011). There was thus still a lack of participation by people in their own development. In addition the Dependency paradigm inherited some of modernisation’s faults (Dyll-Myklebust 2011). By breaking international ties, it practiced a scaled down version of modernisation within borders where an elite had been created that shared the cultural lifestyle of the dominant classes in capitalist states.

Modernisation and dependency/disassociation failed to offer mechanisms to facilitate negotiation conflict resolution and community or individual empowerment (Melkote and Steeves 2001). This realisation led to the emergence of Development Support Communication (DSC). Through this approach, the goal was to ensure that experts in specialised fields “such as health, agriculture and literacy” (Melkote and Steeves 2001:62) and the intended recipients of their skills had the same level of understanding. The DSC practitioner’s task is to “translate technical language and ideas into messages that would be comprehensible to others” (Melkote and Steeves 2001:62). This mutual understanding between beneficiaries of aid and the agencies responsible for it is achieved through various
communication techniques such as EE (Melkote and Steeves 2001; Singhal and Rogers 1999). Due to the constant evolution of communication however, the participatory paradigm soon surpassed DSC in terms of fuelling community members’ willingness to fully immerse themselves into the developmental process (Tomaselli and Shepperson 2002). It succeeded in this regard because whereas DSC had attempted to partially include people, this interaction was driven by what Servaes (2008) refers to as “elitist, vertical or top down orientation” (Servaes 2008:21). Basically, it was not entirely inclusive because although there were efforts to involve the beneficiaries, with regard to decision making and the course of execution, donor agendas often surfaced thus tainting this attempt at participation.

Development practitioners who popularised the participatory paradigm include amongst others Dag Hammarskjold (1960), Paulo Freire (1960-1990) and Jan Servaes (1999, 2005, 2008). Lawrence Kincaid and Maria Figueroa (2009) are also avid supporters of participation within communication. They developed a comprehensive model of participatory communication that outlines the key components for successful developmental initiatives. Their work will be drawn upon at length throughout this dissertation. All aforementioned scholars are firm believers in its capacity to motivate people from the grassroots level to be active participants in the process of improving their lives. Servaes (2008) asserts that through this approach, communication ceases to be a process which is propagated by select individuals. Instead it recognises “the importance of cultural identity of local communities and of democratization and participation at all levels-international, national, local and individual” (Servaes 2008:21). Melkote and Steeves (2001) share these sentiments after having observed that prior attempts at uplifting people, without fully involving them leads to projects being “mere clichés, lacking in substance”(Melkote and Steeves 2001: 338). Instead of tackling problems from the grassroots where they can “perceive real needs and identify...real problems” (Melkote and Steeves 2001: 338). Such approaches actively seek compliance instead of collaboration.

**Core principles of participation**

There are numerous reasons behind the current popularity of participatory communication strategies. The ones that will be elaborated on should in theory, be beneficial if they are applied to the project. Firstly, empowerment is widely considered to be a central concept within development communication (White, 2004; Servaes 2008). It has been defined in different ways. Servaes (1999) understands it as ensuring that people are self-reliant, whilst
Melkote and Steeves (2001) believe it refers to the freedom to create opportunities at will. Where health is concerned Servaes, (2008) states that it is a “strategy [that] emphasizes the role of the community members in planning and managing their own health care” (Servaes 2008: 208). Essentially, these scholars believe that incorporating empowerment into projects translates into beneficiaries eventually being self-sufficient if they have been given the freedom to dictate the direction from the beginning.

According to Melkote and Steeves (2001) an injustice that has occurred in the past is that in society, those who are considered to be minority groups such as women have been disempowered by having their voices silenced. Due to this they believe that “people’s right to communicate their stories should be at the heart of the participatory strategies leading to empowerment” (Melkote and Steeves 2001:355). If the FB project were to be examined based on these scholars’ observations, it appears to be making a concerted effort to instil a sense of empowerment in young women. By targeting a group who qualify as a minority and involving them in the creation of a communication strategy that meets their health needs, they are restoring control to and allowing them to define the manner in which they will be represented in the media and their communities.

Although this counts as an accomplishment for the project, Melkote and Steeves (2001) stress the fact that cultivating empowerment alone is not enough. It is a “labour-intensive process…[that]“evolves through practice in real –life situations” (Melkote and Steeves 2001:364). This suggests that the FB project needs to continuously work at sustaining it. Some strategies that can be adopted to strengthen the chances of sustainable empowerment include creating community “activities that enhance experience and competence” (Melkote and Steeves 2001:362). These could range from “listening sessions” (Melkote and Steeves 2001:362) where weaknesses can be identified and concerns addressed, to having workshops where people’s leadership abilities are honed (Melkote and Steeves 2001).

Secondly, Melkote and Steeves (2001) suggest providing as much support to beneficiaries as possible in order to improve their cohesiveness and capacity to “combat social and environmental barriers” (Melkote and Steeves 2001:363). This suggests that should the project wish to mould these young women into health conscious people with the potential to defend its work in the face of criticism from their communities for instance, they need to secure resources for them(Kincaid and Figueroa, 2009). These can be financial, it can be equipping them with technical skills which will teach them the value of “strategic planning”
(Kincaid and Figueroa 2009:362). Other possible steps would be to teach them interpersonal skills such as “conflict resolution” (Kincaid and Figueroa 2009:363) and dealing with media criticism (Kincaid and Figueroa 2009). Receiving this type of guidance may be advantageous in many ways. It could create a sense of ownership and pride in the FB project being truly theirs (Kincaid and Figueroa 2009). It could also instil in them the resilience needed to withstand criticism and the willingness to enlighten community members who might misunderstand the project’s motives. Furthermore, if young women have these skills they can think ahead and discover new ways in which the project can flourish.

Another important aspect of a participatory intervention is to ensure that it has the support of the community in which it is located (Kincaid and Figueroa 2009). This can be done by consistently monitoring the feedback received and aligning the project with existing community structures (Kincaid and Figueroa 2009). Further, all involved need to ensure that this is done in an unobjectionable manner that respects local traditions (Kincaid and Figueroa 2009). From this we can gather that it may assist the project if they contacted local leaders and explained the value of the work it does in order for them to possibly endorse it. Not only would this enhance the project’s image in the eyes of their community, it would gain the trust needed for them to support other young women who wish to be involved.

*Stirring “critical consciousness”*

An important attribute of the participatory approach is that it can stimulate a state of being known as “critical consciousness” (Freire 1990:47). This is a term coined by Brazilian educator Paulo Freire after he witnessed first-hand the effects of prescriptive approaches to education and social change. It has since become an umbrella term used to signify that people have the capability to reflect, think rationally, develop plans for future amelioration and implement change (Freire 1990). In order to fully appreciate the concept it is important to understand the history behind it. Prior to becoming a renowned scholar Freire (1985; 1990) was an educator and during his time in this field he identified two different methods of teaching and learning. The first is the banking method of learning where the teacher assumes the role of an expert and the learner is regarded as a vacant container which needs to be filled (Freire 1990:49). In this way the process of learning is reduced to one of making ‘deposits’ of information (Freire 1990). Through this method learners are expected to “patiently receive, memorise and repeat” what they have been taught (Freire 1990:46). This method discourages any genuine learning or interaction with the world of which one is part. It breeds docile
individuals who are incapable of ingenuity and are at ease with bearing the “title of welfare recipients” (Freire 1990:48).

The second is the problem-posing (Freire 1990:52) method of learning and it defies all that is embodied by the banking method of learning. It refers to a state of consciousness that entails actually being aware, of “exist[ing] in and with the world” (Freire 1990:49). With this method there are no positions of superiority. Instead through dialogue learning becomes a process of reciprocal sharing and understanding. Both teachers and students “become jointly responsible for a process in which all grow” (Freire 1990:53). Within this system one is encouraged to immerse one’s self in the world without fear of domination and is free to question or critique. Freire emphasised that within this system expression through dialogue is essential because it allows people to reflect which stimulates action, which in turn transforms the world (Freire 1990). More than dialogue being the pre-requisite for change, Freire believed that it was the not just the “privilege of an elite, but the birth right of all” (Freire 1990:46).

Having made the distinction between the two methods, Freire became an advocate of the latter. According to Freire, the combination of empowerment and “conscientization” (Freire 1985:67), leads to “people gaining an understanding of their situation, confidence in their ability to change that situation” (Servaes 1996:80). Based on Freire’s theories, the project needs to refrain from adopting a banking method of teaching the young women about FB and the risks it poses to their health. It would defeat its purposes if participants became passive recipients of its messages and services. Rather, they need to have a sense of their own agency in their health and finding solutions to challenges that jeopardise their health. Also, the passive absorption of information does not enhance maintained behaviour and social change.

Freire’s (1960- 1990) work suggests that if the young women are cognisant of all that Bilharzia entails, then the belief in their ability to combat it will increase. For example, if a young girl who frequented the river for recreation was educated about Bilharzia in a manner that left her convinced of her ability to avoid getting it; this may motivate her to seek other leisure alternatives. Once the severity of the danger this activity poses to her health sets in, its appeal may wane and she may seek other means of having fun. Also important about Freire’s (1985; 1990) work is that it highlights paths that the project needs to steer clear off if it intends to realise its goals.

In educating women about Bilharzia, the project would need to avoid treating them like containers waiting to be filled and rather aim to engage them. The parties involved in the
project need to open themselves up to the possibility of learning new things from the participants, that if applied to the project can contribute to its growth. Since Freire’s theories dismiss the notion of an expert, and “rejects the notion that knowledge production is a monopoly of professionals” (Kronenburg 1986 in Servaes 1996:82), this hints at a change of mindset by project staff towards the women. “Self-management is the most advanced form of participation” (Servaes and Malikhao 2005:171). This suggests that the FB project can only claim to be authentically participatory once it has successfully motivated participants to take control of their health. This can occur if hierarchies of authority are abandoned during interaction with the young women. However, it is also important to note that a lack of hierarchies of authority should not translate into a lack of structure (Cornwall 2008). Cornwall (2008) believes that as much as true participation entails mutual sharing and unity for the achievement of developmental goals, certain structures do need to be in place in order to “help build capacity, nurture voice and enable people to empower themselves”(Cornwall 2008:275). Within the project, this structure is offered by the professionals as they are the experts on how to avoid getting FB. The challenge for these professionals now is to encourage agency by these young women.

A critique that has been levelled at Freire’s approach to communication is that it is heavily reliant on dialogue as opposed to magnifying mediums such as television, newspapers and radio (Servaes and Malikhao 2008). This then limits the scope of change that a project can achieve. Although dialogue is an important component that determines the success or failure of an initiative, media tools such as radio and television help to accelerate the diffusion of information (Servaes and Malikhao 2008). Granted dialogue is appropriate in the early stages of communication with young women. However, it does not suit the long term ambitions of an organisation that aims to initiate changes in both women’s health and their attitude towards maintaining it. Furthermore, Servaes and Malikhao (2008) argue that the media is a critical educational tool that has the power to inform or mislead an audience. It can be utilised to reveal or obscure information thus controlling the manner in which people understand events (Servaes 2008). This supports the view that failing to integrate them (the media) into a project’s communication strategy severely restricts its impact.

Further criticism directed at Freire’s theories is that to an extent its view of development and participation is narrow and uncompromising to the point of being impractical. For example it strongly promotes “self-management” by beneficiaries of a project from the onset which is not always possible or realistic (Servaes and Malikhao 2008:171). It is unyielding in this
regard and fails to accept the idea of a community initiative gradually [my emphasis] progressing into a community run operation.

Participatory intervention critiques

Like other established ways of thinking that have been practiced and had their success determined by their aptitude to create change, the participatory paradigm has also been faulted. Within the participatory paradigm there is a fine line separating an organisation willing to offer assistance and one soliciting submission in a subtle manner because it has resources. Power dynamics come into play when people from an outside agency offer their assistance because the funds they can utilise to create changes put them in an “expert” position and render those in need submissive to them. Mohan (2001:158) argues that despite participatory approaches being about the “valorization of local knowledge” the relationship between the expert and non-expert demands that there be a decision maker. Due to their status, experts are generally the ones making the final decisions and this contradicts the core values of the participatory paradigm which stipulate that beneficiaries be involved from the initiation to the end of interventions. Kincaid and Figueroa (2009:1311) have also encountered this and believe that despite “the problem –specific nature of funding [that] often means change agents impose developmental goals on communities”, the “motivation and leadership needs to come from within the community itself” (Kincaid and Figueroa 2009:1311). This suggests that although the FB project has a lot to offer in terms of qualified staff that has a wealth of knowledge, the drive to expand its reach needs to come from the young women themselves.

Another concern Mohan (2001:160) raises is that in many instances interventions which claimed to be participatory worked to the advantage of what he refers to as “village elites”. They are people who are regarded as superior for various reasons such as the position they occupy in a community. This also violates the foundations upon which the participatory paradigm is constructed. In their work Kincaid and Figueroa (2009) stress the importance of overcoming unequal power relations and eradicating what they refer to as a “what’s in it for me?”attitude (2009:1317). According to them this negative state of mind can be the downfall of an entire project and they recommend dialogue to shift it into a “what’s in it for all of us?” attitude (Kincaid and Figueroa 2009:1317).

Issues of inequity as well as other conflicts that arise during the implementation of an intervention can be dealt with successfully as long as there is a “clear, ideal picture of the
future it wants to achieve” (Kincaid and Figueroa 2009:1317). In this way each individual can see that their contribution is valuable towards the achievement of the main goal (Kincaid and Figueroa 2009). This indicates the importance of making every young woman who volunteers their participation feel like they are an asset. In general during group activities those with strong personalities often dominate discussions and emerge as opinion leaders. The group members who are reserved are then overshadowed. Based on Kincaid and Figueroa’s work, this then suggests that the project needs to manage group interactions and ensure that every woman is made to feel that what she has to share is valid. Only then can the project claim to adopt a participatory approach.

For these scholars, the participatory paradigm is powerful enough to facilitate drastic changes which can improve the lives of beneficiaries greatly. It is best to bear in mind, however, that despite the best intentions, change agencies can “foster dependence” (Bandura 2004:149) when they fail to engage people fully. Therefore, every project needs to be realistic about the resources at its disposal and clear about the beneficiaries’ role because being overzealous can have consequences that can damage its image beyond repair. Another problem that can tarnish an organisation’s image is a failure to identify the type of participation it is prepared to operate within [my emphasis]. Cornwall (2008) details different participation typologies and based on her work we can surmise that every developmental project needs to be transparent about this. This is because at one end of the spectrum there are exploitative forms of participation that can lead to people over-estimating the rate of change a project can have in their lives(Cornwall 2008:272). The project needs to aim for the most advanced form of participation known as “self-mobilization”(Cornwall 2008:272) where all parties have a clear understanding of their role and the beneficiaries are in control with outside agents in the background providing “a framework of support” (Cornwall 2008:272).

**Assessing the Social Cognitive Theory: self-efficacy beliefs and role modelling**

Thus far the literature that has informed this paper highlights the need for the FB project to encourage a sense of empowerment and to engender a communal spirit if it intends to strengthen and expand its reach. However, a key area that needs to be discussed before solutions to the problems under examination are suggested is the concept of self-efficacy. This is a notion that is integral to Bandura’s social cognitive theory, which is often used within public health communication to explain behavioural patterns (Bandura 1995; 2004). Social cognitive theory explains how people acquire and maintain certain behavioural
patterns, while also providing the basis for intervention strategies or campaigns [my emphasis]. Further it proposes that an individual behaviour is the result of the interaction amongst cognition or information processing, behaviour, the environment and physiology (Bandura 1995; 2004). Bandura’s (1995) definition of self-efficacy introduced refers to an individual’s perceived ability to exert control over events in their life. Bandura (1995; 2004) believed that there is an innate need in every person to have control over circumstances that affect them and this deep need pervades every aspect of one’s life. When an individual feels as if any aspect of their life is beyond their control it “breeds apprehension, apathy, or despair” (Bandura 1995:1). Simply put, Bandura’s work implies that we all strive for control over every facet of our lives, and when circumstances beyond our control occur we feel disempowered. Feeling threatened by disease and being uninformed about the treatment options available is an example of a situation that would create a feeling of helplessness. As a result, “the capability to produce valued outcomes and to prevent undesired ones, therefore, provides powerful incentives for the development and exercise of personal control” (Bandura 1995:1). This means that individuals will embrace opportunities presented to them in order to feel in control of events in their life.

Where health is concerned, efficacy beliefs influence the course of action one takes with regards to either the prevention or management of disease (Bandura 2004). It also affects “the health goals that people set for themselves and the concrete plans and strategies for realising them” (Bandura 2004:144). Based on these statements, as a researcher within the project, I had prepared myself to assess perceptions of efficacy and to discover techniques of developing them if they were lacking. However, during the course of my interactions with young women and based on the observations made during the visits to schools, it was astonishing to see that their beliefs about following health advice were positive. To quote one young woman’s response after being questioned about volunteering to participate despite her peers disapproval:

"After I had filled in the form there were comments like “oh so you also filled in the form?” and others said “please go away with your bilharzia” and things like that from the boys you see? When we came back they would say “Weh...you have Bilharzia” but if you pay attention to that sort of thing it doesn’t get you anywhere in the end especially if you want to know (Interview 31 May 2012)."
Furthermore their level of confidence with regards to adhering to suggested behaviour changes such as going to their local clinic for regular gynaecological examinations or to seek contraception was strong. This is demonstrated by another interviewee’s response:

I would go but the one thing that might make me not want to go is that they scold us there. They scold you even if you want to start using contraception without having a child first. They don’t want that. But I would go and then it would be up to them if they refuse.

(Interview May 31).

These initial observations count as preliminary findings of this study. I am aware that presenting findings within a theory chapter is not the norm. However, this has been done in order to mobilise the theory. I had anticipated that their efficacy beliefs would be lower since studies suggested that “knowledge of health risks and benefits” inherent in following recommendations were the pre-requisites for their development (Bandura 2004:144). Furthermore, prior to their exposure to the project these young women had no concrete information about FB, its possible association with HIV contraction or the benefits of prevention (Kjetland et al, 2012). Therefore, I expected them to harbour self-doubt about their ability to cope with suggestions made by the health staff at the project such as ensuring that they know their HIV status. Discovering that they do not places into question what many scholars have said about self-efficacy. However, this study’s sample was small and results cannot be generalised.

In many HIV and AIDS research studies the social cognitive theory has been used to explain how those afflicted respond to the disease. In Singhal and Rogers’s (1999) review of the successful EE drama SoulCity, they review this theory. They state that vicarious learning (which is the same as what Bandura called role-modelling) is amongst the factors responsible for developing efficacy beliefs (Singhal and Rogers 1999). In the drama vicarious learning is stimulated by observing the behaviour of actors who serve as role models. Their portrayal of ideal behaviour conditions the target audience to believe that they too could imitate it and restore some measure of control back into their lives. In their assessment of the relationship between teachers’ approach to teaching and their students’ ability to learn, Goddard (et al, 2004) also make reference to self-efficacy. They claim that one has to first master an experience in order for one’s confidence to cope with it to be enhanced. They believe that this is “the most powerful source of efficacy formation” (Goddard et al, 2004:5). However, as
mentioned previously, many of the women who are part of the project have minimal information about Bilharzia. Further they appear not to have identifiable role models to imitate in terms of its prevention. Both examples may negate prevailing beliefs about vicarious leaning and mastery of experience being the pre-conditions for inbuilt efficacy beliefs.

Preliminary findings of this study have established that the majority of the project participants are confident in their ability to prevent FB even if it means making changes in their lives. An objective of this study is to discover ways of maintaining this belief amongst young women. Although it has been suggested that vicarious learning is not a strict requirement for developing efficacy beliefs, with regards to maintaining them, it has its merits. Bandura states that “seeing people similar to themselves succeed by perseverant effort raises observers beliefs that they, too, possess capabilities to master comparable activities” (Bandura 1995:3).

If for example, the FB project chose to disseminate messages about FB through an EE technique such as acting out a drama that incorporated characters seeking FB treatment and being ridiculed by their peers, it may strike a chord with young women. By witnessing characters that are similar to them in age and background persevering despite being confronted by negativity, their conviction in their ability to do the same might increase. Furthermore, this vicarious learning spares them the discomfort of having to experience disease first-hand. Instead it teaches them to triumph over such situations should they arise. Another important advantage of integrating vicarious learning into communication strategies is that it increases collective efficacy (Goddard et al, 2004; Bandura 2004). This refers to a group’s certainty in their ability to accomplish the goals they set for themselves and their willingness to persist when they encounter setbacks (Goddard et al, 2004; Bandura 2004). According to Smith et al (2007) it is in the best interests of every project to maintain solid collective efficacy beliefs because they are more steadfast than individual efficacy beliefs, particularly where disease is concerned.

This is due to several reasons. Firstly, collective efficacy makes it easier to cope with “courtesy stigma” (Goffman 1963 in Smith et al, 2007: 58) which is the discrimination shown to individuals who choose to associate with those afflicted by a disease. For instance in their study about the social implications of HIV Smith et al (2007) discovered that those who expressed any sympathy towards people with the virus were subjected to public scrutiny.
and were then questioned about their own HIV status. They also found out that only the community members who were confident and impervious to social judgment were the groups who volunteered their assistance to those living with HIV. This then implies that the project needs to work at maintaining collective efficacy beliefs in young women because such solidarity will determine their response to possible public pessimism [my emphasis]

Possible barriers to efficacy beliefs

Discovering that young women’s perceived self-efficacy is high is an important finding because as mentioned previously it influences the actions they will take. However, there are factors that can potentially inhibit these high levels of efficacy and trigger negative reactions towards the project. Judging by the responses documented earlier from a study participant, the first of these is a community level constraint. The respondent indicated that at the local clinic the staff tends to rebuke women her age when they seek treatment that can prevent a multitude of health problems. This is problematic because it makes it impossible for women to fulfil some of the health suggestions made by the health staff at the project. It also reverses any attitudinal and behaviour changes that may have occurred following exposure to the project. If an authoritative figure such as a clinic nurse disapproves of an action a patient takes regarding her health, then the value of that particular action becomes questionable to her.

The most plausible explanation for the disapproval when women seek these types of services at clinics is that they are probably perceived as challenging social norms. These are the “collectively agreed-on standards and rules that are adhered to and accepted by the members of a particular society or group” (Kincaid and Figueroa 2009:1329). For instance, it is an accepted norm in many Zulu areas for young women not to engage in sexual activity due to virginity being a source of pride (Taylor et al, 2007:31). As a result it is frowned upon when they seek contraception for instance, probably because it is perceived as a violation of a time-honoured social rule.

To combat this social resistance, Kincaid and Figueroa (2009) suggest communication through dialogue in order to generate “social reciprocity” (Kincaid 2009:1323). This concept “refers to the mutual interchange of favours, privileges, and benefits in a relationship” (Kincaid and Figueroa 2009:1323). Basically, if an act of kindness is performed at any level be it individual or communal, the recipient of that act is expected to return it in kind. Failure to do so results in the recipients’ moral fibre being questioned. Based on Kincaid and
Figueroa’s work, in the construction of the communication strategy the project needs to project an image of an organisation rendering a free service that will benefit young women. The second challenge is to alter possible negative perception about issues of sexuality, gynaecological health etc. and turn them into accepted social norms [my emphasis]. The idea behind this is that conservative social settings that pride themselves on their values can be won over by being convinced that the projects work is a benevolent act that can only be repaid in appreciation and approval.

The second factor that may undermine self-efficacy based on the young women’s response is peer mocking. According to Smith et al (2007) self-efficacy also refers to people’s perceived capability to manage emotional difficulties. As adolescents they are at a delicate phase in their lives. This then casts doubt on their capacity to cope with an emotional burden like mockery, particularly if it is from members of the opposite sex. A possible solution to this problem is suggested by Bandura (2004:150) in the form of creating what he refers to as a “socially mediated pathway” (Bandura 2004:150). During this process participants within a project are offered individualised support. Bandura (2004:150) suggests utilising interactive technology because it can provide confidential “social support and guidance during early periods of personal change and maintenance [which help to] increase long-term success”.

Nowadays there are many technological tools available that can be used to facilitate interaction with young people. The cellphone is an example of such a tool. Its advantages include its wide availability, ease of use and it allows for feedback which helps to monitor the impact an intervention makes. According to Bandura (2004:149) if social support is offered in a manner that does not create complete dependence and instead encourages self-reliance, it can effectively strengthen “coping efficacy”.

**Social efficacy boosters**

The phrase “no man is an island” is of particular relevance to projects that aim to maintain high efficacy beliefs at all times. It is important to enlist the help of peers, family members and other influential parties to re-enforce an individual’s self-belief when it wanes. Bandura (2004) attests to this in his evaluation of school based programmes that have tried unsuccessfully to change health habits without social support. His findings apply to the project because it can be argued that it falls under the category of school-based programme since that is where initial contact with young women is made.
By structuring its communication strategy in an intersectoral or integrated manner that accommodates participants’ families and the wider community body, the project would draw attention to the fact young women’s health is an important matter worthy of support (Bandura 2004). Based on Bandura’s (2004) work we can conclude that when influential figures in people’s lives rally behind them during their quest to achieve important goals, their commitment to them increases because they have a revitalised sense of self belief.

Drawing on the previously mentioned preliminary results and the literature which specifies the virtues of having strong efficacy beliefs, the goal of this study now is to assist in encouraging young women to retain them despite the constraints present. The scholars examined above have suggested different ways of accomplishing this and this study will investigate how their ideas are necessarily realistic for participants within the project.

**Applying the Extended Parallel Process Model**

As established earlier in the study, in general people have little correct information about Bilharzia and the extent of the damage it can cause in the body (Schall 1995). Health interventions that have encountered similar problems of trying to convey factual information to the public about a disease have resorted to incorporating what is known as fear based messages into their communication strategy. This may be a worthwhile technique to integrate into the project’s future communication campaign; therefore it is worth further exploration. Firstly, fear based health campaigns work by triggering a frightful reaction to the threat of disease. Once this reaction is elicited the hope is that it will motivate an individual to make the necessary behaviour or attitude changes in order to avoid getting the disease. Fear has been used extensively in health campaigns such as those that aim to encourage early breast cancer detection (Ewoldsen-Roskos, *et al*, 2004) as well as those that aim to prevent HIV and AIDS infection.

Fear based campaigns have encountered their share of resistance not only because they tend to incorporate graphic imagery that instantly evokes fright, but because they raise moral concerns. Some experts believe that it is unethical for professionals to have to recourse to what they term “amateurish, misguided” (Green and Witte 2006:245) schemes that inhibit “one’s ability to consider dispassionately a range of responses to a perceived health threat” (Green and Witte 2006:245). Other arguments which fuel the controversy are the fact that many question their capacity to sustain permanent behaviour changes (Green and Witte 2006). However, in her work, Kim Witte (1992) developed the Extended Parallel Process
Model (EPPM) model which is a revision of earlier fear models. Unlike previous ones, “the essence of this model is that perceived threat (causing fear arousal) motivates action and perceived efficacy (causing hope) determines the nature of that action” (Green and Witte 2006:245).

To explain this more lucidly, the perception of a threat is reviewed according to two different factors with the first being “perceived susceptibility” which Smith (et al, 2007:56) defines as “people’s subjective perception of the likelihood that they will face the situation”. This means that people will evaluate the threat according to the probability of it affecting them “(e.g. am I at risk of experiencing this threat?)” (Smith et al, 2007:56). The second is “perceived severity” which refers to the evaluation of seriousness or how injurious the threat can be to the individual (Smith et al, 2007:56). Once the evaluation of the threat is made and deemed severe enough to warrant prevention, it will then prompt the individual to take action.

The sort of action taken is motivated by two factors which are “perceived self-efficacy” (Smith et al, 2007:56) which as discussed earlier in the study refers to the belief or confidence to achieve a recommended outcome. The second, “perceived response efficacy” refers to an individual’s conviction that the suggested recommendation will be effective in avoiding or eradicating the threat (Smith et al, 2007:56). Based on this model, an individual will only be wary of FB if they believe the likelihood of their contracting it is high. In addition they need to feel the adverse effects of the disease are worth taking preventative action. Furthermore, their motivation to seek ways to avoid infection will depend on their assuredness about following advice such as avoiding fresh water sources which harbour FB parasites or committing themselves to regular gynaecological examinations.

The theorists who believe that fear based messages work when combined with self-efficacy defend their position in several ways. Firstly, they feel that that social context is an important variable that determines the success or failure of fear based messages. They maintain that many of the critics are based in America where factors such as their “value system”, diverse religious views and political climates come into play (Green and Witte 2006:246). However, in African settings where the atmosphere concerning these factors is not as volatile, fear based campaigns have worked well (Green and Witte 2006. For instance in Uganda, HIV/AIDS pervasiveness diminished by 66% from the period 1992 to 2002 and it is believed this is due to fear based campaigns inspiring people to alter their sexual behaviour (Green and Witte 2006).
Guidelines for integrating fear into health campaigns

Despite these conflicting views, this study leans towards the latter because of the strong empirical evidence supporting them. That being said, scholars who support the use of fear in health campaigns stress the need for communication practitioners to exercise caution when crafting fear tinged messages for several reasons. They justify this by stating that an excessive dose of fear may trigger cognitive defences towards the campaign. For instance, Soames Job (1988) discovered that messages that induced high levels of fear about the dangers of risky behaviours were met with resistance by the target audience. The coping mechanism triggered by the intensely frightening messages led them to justify their actions with statements such as:

I have been smoking/speeding/not wearing a seat belt for years and it hasn’t harmed me (yet, or to my knowledge). Therefore, the health promotion campaign is wrong; or I am special and immune in some way (e.g., a very good driver) (Soames Job 1988:166).

Brug et al (2001) report witnessing similar reactions to poorly crafted fear based campaigns. They believe that the reason behind the dismal failure of some health campaigns is because during their construction practitioners neglect to offer a solution. This then undermines the targets belief that they can cope, as a result they will devote their energy towards “fear reduction or control instead of threat reduction or danger control” (Brug et al, 2001:308). If for instance the project developed a media campaign that focused only on cautioning people about the negative effects of FB by depicting unpleasant images of what extreme cases of FB look like without suggesting ways to minimise or avoid the risk, this may prompt them to focus on blocking the information out. They may use justifications such as “I feel fine, I have been swimming in the river since I was a child, so did my mother and she is fine”, etc. The rate at which they choose to engage in the risky behaviour in an attempt to convince themselves that what they saw in the campaign was an exaggeration perhaps, may become exacerbated (Brug et al, 2001).

If the fear element is to be integrated successfully into health campaigns, experts suggest the following guidelines: Firstly, communication practitioners need to be aware that to a great degree it is the manner in which a message is framed that determines its persuasiveness [my emphasis] (Brug et al, 2001). If the intent of a message is to arouse fear and ultimately behaviour changes, Brug et al (2001) suggests that the reasons supporting the recommended behaviour need to be strong which refers to argument strength [my emphasis]. When subtle
fear is evoked in a target population and it is accompanied by a strong argument for the advocated change, the results tend to be more favourable than those that rely solely on the fear factor. To demonstrate the difference between weak and strong arguments Brug et al (2001) uses slogans that were tested to see which one would encourage women to heed cancer warnings and perform breast exams on themselves.

The first: “Performing BSE is a nice way to be intimate with yourself” (Brug et al, 2001:310), was deemed as the weaker of the two probably because the motivation for women to do this was not compelling enough. The second: “By performing BSE you are able to detect breast cancer in an earlier and therefore more treatable stage” is clearly stronger (Brug et al, 310). This is because the threat of cancer is presented as an intimidating yet easily avoidable reality if the advice of performing breast exams is followed. The message is not only conveying the benefits of prevention, it also highlights the ease with which this can be done thus strengthening efficacy beliefs.

Secondly, Soames Job (1988) observed that after some time campaigns that elicit high reactions of fear eventually anaesthetise their targets to the threat of disease. This is (as explained above) due to their developing coping mechanisms that strengthen their resistance to the message. In fact his colleagues Brug et al (2001) believes that fear appeal messages, understated ones at that, work best mainly to promote the early detection of disease[my emphasis]. As far as motivating people to take action, “positively framed” messages which demonstrate the benefits of adhering to recommendation have been found to be more effective (Brug et al, 2001:315). These findings indicate that if fear is applied in small doses it can draw attention to the dangers associated with disease. However, once an audience’s attention has been captured, messages that emphasise their ability to successfully combat or prevent it need to be implemented in order to stimulate behaviour change.

**Conclusion**

The merits of the participatory paradigm were explored and the criticisms against it were documented in order to highlight the fact that every course of action has potential pitfalls. Freire’s (1990; 1985) work demonstrated the difference between genuine learning and pointless recycling of information. The chapter also discussed the weaknesses of Freire’s hypotheses on the correct way to approach learning and evoke individuals’ capacity to change their circumstances. The social cognitive theory (Bandura 1995;2004) and EPPM (Green and Witte) were reviewed in order to explain that when channelled through role
modelling and combined with moderate fear, interventions can alter people’s lives for the better, thus enhancing the impact of health campaigns. The concepts discussed in this chapter are possibilities for the project to explore, and serve as the lens through which this study’s empirical data will be analysed. In sum all the theories examined in this chapter frame the discussions in the chapters that follow. Most importantly, they relate to each other and can be implemented into a communication strategy that not only informs but encourages agency.
Chapter Four: Unpacking the Methodology

Research paradigms

This study operates within the framework of two related paradigms. The first is the interpretative paradigm that “examines how individuals and audiences interpret content” (Teer-Tomaselli 2008:9). A substantial portion of this study is devoted to understanding how the young women who have been to the project receive media content. This is due to the fact that in order to move forward with the implementation of the most suitable mediums that can disseminate FB information; the project needs to understand the possible limitations of existing ones. The interpretive paradigm permits further probing into this matter. Further, this paradigm not only contradicts the notion of people as passive receivers of media messages, it accommodates their “subjective human interpretation...of meaning” (Teer-Tomaselli 2008:39). There is value in subjective interpretation because it allows for media messages to be tailored in a manner that facilitates instant comprehension in a context-sensitive fashion.

The second paradigm that this study is working from is the radical humanist paradigm because it “exposes power relations in terms of class, race and gender” (Teer-Tomaselli 2008:39). As mentioned earlier, the study participants are a minority group despite being in an area where their ratio exceeds that of their male counterparts. Also, they are from diverse geographical locations and therefore have different standings on class hierarchies. Their experience of different media tools will be explored in relation to these variables. Teer-Tomaselli (2008:39) stated that within this paradigm an audience is believed to be endowed with the “agency [needed] to make meaning”. Thus far the concept of agency has been examined at length using mainly Bandura’s (1995) work, as well as the principles of the participatory paradigm. The methods used will indicate whether participants are conscious of their agency and the possibilities they can create for themselves through being aware of it.

Qualitative research

This chapter aims to provide a detailed account of the methods that were employed in order to generate the data to be analysed. Since this is a qualitative study and the tools used to obtain the data are favoured within the qualitative research field, it is important to have a proper grasp of this research approach. Scholars agree that qualitative research refers to research that seeks to understand how people make sense of phenomena that affects their lives (Terre Blanche and Durrheim 1999; Flick 1998). It is characterised by several features
including precise “description, analysis and interpretation” (Wolcott 1994:9). It suits the purposes of a researcher such as myself who is an outsider seeking to see the world through the eyes of young women. This study aims to understand the logic that informs their health decisions, actions and general perceptions. The ‘lessons learnt’ from this data will be comprehensively describes and analysed in order to be considered for inclusion in a possible future project campaign.

**Research Design**

Qualitative studies are initiated to answer the specific nuances of a research subject (Terre Blanche and Durrheim 1999). The questions under investigation in this study are relatively novel because record of a similar study in KwaZulu Natal has yet to surface. Therefore, this study can be categorised as exploratory. Terre Blanche and Durrheim (1999:39) assert that exploratory studies “employ an open, flexible and inductive approach to research as they attempt to look for new insights into phenomena”. This means that innovative solutions to research problems are deduced using the data set. Solutions emanate from the data set as opposed to being prescribed by the researcher (Hardy 2011). FB has been researched before as discussed in the previous chapters. However, these studies have attempted to understand the biomedical impact of the disease on the body as opposed to measures that can be instituted to improve communication about it. It was anticipated that the responses gathered from the participants who bear the brunt of FB, would reveal new ways in which communication can be enhanced. Therefore, the methods used were not the rigid (often restricting) types common in other disciplines (Flick 1998). Instead, the qualitative tools used gave participants the freedom to suggest different ways in which communication can be improved.

**Sampling**

I elected to use a non-probability sampling method known as quota sampling. This type of sampling is advantageous to researchers because of the ease with which participants can be selected (Terre Blanche and Durrheim 1999). This method also allows researchers to pre-determine the number of participants they wish to interview and the requirements they need to meet in order to qualify as part of the sample (Mack *et al*, 2005). In order to be considered for inclusion in this study, the young women had to be sixteen years of age or older (See Appendix C and D). They had to have already been to the FB project and consented to a gynaecological examination. In total there were twenty young women from ten schools across the Ugu District. Half of the interviewees that were interviewed were from rural
schools. The other half were from peri-urban schools. The level of schooling ranged from grades eight to twelve. Since qualitative research is concerned about the quality of responses instead of the ratio of participants, I was comfortable with the number. All the interviews were conducted at the FB project clinic upon their second visit. This eliminated problems related to logistics because no travel expenses were incurred by either the participants or myself.

Selection of research methods

The methods employed in this study were selected on the basis of their capability to document participants’ viewpoints. The amount of time spent in the research area interacting with them generated substantial data. A single method would not have adequately captured all of it. This then necessitated the use of more than one research instrument to produce and collect the data. Employing different research methods allows a researcher to assess the quality of their findings by presenting them from different angles (Terre Blanche and Durkheim 1999). As a result I chose two qualitative methods that I believe complement each other when combined. They are participant observation and in-depth semi-structured interviews (See appendix E).

Participant observation

Alan Bryman (2008:402) describes participant observation as a process where the “participant observer/ethnographer immerses him-or herself in a group for an extended period of time, observing behaviour, listening to what is said in conversations…and asking questions”. Having arrived at the FB project site in early January 2012 intent on absorbing as much information as possible, this method oriented me to surroundings that were initially daunting. This disconcertion was due to the fact that despite being a native Zulu speaker and sharing the same cultural background, every social setting has subtle differences that one needs to acquaint one’s self to. This type of observation, at the start of the research process where I took the time to familiarise myself with the research environment, is known as “descriptive observation” (Flick 1998:142).

As time progressed, the FB project conducted meetings with different headmasters of schools as well as with the parents of school going young women. My presence at these meetings allowed me to gain valuable direct access to the inner workings of community member’s lives. Also, I had the opportunity to observe even the almost imperceptible reactions of
school heads to not only Bilharzia as a disease, but the presence of a research initiative in their area. At the meetings community members spoke candidly. I observed the following: the issues that arose about Bilharzia, expectations following young women’s involvement with the project and cultural taboos. This type of purposeful observation can be understood as “focused observation” (Flick 1998:142).

The observations made at the meetings as well as those made further on during other informal visits to schools were documented through field notes. All communication that occurs in the field is an “explicit part of knowledge production” (Flick, 1998:6). This assertion conveys the function of field notes as an integral aspect of qualitative research that captures both the researcher and participants’ experiences (Flick 1998). In order for the notes to be as comprehensive as possible I followed Spradley’s (1980:78) guiding principles on aspects to consider during their documentation:

**Table 1:** Adapted from Spradley (1980:78)

<table>
<thead>
<tr>
<th>Guidelines on Field Note Taking</th>
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<tbody>
<tr>
<td><strong>1. Space</strong></td>
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<tr>
<td><strong>2. Actor</strong></td>
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<tr>
<td><strong>3. Activity</strong></td>
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<tr>
<td><strong>4. Object</strong></td>
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<td><strong>5. Act</strong></td>
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<td><strong>6. Event</strong></td>
</tr>
<tr>
<td><strong>7. Time</strong></td>
</tr>
<tr>
<td><strong>8. Goal</strong></td>
</tr>
<tr>
<td><strong>9. Feelings</strong></td>
</tr>
</tbody>
</table>

Basically these tabulated steps guide a researcher to write notes that are as authentically representative of occurrences as possible (Wolfinger 2002). “This can aid in the recall of details that might otherwise have been forgotten” (Wolfinger 2002:91). In his paper that details how field notes can enhance ethnographic research Nicholas Wolfinger (2002) outlines several practicalities that need to be considered if they are to be employed as a research tool. Amongst these is “tacit knowledge” which he believes outweighs other elements of note taking in its importance (Wolfinger 2002:88). This term refers to the
“background knowledge” that assists researchers to make inferences about the real meaning behind their observations (Wolfinger 2002:88). In the course of this study his statements proved accurate as the background knowledge I had about the norms of Zulu culture and teaching methods at urban and peri–urban schools contributed to my interpretation of events in the field.

Due to my status as a researcher being known by all parties at the meetings and schools, the note taking was accepted and did not affect proceedings. Furthermore, the openness about being a researcher minimised the risk of “going native’ (Flick 1998: 144). This is a problem encountered by researchers who struggle to maintain objectivity due to being immersed in the field for extended periods of time (Flick 1998). Despite being given permission to observe them during moments when they were emotionally vulnerable, they continued to regard me as a researcher.

Mack et al (2005) suggests that during the observation process researchers need to be well prepared and remain objective throughout. Although my role as a researcher was clear and I was able to maintain a professional relationship with participants, I struggled with remaining objective in all instances. This was due to several reasons. Firstly, due to some of the observation taking place at the project offices, the participants were initially nervous and more composed than necessary. Despite my best efforts to assure them that they could be as informal and jovial as they wanted to be, many of them maintained their impenetrable composure. It was only when I began to share my own experiences and my own absurd assumptions about what I had thought Bilharzia to be that they relaxed. I struggled to remain objective whilst sharing some of my personal experiences with gynaecological exams and other personal matters. It is difficult to remain objective when you make yourself vulnerable in the presence of an anxious teenager with the hope that they will reciprocate with sharing their perceptions.

Furthermore, probably on account of their age, many of their opinions on matters such as sexual health were misguided. I became aware of this during several casual conversations that we had. Although, it was vital to avoid giving them the impression that they were being chastised or judged, I felt a moral obligation to gently correct them based on the knowledge I had gained from the FB Project (Mack et al, 2005). I also justified my actions by reminding myself that the title of this dissertation makes reference to addressing misconceptions.
Therefore, by casually imparting correct information I was staying true to the objectives of this study.

**In depth, semi-structured interviews**

The observations that I make as a researcher about the issues under examination can easily be dismissed as the subjective speculation of an outsider. However, interviews from the population under study cannot be disputed as easily. The interview as a research method allows the researcher to get to the crux of problems and facilitates unrestrained discussion with participants (Flick 1998). This can be done by listening intently to what the participant has to say, probing further to reveal underlying issues or to gain clarity on sensitive matters that are difficult to speak about (Mack *et al*, 2005). I opted to conduct in-depth semi-structured interviews for several reasons. Firstly, they give participants the freedom to speak their minds without digressing from key issues (Flick 1998). Secondly, they promote role reversals because the researcher ceases to be the expert and becomes the student instead (Mack *et al*, 2005). Thirdly, the insights gained within the confines of an interview room (where a single individual is interviewed) are invaluable since they are almost impossible to obtain in a group setting (Mack *et al*, 2005). The interviews were conducted using an open ended question guide (See Appendix E) (Flick 1998; Mack *et al*, 2005). Every participant was asked the same set of questions during the interviews. Throughout the duration of the interviews, there were deviations from the interview guide. This was done deliberately to ensure that the interviews assumed a conversational and natural tone (Mack *et al*, 2005). The interviews were recorded and translated at a later stage. Participants were informed of this verbally and in writing (See Appendix C).

**FB Projects Communication Sequence**

In order to adequately review the project’s current communication, it is important to understand the different phases of this process. They are illustrated in the table below:

**Table 2**: Stages of the FB Project’s Participation Process

<table>
<thead>
<tr>
<th>Contact School</th>
<th>Visits are arranged. Arrangements for parents meetings at schools are made</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Project Team visits school</td>
<td>Talks are conducted and the following are explained: FB, the projects study and the</td>
</tr>
</tbody>
</table>
2. **FB Project arranges a second visit**

   Permission to speak to participants regarding the following: Individual informed consent forms (IC’s) and Interviews

3. **Project Fetches Consenting Participants to its Clinic**

   The following are explained: the personal interview, biological samples (urine, blood), examination (height, weight and the gynaecological examination undertaken by a female doctor)

4. **Samples are tested and Participants receive Treatment**

   Young women are provided with the following health services: STD treatment, contraception services to those who request it, HIV testing (before and after counselling). Those participants whose health needs are greater than the projects resources are referred to the local hospital. Afterwards light refreshments are provided

As depicted above the first phases involve establishing relations with the schools from which prospective participants are. The project considers it imperative that parents are notified about its work. Therefore, arrangements for parents meetings are made relatively early in the communication process. A challenge that is frequently faced by the project is that in many instances attendance by the parents at these meetings is poor. Once permission has been granted by the schools, the project team delivers introductory talks which detail Bilharzia as a disease, the goals of the projects study, as well as the implications of involvement. After these initial talks, the team re-visits schools to conduct more comprehensive individualised sessions with those young women willing to participate. They are then collected and brought to the projects clinic where all the information they have been furnished with is re-iterated. They then undergo various tests and a gynaecological examination. The latter entails examination using a medical instrument, known as a speculum, which is inserted vaginally\(^\text{11}\). This examination is critical to the accurate diagnosis of FB (Kjetland *et al*, 2012). The fact

that each procedure that participants undergo is voluntary is emphasised continuously. Importantly, those young women who indicate an interest in knowing their HIV status are granted the opportunity. Further, in the event that diseases such as STD are detected, treatment is provided. These different stages are vital to the overall success of project. The problems encountered during each of them will be discussed in forthcoming chapters.

### Ethical considerations

A key issue that I tried to be mindful of throughout the course of this study was that of ethics. It is a priority in every field including that of participatory research. The consensus amongst many researchers that are ethically conscious is that the well-being of the participants matters above all else (Mack et al, 2005). I associate myself with these researchers and thus during the observation and interview periods I took care not to violate any of the participants’ rights. During the interviews I ensured that participants’ decision to be involved was based on their being well informed (Mack et al, 2005). All the details pertaining to the study were disclosed. They were aware that the interview sessions would be recorded and documented in dissertation form. They were provided with an informed consent form written in either Zulu or English. It detailed the nature of my involvement with the FB project, the institutions supporting the study and the extent of their participation. Many of them opted for the English version of the form despite it being a Zulu-speaking community as they claimed it was quicker to read. Before the interview commenced they were also required to consent verbally. They were also informed that they could decline participation at any time during the interview with no repercussions. They were also not obligated to answer any question that brought them distress of any kind. In addition, the majority of them chose to withhold their real names opting for pseudonyms out of fear that their real identities could be traced. I respected their right to request this and in an effort to ease their minds further, the names of their schools will not be disclosed at any point in this dissertation.

### Data analysis

The data will be analysed using a manual thematic analysis. This means that no software packages are used. The data obtained was rich and elaborate, however it was a quantity that could be managed and sorted without the help of technology. This method of data interpretation is used for both the interview portion of the findings as well as the field notes. It is a “form of pattern recognition within the data where emerging themes become categories
for analysis” (Fereday and Muir-Cochrane 2006:4). The table below illustrates the entire thematic analysis process:

**Table 3: Phases of Thematic Analysis-Adapted from Braun and Clarke (2006: 87)**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Familiarise yourself with your data:</strong></td>
<td>Transcribing data (if necessary), reading and re-reading the data noting down initial ideas.</td>
</tr>
<tr>
<td>2. <strong>Generating initial codes:</strong></td>
<td>Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.</td>
</tr>
<tr>
<td>3. <strong>Searching for themes:</strong></td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme.</td>
</tr>
<tr>
<td>4. <strong>Reviewing themes:</strong></td>
<td>Checking if the themes work in relation to coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.</td>
</tr>
<tr>
<td>5. <strong>Defining and naming themes:</strong></td>
<td>Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definition and names for each theme.</td>
</tr>
<tr>
<td>6. <strong>Producing the report:</strong></td>
<td>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature,</td>
</tr>
</tbody>
</table>
The data is read and arranged according to the different themes that generate from it. The themes were identified after countless hours spent perusing the data sets. The most compelling ones that surfaced continuously were the first to be deemed worthy of further analysis. The “thematic map” below further illustrates how one of the main themes was developed (Braun and Clarke 2006:90):

![Thematic Map](image)

**Figure 1: Thematic map depicting a theme that forms part of the final analysis**

As indicated in the diagram above, one of the main themes that were selected for analysis was the contraception issue. The arrows indicate the subthemes related to this subject (Braun and Clarke 2006). In order to derive the final themes the data was read repetitively and extracts that added to a respective theme were identified. Afterwards the “validity of individual themes in relation to the… data set as a whole” was assessed (Braun and Clarke 2006:91). Once I was satisfied that my themes formed an intelligible pattern that contributed to my overall argument, I settled on them for analysis (Braun and Clarke 2006). I will now explain this more lucidly using Figure 1 as an example. While reading the data, responses regarding contraception emerged continuously. Since my goal was to provide an accurate representation of young women’s attitude towards different facets of their gynaecological health and the FB project, I decided their thoughts on contraception would add value to my final arguments. The overarching opinions (subthemes) that could support the discussion related to contraception were then identified (Braun and Clarke 2006). Other themes that comprise the final findings chapter were selected in a similar manner.

The decision to conduct a thematic analysis was influenced by the following reasons: firstly, it is a convenient method that can be mastered easily and accommodates both researchers and study participants (Braun and Clarke 2006). As a researcher it allowed me to thoroughly immerse myself in the data set in search of the answers to the research questions. By the same
token, the research participants’ thoughts can be presented through what is referred to as “thick description” (Braun and Clarke 2006:97). This means that findings can be described at length and even seemingly minute details can be read meticulously. As a result, the essence of participants’ thoughts is adequately captured.

Secondly, a thematic analysis “can highlight similarities and differences across the data set” (Braun and Clarke 2006: 97). This is an important characteristic of this method because both the interview and field note findings can be compared against each other. I do concede that the field notes are subjective because due to their being based on personal observations. Before being a logical researcher, I am a human being with inherent emotion and personal bias. The environment that I was embedded in further amplified those emotions and biases. However, in no way was my subjectivity a limitation because as Flick (1998:6) asserts: “researchers reflections on their actions and observations in the field, their impressions, irritations, feelings and so on, become data in their own right, forming part of the interpretation”. This suggests that the emotions expressed in the narrative assist the reader to get a more vivid and balanced understanding of the situations that I describe.

Also, the decision to refer to myself in the first person (“I”) instead of in the third person (e.g. “the researcher”) was taken consciously. In the early chapters of the dissertation first person references are used minimally in order to create the distinction between scholars’ work and my interpretation of it. In the latter chapters they are employed more liberally for two reasons. Firstly, they are intended to denote my positioning within the study due to it being an ethnographic one. Thus far the ethnographic nature of this study has been implicit. However, at this point in the dissertation it is made more explicit in order to frame the final discussions. Secondly, although there was a concerted effort on my part to remain neutral and rational, my voice can be detected particularly in the final analysis. In this way the study can be categorised as reflexive. According to Ruby (1980:266):

To be reflexive is to be not only self-aware, but to be sufficiently self-aware to know what aspects of self are necessary to reveal so that an audience is able to understand both the process employed and the resultant product and to know that the revelation itself is purposive, intentional and not merely narcissistic or accidentally revealing.

Essentially this means that when presenting work they claim is reflexive, researchers need to make certain considerations. First they need to find the balance between subtly communicating their presence and subjectivities in their works and dominating it to an
excessively personal extent (Ruby 1980). For instance while I make the reader of this dissertation aware of subjective elements of my interpretation of the findings, I am obligated to present them in a manner that reflects events as they happened without misleading the reader [my emphasis]. There needs to be a purpose behind every assertion I make in order to stay true to the original objective of this research which was to give young women [my emphasis] and not myself, a voice. Secondly, the reader needs to be aware of the methodology used and how it contributed towards garnering the final findings (Ruby 1980). In so doing the reader has a fairly accurate mental picture of the entire research process. In sum, taking a reflexive approach to research allows the audience to understand precisely how the researcher set about answering the research questions and the components that may have influenced the final findings (Ruby 1980).

Another important attribute of thematic analysis is that it allows a researcher to analyse findings at a “latent level as opposed to a solely semantic” one (Braun and Clarke 2006:84). At the semantic level the goal is to present the findings as they are with no intention of conducting a deeper analysis (Braun and Clarke 2006). The issues that surface are merely described and not scrutinised further (Braun and Clarke 2006). In contrast at the latent level the researcher “goes beyond the semantic content and starts to examine the underlying ideas, assumptions and conceptualizations” (Braun and Clarke 2006: 84). With the study objectives in mind, the findings were analysed at the latent level. It would have defeated the purposes of this study if the findings were simply described and not interrogated further. In order to fulfill the study goals, the findings were analysed within the framework of the theories that were introduced earlier such as self-efficacy (Bandura 1995), fear appeal (Kim Witte 1992; Green and Witte 2006) and those of participation (Melkote and Steeves 2006).

**Limitations**

*Negotiating Between Two Disciplines*

In Chapter Two Scalway’s (2010) work was employed in order to explore the merits of combining different disciplines during research. This study intersects biomedicine due to the nature of the disease being investigated (FB) and the approach (communication) utilised in order to examine some of its impact on participants. Scalway (2010) outlines what are predominantly the virtues of merging two disciplines. During this study; however, there were challenges in this regard. Being a communication student embedded within a science-driven project necessitated navigation through the conflicting aspects of these two fields. For
instance, in the communication field it is the norm to examine an issue from different perspectives thus presenting a debate around it. Including recommendations within a dissertation however, is considered unconventional. This study was undertaken with the intention being to abide by these standards to which I am accustomed. This was not possible as authorities at the FB project were unwavering in their requests for recommendations to form part of the study. As a result of this, the discussion of the latter portion of this dissertation focuses strongly on communication intervention suggestions for the project’s future communication campaigns.

Another issue that needed to be reconciled due to interdisciplinary differences was the academic style of this dissertation. To all intents and purposes this study adopts an ethnographic approach. Within the communication and cultural studies discipline, detailed explications of phenomena that arise during the research are permitted. As mentioned earlier this is known as “thick description” (Braun and Clarke 2006:97). Within the science field, however, factual reports that exclude anecdotal evidence are preferred (Albert et al, 2008). As a result of this, in an earlier draft of this dissertation, the perceptions that were discussed were misconstrued as ‘fact’ by some project members. It then needed to be clarified that the perceptions that are presented made no claims to an ultimate Truth. In no way are they scientifically proved. They are merely people’s beliefs that were compiled and interpreted in order for the FB project to understand and address through their future communication strategy.

Budget and logistics

Due to logistical and budget constraints this study did not work with a larger sample of young women. This was considered a limitation due to every opinion being valid and having the potential to contribute to the wider FB Project’s research. Despite this, this study is both valid and rigorous. This is because based on the observations I have made thus far whilst in the field; young people are highly opinionated, insightful and eager to share their views. Therefore, they are entitled to a platform where they can be heard. In retrospect had these limitations not existed the findings would probably have been the same due to the pattern of the responses indicating data “saturation” (Mack et al, 2005). This means that the sizeable portion of the responses of the participants were in accordance with each other. I doubt, therefore, that there would have been differences in opinion had the sample size been increased.
Time

Another factor that impacted negatively on me during the research period was time management challenges. Being embedded in the FB project led to my acquiring responsibilities that affected the proper management of my time. At the onset the goal was to interview participants, document their responses as well as my observations and then present them within a dissertation. However, this plan changed upon my arrival at the project. I assumed a title as one third of its information team. The requirements of this position included the planning of lunch break information sessions at schools (“info desks”), delivering talks at assemblies and developing print material such as pamphlets and posters. I was also required to attend briefings with school principals and meetings with officials from the local department of health. Further, for a period of approximately six weeks myself and project staff underwent intensive eight hours questionnaire sessions. During this time we were familiarised with the questionnaire that is prepared for young women. All these activities contributed to my gaining a balanced view of the projects operations and the exchanges it has with participants and other stakeholders. However, to an extent I consider the amount of time that I devoted towards fulfilling these responsibilities a limitation because it delayed my reading and writing work on this dissertation.

Conclusion

In sum, this chapter has provided a detailed overview of the data collection process. It introduced the methods employed in order to gather the data and expanded on their suitability for this study. The manner, in which the data was analysed, was also discussed and this will hopefully facilitate understanding of the findings chapters. In addition, my position as a researcher was clarified and the challenges that I encountered in the field were discussed. Further, whereas the previous chapters were a hypothetical discussion guided by scholarly articles, this one is an introductory glimpse into the realities of research that will be presented in latter chapters of this study.
Chapter Five: Presenting the Perceptions: Findings and Discussion

This chapter presents the findings garnered during the research period. They will be discussed in depth using the theory and literature examined throughout this dissertation. This chapter is divided into two sections. The first section evaluates the existing communication strategy according to participants’ perceptions. In order to mobilise the findings further, both the interview findings and the observations from the wider community will be integrated into the discussion. The second section is similar; it proposes a way forward for the FB project to address the issues that were identified through the study. Essentially, the discussion from this chapter will define possible communication considerations for a future campaign. These will also be supported by theory and academic literature. The findings are structured so that the text in bold denotes the actual themes that emerged.

Perceptions of Female Bilharzia

Female Bilharzia: An obscure disease

Amongst the most unanticipated revelations to emerge from the interview sessions is the general lack of accurate information about Bilharzia. The first questions posed to the participants required them to demonstrate their understanding of what they believed Bilharzia to be. The responses received were vague and insubstantial. Only a fraction of them had some semblance of accuracy. They highlighted the need for a more aggressive education strategy. These were some of the responses:

I\textsuperscript{12}: Ya [laughs] I didn’t know that you got it by crossing rivers. I just thought you got it by jumping over a fire and then you would see that you had it by urinating blood. I didn’t know you could get it by crossing a river at all. (Interviewee 04 Sept 2012).

I: ... The teachers would explain to them [the boys] that no, a woman has problems when she has bilharzia... The woman would have problems with her kidneys...mmm (Interview 13 Aug 2012).

The first response indicates that some young women’s understanding of Bilharzia is based on stereotypes. It highlights the power these social beliefs can exert over a target group when

\textsuperscript{12} I- Interviewee 
D-Dudu
efforts to raise awareness about a disease resonate poorly with them. The excerpt seems to corroborate Bandura’s social learning theories which as mentioned in previous chapters, states that people’s attitudes and subsequent behaviour is reliant upon a variety of factors including environmental ones (Bandura 1995; 2004). In this instance it seems that participants’ attitudes towards Bilharzia were formulated on the basis of a socio-environmental reality represented as ‘the stereotype’. The fact that young, intelligent women seem to believe what appears to be modern day myths instead of reasoning logically, suggests that the projects current communication strategy may not have the intended impact. The second response suggests that even educated people such as teachers have an insufficient understanding of Bilharzia. As educated professionals who should be relied on to impart correct information their responses to questions appear to be misguided. These were some of the responses that demonstrated this:

This school principal listened politely during the briefing. Afterwards, she said she did not think the children in her school needed treatment because they did not swim in rivers. She said she knew for a fact that they did not swim, they had clean water and they showered. After it was explained that none of those factors guaranteed immunity to Bilharzia she seemed shocked and said “Well then maybe I have it too, is it as common as HIV?”(Field Notes 24 Feb 2012 “K13” High School).

This excerpt illustrates the fact that educated opinion leaders such as school headmistresses have an inaccurate understanding of Bilharzia (Melkote and Steeves 2001). It appears that they perceive Bilharzia to be a disease associated with one’s social class levels and the availability of basic amenities (Schall 1995). The enquiry about whether Bilharzia is as prevalent as HIV suggests that basic information about it such as the susceptibility to it is unknown (Witte 1992; Green and Witte 2006).

Insignificance of Bilharzia

Overall it appears the impression that young women have of Bilharzia is that of an insignificant and fleeting illness. When asked to describe how severe they believed it to be, only a minority of the participants indicated perceiving it as a threat:

_______________

13Letters of the alphabet are pseudonyms for all the schools.
I: ...I used to think that something happened to you like maybe you got a rash all over your body and when you took pills it was like taking HIV pills, so ya. (Interview 13 Aug 2012)

This response indicates that there are participants who consider Bilharzia to be a legitimate disease [my emphasis]. However they expect outward bodily symptoms such as a rash in order to regard it as an actual threat to their health [my emphasis]. To some participants the fact that bilharzia is treated with a dose of Praziquantel tablets (Kjetland et al, 2012; WHO 2011) as opposed to a daily dose of antiretroviral drugs does little to convey its severity. This excerpt seems to confirm Smith et al (2007) and Green and Witte (2006) assertions about how the combination of fear, susceptibility and severity of a health threat affect reactions to health messages. In this instance, the lack of these three elements in participants appears to have desensitised them to the Bilharzia projects warnings about Bilharzia. What did make participants anxious; however, were the side effects:

I: It was a little bit scary because you don’t know whether you have it or not. But what made people not want to sign the forms the first time they came is because they told us that the pills had some “after effects”. So when I’m standing with my friend who’s going to say “Ooh I’ll get stomach cramps, I can’t do it”, even if I do want to get tested I end up not getting tested because I then think that maybe I’m weaker than she is you see. (Interviewee 31 May 2012)

Based on this excerpt it was the “perceived severity” (Smith et al, 2007:56) of the side effects as opposed to the susceptibility to bilharzia that the participant was afraid of. After evaluating her options, the fear of being unable to cope with the side effects was stronger than the fear of bilharzia. Essentially, the “perceived response efficacy” was low (Smith et al, 2007:56). If the fear of momentary side effects is stronger than the fear of the health risks posed by Bilharzia, it suggests that existing communication may not be as compelling as it should be. Others were more afraid of the stigma attached to having bilharzia more than they were of being diagnosed with it:

I: I was scared that they would tell me that I had it and I didn’t know how they would treat me at school and in class. I was also afraid that the people that I had left with would sell me out when we got back to school and say “I don’t have Bilharzia; she’s the person who has it”. (Interview 04 September 2012).

This response demonstrates the reasoning behind Smith et al’s (2007:57) claim of stigma being borne out of things that can be considered as “arbitrary”. Despite regarding bilharzia as...
a trivial disease, the fear of exclusion as a result of having it is strong. The participant believed that in an attempt to shield themselves from “courtesy stigma” (Goffman 1963 in Smith et al, 2007: 58), her classmates would expose her and she would then be ostracised by the rest of her peers. Although this is a valid concern, it is also an indication of a low sense of self efficacy in some participants (Bandura 1995; 2004). It appears that in some instances participants’ perceptions of their ability to cope with the exclusion that can come with seeking Bilharzia treatment are low. Like the interview sessions, participant observations via field notes suggest that knowledge about Bilharzia amongst participants and their peers is limited. Despite this, the following extracts indicate that there are young people who are willing to acquire more information about it:

Reception of Bilharzia Information

Some of the questions were very interesting for instance: Why does bilharzia manifest itself as red urine as opposed to phlegm or mucus? Also, other learners admitted to having Bilharzia yet they were concerned that the pills received from the clinic were ineffective (Field Notes 19th May 2012 “KM” High School).

The range of enquiries about Bilharzia in the extract above suggests that some young people have a genuine willingness to learn more about Bilharzia. Further, the public admission about being affected by it, suggests that they regard it as a regular ailment such as the common cold perhaps. However, it is evident that there may be gaps in the projects basic information shared with the youth. Questions about its manifestation in the body suggest that the first few stages that focus on delivering the facts of Bilharzia may be misunderstood (See Table 2). Other uncertainties about the efficacy of treatment further indicate incomprehension of the health risks posed by Bilharzia. This is despite the talks held by the project and the availability of educational material.

Significant portions of the personal interviews regarding this matter were a sharp contrast to those obtained through observation. A major contradictory theme regarding Bilharzia awareness and receptivity to the treatment emerged from the observations. The interviews suggested that the challenges with the project’s communication in this regard were due to factors that were not related to social context [my emphasis]. It appeared as if they originated from inaccurate beliefs. The observations documented below however, challenge this finding.
Pressure from Teachers

This excerpt below illustrates that people in positions of authority do affect the participants’ comprehension of information from the FB Project [my emphasis] (Melkote and Steeves 2001).

The teacher who had been exceptionally warm towards us was incredibly strict with the girls. She constantly shouted at them to be quiet and to fill in the consent forms. I got the sense that she wanted to portray the image of the school as orderly, hence her abrasiveness with the girls. One of them made an error on her form and as I was handing her another, the teacher stopped me and told her to return to her seat. I tried telling the teacher that it was perfectly alright, we had plenty of other forms. She replied: “She must learn to use what she has”. The girl timidly returned to her seat and I stood there awkwardly because I did not want to undermine the teacher’s authority.

The atmosphere was serious and it was only when we were about to leave that a girl shyly asked to speak to me privately. She enquired if consenting on her own was a problem because she did not have parents (Field Notes 21 Feb 2012 “X” High School).

Although this excerpt does not indicate how a teacher may impart knowledge on Bilharzia, it indicates that to a great degree they influence their decision to consent to visiting the FB project. Despite project staff emphasising that the decision should be theirs, in some instances they are pressured to participate by their teachers. In this way the participants’ agency is subverted (Bandura 1995: 2004-Freire 1985-1990). This excerpt was documented following a visit to a rural school where values such as respect for elders are strictly upheld. As a result, asserting their right to choose for themselves whether they participate or not in the presence of an adult may have been intimidating for them. Clearly, the teacher regarded the FB project team as esteemed visitors to the school and was eager to assist. Her eagerness to please the team interfered with the manner in which the information shared was interpreted by the young women.

The teacher’s behaviour validates Freire’s (1990) observations about how teachers can hinder their student’s comprehension of their circumstances and the options available should they wish to change them. In retrospect, the group that was spoken to probably consented to participating in the project without fully understanding what they were committing themselves to. The young woman who approached me seeking clarity about the issue of consent in spite of the talk held by the team, exemplifies how authoritarian teachers make “two way communication” or participatory communication difficult (Dyll 2004: 8). In this
way, young women’s participation can be classified as what Freire (1990:48) referred to as “pseudo-participation [and not] committed involvement”. In instances such as this the project’s team cannot confidently conclude that their talks were delivered successfully. Conversely, in a peri-urban school different observations were made on one of the two separate visits made:

The students were a pleasure to work with. We spent most of the assembly session fielding questions from the learners. It was clear that questions had been carefully considered due to the confidence with which they were asked. The questions they asked were related to the health risks of FB and the consequences of declining treatment. Others were also health related, albeit slightly unconventional. However, they were asked in a jovial and respectful manner. Afterwards many of the learners appeared very open towards the project once we had explained everything to their satisfaction (Field Notes “MK” High 18 May 2012).

On this particular visit to “MK” High School, all the learners were congregated at the assembly awaiting our talk. Afterwards the teachers informed them that the FB team were eager to answer their questions. During the talk by the FB project’s team, they listened intently. As the field note excerpt indicates they asked questions incessantly. The questions required detailed explanations and they seemed concerned about the health complications that could arise if the Bilharzia was untreated. The range of questions indicates that before they committed to the project, they wanted to know what every aspect of their participation would entail. To an extent their forthrightness conveys an awareness of their agency regarding their decision making capability (Bandura 1995; 2004; Freire 1990). Being from a peri-urban background myself, I know that the schools in such areas operate differently. Their belief systems are slightly different to those of schools in the rural areas. For instance while respect is of the utmost importance and every effort is made to inculcate it in learners, it is not practiced at the expense of their right to being informed. In peri-urban schools the learners are encouraged to be assertive respectfully [my emphasis]. In other words, they are taught to be politely inquisitive. In the rural schools, I got the impression that being inquisitive could be misinterpreted as insolence hence the silence from the learners (Field Notes “X” High School 21 February 2012). Based on the observations I assert that these differences could possibly be attributed to differences in teaching methods. I came to this conclusion following our second visit to “MK” High school.
**Differences in teaching methods**

On the second occasion that the FB project visited this school, the purpose was to conduct what was referred to as an information desk (Field Notes “MK High” 23 May). Educational pamphlets are distributed to students and teachers upon request. I believe that the initial curiosity from the students was due to the unfamiliar presence at their school. However, once they recognised that it was the Bilharzia team, they politely asserted their right to decline the pamphlets and treatment. Their demeanour suggested that they were comfortable with their choice to decline and would not be dissuaded.

Unlike at the rural school, these learners did not timidly consent out of a fear of disappointing their teachers. I argue that this difference in attitude is due to the differences in social context and values. I also assert that these differences indicate that communication from the FB project is received differently in varying social settings. Based on the observations made at schools in both settings, I believe the reason for such marked discrepancies in understanding information from the project may also stem from teaching methods. It appears that in rural schools teachers unconsciously practice the “banking” method of education (Freire 1990:52) where the teacher is a revered source of information. The students seem to have no recourse other than to accept what they are told.

During the visit to these rural schools, I could sense that this repression of the learners was not done intentionally. It was done to teach them the basics that they would need later on in life such as humility and respect for authority. Teachers at these schools seemed unaware that this limits the level at which learners make sense of occurrences in their lives (Freire 1990). Bilharzia for instance is a disease that can drastically affect their health (Kjetland et al, 2012; Hotez et al, 2009; Feldmeier et al, 2001) and the teachers saw the value in the learners acquiring this information. However, they did not allow for questions and feedback that would allow for deeper understanding. Further since learners assume passive roles, the opportunity to discover more about it during the talks passed them by. Due to these constraints, the projects communication strategy could not fully reach young women from this rural school. This is because it worked on the premise that information would be understood and consent to participating in the project would be given. It made no provisions for possible barriers that could come as a result of varying teaching methods at schools.

In peri-urban schools it appears that “problem posing” education where students are encouraged to interact with information is practised (Freire 1990:52). This is illustrated by
the manner in which learners reacted to talks. The talks took the form of a conversation as opposed to a “one way flow of information” (Melkote and Steeves 2001:56). As demonstrated by the field notes, the learners were conscious of their choice regarding participation. Through their endless enquiries they challenged the information that the project team shared with them. In sum the observations from the field indicate that the existing communication approach is more beneficial to participants from the peri-urban schools. Those in the rural schools appear to be at a disadvantage because of the restricting presence of authority figures and social values that forbid them from interacting with information on their own terms.

**Perceptions: selection process of participants, provision of information to schools/parents and participants**

It appears that the selection process that only includes girls is the source of numerous problems. The exclusion of boys during school talks creates communication problems and perpetuates many of the existing misconceptions. The surrounding values and the presence of the project with what may be considered a ‘taboo’ and gendered disease highlights issues of stigmatisation. The excerpt below was documented while the project was conducting an information desk. It conveys general perceptions towards the prospect of being involved with the project and highlights the poverty stigma that is at times associated with Bilharzia.

*Poverty stigma*

The students were also very respectful. I did notice however that the instant we mentioned the word “bilharzia” most of them were not keen to be involved. Some of the girls went as far as saying that they do not swim in dirty water and that they drink fresh tap water. I got the impression that they think that bilharzia is a class disease associated with poor people. I approached a group and told them that I wanted to find out why they were against taking bilharzia treatment. They all said that bilharzia does not apply to them because they had lived in the suburbs all their lives (Field Notes“XX” High School29 May 2012).

This observation highlights the following: firstly, to a great extent Bilharzia is indeed considered a social taboo (Schall 1995). Secondly, volunteering to participate in the FB project does sometimes have unwanted social repercussions. It seems many learners regard Bilharzia as a poor man’s condition (Schall 1995). It appears that association with the project attaches the label of impoverished people who are given free treatment by an exogenous organisation (Servaes 1999; 2008). Third; it appears that the stigma of poverty obscures the
facts about this disease. This is demonstrated by the emphasis on avoiding swimming in dirty water and access to clean tap water. It was discussed in Chapter 2 that Bilharzia can be found in any fresh water source that allows it to thrive (Kjetland et al., 2012). Also, many people have had contact with infectious water at some point in their lives whether it is for “recreational or domestic” purposes (Lillerud et al., 2009:457). In fact even individuals who deny ever having “risk water contact” have been diagnosed with Bilharzia infection (Thomassen Morgas et al., 2010:32). Therefore, the likelihood of the bilharzia parasite penetrating their skin and inhabiting their body for years without their knowledge is there (Kjetland et al., 2012). Based on this logic anyone can be a Bilharzia carrier unwittingly irrespective of their standing on the class hierarchy. Ideally, these basic facts should be well known at this stage in the FB project’s work with schools.

Mockery

The second stigma originates from the mockery that the selected young women stated they were subjected to. It appears that it is a factor that furthers the misperception of male immunity to Bilharzia. During the interview sessions participants had the following to say on the matter:

I: ...It’s just that the boys laughed at us because I was one of the first to come because I was in grade 12. They made fun of us and said “you are going to be klenulwa’d there” you see? (Interview 29 Aug 2012).

I: Ya, the boys ridiculed us. When we got into the class they said “you have Bilharzia”. It was even worse when we were selected because they called us and when we got back to class from Marburg [clinic] I remember there were two of us from my class and they poked fun at us seriously. When we got back, they teased and teased. Even my teacher asked me “what did they do to you?” after I came back from here and I was sullen because I didn’t want to seem approachable.

D: Even the teacher?

I: Yes, she also tried to make jokes about it and I don’t understand why because she is also a girl (Interview 04 Sept 2012).

The first response suggests that the gynaecological examination aspect of the visit to the project is sometimes a source of amusement to the boys and a large contributor to the

14Crude term in Zulu that connotes sexual intercourse
mockery. Traditionally, young women everywhere are conditioned to refrain from engaging in “questionable” activities and to engage in those that portray them positively. This conditioning is prevalent in the Zulu community (Taylor et al., 2007). Therefore, when a routine medical procedure fails to be understood for what it is and is instead misconstrued as being “klenulwa’d”, this can affect even the most confident young woman. Based on this crude view of the gynaecological examination, it does not seem to be a socially sanctioned activity within the community. As a result, seeking it translates into a young woman having to cope with the burden of the negative judgements that are associated with that decision.

Another contributing factor to the negativity appears to be the manner in which the women who participate in the project are selected. Interviewees’ perceptions suggest that it draws attention to them and inadvertently confirms that they have Bilharzia to their peers. This public scrutiny exposes the young woman to supposition about details that should remain private such as whether or not she is a virgin. Two respondents narrate this:

I: Ya, it is embarrassing because some boys discriminate against us and say things like “well this one is not a virgin”. Others, if they hear that you went to get a pap smear done, they ridicule us and ask us if they used their hands on us or...? I told them that I didn’t do it because others were saying that some girls got poked with metal (Interview 04 Sept 2012).

I: In a classroom, it’s not as if all of us are virgins. There are some who are not virgins. Then there are others who write that they are. Some were asked if they had kids and then they said they don’t... There was someone who arrived here with us, and then when we were told that they would do a pap smear, she then said she was a virgin. She also came the last time and now she says she’s a virgin (Interview 29 Aug 2012).

These responses highlight several important points. The first is the social reverence of virgins. Young women go to great lengths to maintain an image of chastity due to the pressure to remain a virgin being high (Taylor et al., 2007). The problem is that their attempts to protect themselves from being stigmatised as non-virgins backfire occasionally. For instance, the second interviewee’s response suggests that although her classmate succumbed to the pressure and lied about being a virgin, this discredited her more. Her previous agreement to a gynaecological examination was evidence of this. Secondly, it appears that there is an association between the gynaecological examinations and morality. It is common knowledge that abstinence is not an indication of how virtuous an individual is. Based on
discussions earlier in this study, this exam is important to the wellbeing of women (Kjetland et al, 2012). Therefore, it is imperative that the negative connotations that sometimes seem to come with it be addressed. Again, this highlights the need for more accurate information to tackle such misguided yet socially prevalent belief.

Thirdly, there appears to be confusion between the participants’ visits to the project and the treatments at schools where both sexes receive tablets. To an extent it seems that people are aware that Bilharzia affects both males and females. However, the exclusion of boys during discussions about female participants visiting the project for examinations destroys the foundation of accurate knowledge that the project had built. Excluding the boys from these discussions seems to result in them having inaccurate information about Bilharzia as a health issue. As a result, they compensate for this by creating stories about participants being ‘poked with metal’ (Interviewee 04 Sept 2012). Many of the female participants had mainly positive comments about the FB project and their involvement with it. However, there are other stakeholders in the project such as teachers, school principals as well as parents. In order for the projects work with participants to be successful their approval is needed. As is evident in the discussion below, the aforementioned parties’ reactions to the project varied:

*) Guarded parents

The parents who reserved their approval of the project did so due to seemingly justifiable concerns that the project team attempted to alleviate during the meeting. The following was observed:

It was on a Saturday and the meeting took place at the school hall which was relatively full. These were some of the questions that were asked:

- Are the doctors donating their services or do the parents have to pay? (This was asked by an old man in the front row who apologised for the question in case it was offensive).

- Will their children be tested for Bilharzia first or will they just receive treatment? (The lady who asked first apologised for being a nuisance. She said she was really trying to get to the crux of the bilharzia treatment issue).

Parents seemed overwhelmed by concepts such as “random sampling”, however they were explained further.
The parents were also anxious about their children travelling two hours into a town that they were unfamiliar with. They wanted to know how they would get there and if they would get lunch?

Another concern was that in the area there was no clinic. If a child got sick at night due to Praziquantel, whose expense would it be? Would there be a health worker there to assist should that happen? (Field Notes “VM” High School 23 May 2012).

These observations uncover issues that can hamper the reception of the project by parents. Firstly, it appears that the fear of being exploited financially by outsiders is pervasive in the community where the project operates. Secondly, the questions about tests that can confirm whether children have Bilharzia or if they are treated indiscriminately suggest confusion amongst parents. It seems that they mistake Bilharzia treatment for vaccines. The distinction between regular vaccines and the annual Bilharzia treatments may not be clearly communicated. This is because even if community members trust a health project, if they believe they are being treated to avoid the possibility of contracting an illness, they may dismiss it [my emphasis] (Wynia 2007). Further, the constant apologies from the community members when they asked questions indicate their insecurity about their education levels. Instead of accepting that they were entitled to questioning information they did not understand, the enquiries were made tentatively. This is problematic because although parents are not involved in the project to the same degree as their children, their input is valuable. Therefore their fear to ask questions could further expand the “knowledge gap” and affect their willingness to support the project’s work (Kincaid and Figueroa 2009:1321). This is a term used to signify the inequitable distribution of knowledge which comes about as result of differing levels of education (Kincaid and Figueroa 2009). If parents have a solid understanding of the FB project, they can envisage their role in the vision it hopes to realise with their co-operation (Kincaid and Figueroa 2009).

The observations suggest that the other communication challenge within the FB project’s communication strategy is its “pro-literacy bias” that refers to the tendency of a communication source to encode messages in terms of symbols, either written, printed, or verbal, which imply literacy and numeracy skills on the part of receivers, even when they are known to lack both skills (Melkote and Steeves 2001: 233). It appears that the project unintentionally communicates in a manner that may be unsuitable to an audience whose education levels are low [my emphasis]. This is illustrated by the usage of terms such as ‘random sampling’. These terms can be categorised as scientific jargon that mainly
researchers are familiar with. The project widens the knowledge divide by not delivering information in layman’s terms (Kincaid and Figueroa 2009). This can affect the community’s willingness to sincerely trust it (Wynia 2007).

The observation excerpt also illustrates how the immediacy with which parents are expected to allow their children to visit the project, causes safety concerns. This suggests that trust may take time before it is given confidently.

“This guiding philosophy of CFPD...can be traced to the work of Freire (1970)...who conceived of communication as dialogue and participation for the purpose of creating cultural identity, trust, commitment, ownership and (in today’s term) empowerment” (Kincaid and Figueroa 2009:1313).

However, in instances such as these, it seems that the demands of science hasten what is intended to be a gradual process. Further, the excerpt illustrates that before a community can fully trust an outside agency, it needs to demonstrate its willingness to accept accountability should the need arise. This is suggested by enquiries about the projects availability in the event that the side effects of Praziquantel become severe. This finding supports Kincaid and Figueroa’s (2009:1323) assertion of trust being the “glue that holds a group or community together, making co-operative action possible”. Had the project been unable to accept responsibility for the side effects, it may not have been trusted to work with their children.

**Teachers’ reactions to the project: unreceptive teachers**

During the course of the observation period it became evident that to large extents teachers determine the level of success the FB project attains in its work with young women. This is because they are powerful opinion leaders (Lazarsfeld et al, 1948; Melkote and Steeves 2001) who are instrumental in their learners’ receptiveness to the project and their decision to participate. Based on the observations made at various schools, it appears the project needs to gain their support first before they can work well with participants. The following excerpt illustrates this:

We spoke to the principal and two teachers were also present. There was some tension when the principal said we were treating the kids like “guinea pigs”. She openly mocked the project and the other two teachers present who had been quiet at first, agreed with her. We tried to explain that the FB project was not testing out a drug. We tried to emphasise the fact that Praziquantel was safe and had already been in use for
decades. The other teachers said if that was the case, then their learners were “civilised participants” (Field Notes “I” High School 08 Feb 2012).

The attitude of the school principal persuaded the other teachers who were present to think in a similar manner. This illustrates the level of influence people in superior positions exert over others who occupy ‘lesser social positions’. It is evident that the school principal at this particular school believed that the FB project was an organisation that was using Bilharzia which is a legitimate health issue, to fulfill its own scientific goals. Her usage of the words “guinea pigs” suggest that she believes that the children in her school were an easy target that could be exploited under the guise of free FB treatment. Despite attempts to communicate that no drug tests were being conducted, her adamant attitude that the learners would be treated as “civilised participants” conveyed her mistrust of the projects motives.

Her reaction to the project was troublesome because opinion leaders (Lazarsfeld et al, 1948) such as school principals are more adept at swaying public opinion than outside agencies or even the mass media (Lazarsfeld et al, 1948, Melkote and Steeves 2001, Cornwall 2008). This finding suggests that influential parties in general need to be properly educated first and for their misgivings to be altered before they filter down to potential participants and community members. The project’s existing communication approach appears not to adequately convey that it seeks collaboration and not temporary compliance from them [my emphasis]. Further, the mistrust appeared to originate from the (misconceived) assumption that the project would abandon participants once it had achieved its research goals. Again, this suggests that in its communication, the project should convey its plans for participants and its hopes for longevity.

**Receptivity to the gynaecological examination**

During the course of the data collection phase, the gynaecological examinations arose as a slightly disputative issue. Given the possible physical discomfort, this mixed reaction towards it is not unexpected. As mentioned previously however, it is necessary for health reasons (Kjetland et al, 2012). Most responses were positive whilst a few were negative due in part to a combination of poor communication and anxiety about the alleged painfulness of the examination. In fairness, it is important to acknowledge that the number of young women who reacted positively to the examination exceeds those who criticised it. Since it is a critical aspect of the project’s work, I believe it is important to highlight the complaints. Doing so will verify whether they are indicative of a need for change on the project’s part or if they are
inconsequential incidents. Overall, however, it seems as if the fear of the unknown is the greatest barrier that many of the participants needed to overcome. A participant relates her experience of it thus:

I: I was very scared ashamed. When I went they were returning to pick up girls for the fifth time so it had spread across the whole school that this thing is painful, they stick things inside of you, so there was that...so when I got there I asked first. There was a white lady and another lady who was translating. I spoke to the white lady and I told the other one to hold on a little bit I would speak for myself. So I asked her before she did it if it was painful. By then there were two white ladies in the room. She said no, and then she did it. They confused me when they started speaking in another language that I didn’t understand. So I got up and asked them if there was something wrong. They said no and we’ll let you know if there is something wrong. So I asked them why was it that they were speaking in a language that I didn’t understand. Then the other one said...now I don’t remember what they said. I really didn’t understand what language they were speaking because it wasn’t even Afrikaans. They then explained and I understood but I did feel as if they were making a fool of me a little bit. (Interview, 31 May 2012).

This response draws attention to several seemingly minor communication oversights that can facilitate the perpetuation of negativity about the examination if they are not addressed properly. The first point is again the lack of clarity about the gynaecological examination. In this instance as well as many others, participants’ apprehension of it is based on unsubstantiated reports. The response indicates that the power of word of mouth should not be under-estimated because it can plant seeds of fear within a short period of time. The participants anxiety was further intensified by the foreign dialogue that effectively (although perhaps unintentionally) excluded her from the conversation. Further this participant had anticipated that “things” would be inserted inside of her. Despite all of that, her high self-efficacy beliefs (Bandura 1995; 2004) outweighed the angst (Witte, 1992; Green and Witte 2006) that had been caused by the ominous description of the gynaecological exam, hence her consenting to it.

By excluding her from the conversation, the doctors did not follow a key principle of participation referred to by Kincaid and Figueroa (2009:1321) as “information equity”. It describes “the distribution of knowledge about a problem [and] how well knowledge is shared amongst individuals...” (Kincaid and Figueroa 2009:1321). They argue that equal
sharing of information generally increases the rate of participation within a project and heightens feelings of “shared ownership” (Kincaid and Figueroa 2009: 1321). This implies that professionals such as doctors within the project need to share information and involve participants during every step of every interaction they have with them. If this is done, participants may be more inclined to think positively about the project and the value of their participation. They may also believe that they are equal partners who share a responsibility in ensuring the success of the project. Once this is done, it might break the cycle of wrong information that is continuously recycled about procedures such as the gynaecological exam. Judging from the above response, an isolated incidence of poor bedside manner can potentially widen the “knowledge gap” (Kincaid and Figueroa 2009:1322) by being the source of unpleasant rumours about an organisation.

*Positivity towards the gynaecological examination*

As stated previously the majority of the young women reacted positively to the gynaecological examination despite it being their first experience of it:

D: Can you please tell me about the gynae exam and what it was like for you?

I: Well they welcomed us very nicely. They told us about this thing and told us to ask questions if we had any. Then we had to go and meet the doctor and I was very scared but they told me not to be scared. And also I thought it was painful (31 May 2012).

I: I walked into the room and there was the doctor and another lady. So we first spoke because the doctor was very chatty. Then she asked me if I consented to the Pap Smear and then I said yes I consent. Then they did the Pap Smear and we were still chatting casually ya she was alright (Interview, 04 Sept 2012).

This excerpt illustrates several strengths of the project’s communication strategy with regards to the gynaecological examination. Firstly, it appears that project staff ensures via dialogue that participants are aware of their right to either consent or decline or withdraw from the examination at any stage (Kincaid and Figueroa 2009). Essentially, they are conscientised about their agency in the matter (Freire 1960, 1970; Bandura 1995; 2004). Therefore in the event that they consent, their participation is given freely. In so doing the project exemplifies the progressive type of participation that many scholars advocate (Cornwall 2008, Servaes 2007, Melkote and Steeves 2001). Also, the willingness of the staff to answer questions demonstrates their commitment to making their interactions with young women mutual learning sessions (Kincaid and Figueroa 2009; Freire 1960; 1970). Further, it appears that the
staff work hard to allay the fears of participants thus making the atmosphere relaxed and conducive for an introduction to the examination. I believe this is a major accomplishment for the project and could serve it in good stead in the long term because of the positive word of mouth it can generate. Word of mouth spreads rapidly and can enhance an organisation's image to the community at large (Kincaid and Figueroa 2009).

*Cultural receptivity to the gynaecological examination*

In closing, based on the interview findings, there appears to be no cultural oppositions to the gynaecological examination. Participants who consent to it seem aware of its purpose and the fact that it is voluntary. However, as much as they are aware of why the examination is necessary, the importance of undergoing it regularly has yet to be impressed upon them. As stated earlier, participants’ accounts of this examination were largely positive. The minor complaints that were reported stem from a lack of experience with it and negative word of mouth. From my vantage point I believe that communication from the project needs to focus on familiarising young women with the examination. The plans of a public health campaign that the project has, could assist in this regard. It could also assist in acquainting community members at large with it and possibly curbing the previously discussed allegations of peer mockery.

*Receptivity to sample collection*

*Unease about sample collection*

Regarding the collection of the blood, urine and stool samples, participants expressed their unease thus:

I: I didn’t have a problem with the urine but when I asked them about the blood they just said that when you give the urine you need to give the blood also. The Sister that I came across told me that they have to take the blood to check for Bilharzia. Even today I first asked where the blood was going so, ya... I just don’t understand how bilharzia and blood are connected because it’s something you see in your urine. So where my blood is going, I don’t know but I would like to know.

D: Do you have superstitions about blood?

I: No I don’t have superstitions about blood. I just don’t want you to test me without us agreeing that you would first. You can’t just take my blood *randomly*.

D: Yoh. So you weren’t happy with the explanation that the sister gave you?
I: Again she told me that the blood also had to be tested for Bilharzia because they want to see if the results will be the same as the last ones. But I’m still not “highlighted” about the blood. (Interviewee, 29 Aug 2012).

This excerpt highlights an instance of miscommunication between participants and project personnel. It seems participants are aware that diseases can be detected through urine analysis. In their minds, this is the sole method of detecting FB in their bodies. By taking blood samples without first explaining the reason for doing so, some participants appear to doubt that their right to informed consent is considered. Although this seemed like an isolated occurrence, it seems that the nursing staff’s explanations may not always be thorough. This excerpt is yet another example of the problems that can arise as a result of the “knowledge gap” at the project (Kincaid and Figueroa 2009:1322). Further, the nursing staff at the FB project has higher education levels than the participants. By giving participants inadequate answers to questions they consider to be important, they may undermine their beliefs of “shared ownership” in the project (Kincaid and Figueroa 2009:1322). By this I mean that they may begin to doubt the significance of their roles in the project and question their value as partners who are crucial to its success. In fairness, dissatisfied responses such as this were intermittent. However, I believe they are valuable as they may signify the need for consistency regarding communication about sample donation.

**Responses to FB personal interview**

*The personal interview as a compromise*

The FB projects personal interviews produced varying reactions from the participants. However, the majority of the comments were balanced and suggested that most of the participants understood their purpose. Many of them viewed it as a necessary and mutually beneficial exercise (Servaes 2008, Melkote and Steeves 2001). To their way of thinking, if they wanted to receive FB treatment from the FB project, they needed to sit through the interview in exchange for treatment:

D: Well as a person who was being asked these questions for the first time, there was that “mmm this person is just asking me about my personal life just like that “but I realised that in the end she had to ask me those questions before she could do what I wanted her to do for me. But it was alright, there was no problem (Interviewee 31 May 2012).

I: Eish...nje well it was hard but in the end-
D: How was it hard?

I: It’s hard to answer some of them but in the end it helps because as they ask you the questions and you answer and deny some things, they can find out things that affect you that would not have been found out otherwise. (Interview, 07 June 2012).

Although some participants were not particularly comfortable with the prospect of sharing intimate details about themselves with the project staff, it is encouraging to note that they are aware of the reciprocal nature of working with developmental programs (Melkote and Steeves 2001; Servaes 1996-2008). As much as they are the beneficiaries of the services that the FB project renders, on some level they seem to be aware that they have a responsibility to contribute too (Melkote and Steeves 2001; Servaes 1996-2008). Participants seem to consider the interview as a common practice in medicine and medical services—like any doctor consultation. In sum the questions appear accepted as part of a conventional doctor-patient experience.

The personal interview as an opportunity for sharing

For other participants, being enclosed in the interview rooms and sitting through the questionnaire is a platform where they could voice their innermost thoughts and feelings unreservedly:

I: They asked you questions that you just couldn’t discuss with someone else. They asked you what type of sex you had. When was the last time you had sex?

D: [Laughs]

I: Is it painful when you have sex? That’s not an easy thing to discuss with just anyone but when you are here you do talk... That’s the type of thing we talked about. There are things that you can’t discuss with your friends. If you told your friend that when you have sex it hurts, they would laugh and tell everyone. So it’s better here. The person you talk to is open and does not laugh at you. (Interview, 29 Aug 2012).

Judging by this response, for some participants the personal interview sessions are an outlet where they can have candid discussions without the fear of being mocked. These sessions become a space where through the process of dialogue, they are able to reflect on health related problems and explore possible solutions with the help of project staff. As discussed in an earlier chapter this type of interaction highlights the shift from being what Freire (1990:46) refers to as “collectors or cataloguers” of information. Instead, both participants and the interviewers subvert the roles of ‘staff member’ and ‘participant’ and use the
interview as an opportunity for reciprocal learning (Freire 1990). The fact that the project can create an environment where participants feel safe divulging private information is yet another accomplishment. It indicates that in some instances their current communication strategy works well.

**Clinic services: HIV, contraception, treatment of STIs**

As discussed in Chapter 4, in addition to FB treatment, the project also renders a multitude of other services pertaining to young women’s overall gynaecological health (See Table 1). They offer free contraception and they also have a voluntary HIV counselling and testing facility (See Table 1). Contraception was a contentious subject amongst the participants. They relayed the following:

**Contraception’s effects**

The issue of contraception was a contentious one amongst the participants. It is important to first acknowledge that a large number of them did not know that the project offered this service at no cost. When they were informed about it during the interview sessions their reactions varied. Although the FB project is primarily concerned with rectifying the gynaecological damage done by Bilharzia to young women, women’s health in general is also important to them. Therefore, offering contraception to participants who request it is a strategy for raising awareness about gynaecological health and the options available to them. Participants reacted thus to this service:

I: I don’t like them.

D: Oh ok, can you please explain to me why not?

I: I just don’t like them because taking a pill is irritating. They also say that if you keep drinking the pills you end up smelling like them. Even with the injection it’s just ayi...it ruins your body. You become too fat. Since I’m already this size how big would I get then? (Interviewee, 04 Sept 2012)

It seems some young women are against the use of contraception because it requires some level of commitment on their part. Furthermore, based on the response it seems the prevailing perceptions about contraceptive pills are negative. Some participants appear convinced that in the long term they alter the body’s natural scent to that of the pill. Regarding the contraceptive injection, some participants perceive it as being detrimental to the body’s natural shape because of the alleged weight gain it causes. It seems that for some young
woman physical appearance is a major concern. Therefore, using contraception at the expense of being physically appealing does not seem like a worthwhile compromise. Judging from these responses it seems participants’ attitudes are the greatest barrier the project needs to overcome if it intends young women to avail themselves to contraception (Airhihenbuwa and Obregon 2000). This is because presently it seems the lack of information about the facts of contraception appears to have shaped their negative attitudes towards it. As a result it is perceived as “taboo” (Hindin and Fatusi 2009:58). Based on theories of behaviour change, access to correct information could encourage them to make the shift from “awareness to attitude to action” (Airhihenbuwa and Obregon 2000: 12). In fairness the area in which the project operates is conservative which a significant constraint it must work within (Ugu Profile 2010). However, by offering contraceptive services it automatically assumes the responsibility of dispersing correct information about it. Therefore, more communication structures need to be made available to them about this topic.

Contraception as protection

Despite some negative attitudes towards contraception, there were participants who were completely supportive of the FB projects provision of it. They responded as follows:

I: It’s worthwhile to school children. It does not look good when a school kid is wearing a school uniform and she’s pregnant. It’s not nice. Contraception is good because it helps to protect children from pregnancy and pregnancy is not good because sometimes people have to leave school because they don’t know who they are going to give the child to. (Interview 29 Aug 2012)

I: Oh it’s for the best cuz there are those who give birth and abandon their children. So it’s for the best if they give us that instead of getting rid of an innocent soul. (Interview, 20 May 2012)

Some participants perceive contraception as empowering because it gives them control regarding the planning of pregnancies (White 2004). As a result they do not have to forfeit some of their highly held priorities such as education. Also, it appears that young women are appreciative of the fact that the availability of contraception because it spares them the unwanted repercussions which could force them to make difficult decisions such as abandoning their children. Essentially, contraception gives them the agency to make informed choices that will not impact negatively on their lives (Bandura 1995; 2004). To conclude this discussion, the responses regarding the contraception debate indicated a lack of
knowledge about it. It demonstrated that there is a need for the dissemination of correct information about how contraception works the possible hormonal changes and other side effects. The little information that young women have about contraception is incorrect yet it continues to circulate and get distorted further. In fairness, there are significant social barriers impeding receptivity to communication about it. However, the participants who were open to it highlighted seemingly valid reasons. This suggests that in future, resources permitting, the FB project may need to work harder to shift misperceptions of it.

**Communicating the relation of FB to HIV**

As stated earlier, the project is currently researching further about the increased susceptibility to HIV in women who have advanced FB (Kjetland et al., 2012). Therefore at this stage they do not communicate the possible correlation of between the two diseases. However, they do encourage HIV testing possibly on account of its reported prevalence amongst young women (Hotez et al., 2009; Kjetland et al., 2012). As a result of this noted HIV risk, raising awareness about it is a possible area for consideration once the research proving the connection has been validated. A positive finding was that almost all the participants are aware of the free HIV counselling and testing available at the project. They had the following positive reactions:

I: I think it’s better to know while you are well before you really get sick than to know when they have to carry you around because you don’t have any strength. I don’t want that. I want to know now so that whatever I do, I’ll know what I’m doing it for- it doesn’t help to lie to yourself. I don’t want to keep telling myself that I am well because nothing shows. I don’t want that. (Interview, 29 Aug 2012)

I: I don’t have a problem anymore. If you skip three months without coming over to get injected they first take your urine to check if you are not pregnant. And then they take your blood to see if during the time spent away maybe you haven’t had unprotected sex and they check to see if you did not get any infections. (Interview, 7 June 2012).

Although these responses are not a conclusive representation of every former participant’s perceptions of HIV, I believe they are significant for the following reasons: firstly, they indicate that there is a segment of young women who are cognisant of the magnitude of HIV as a threat (Green and Witte 2006). This is evidenced by their recognising that its early detection is important. This sound logic about HIV can be expanded on by the project in their communication about the risks of FB due to literature about it suggesting that its early
diagnosis may result in better reaction to treatment (Kjetland et al, 2012; Hotez et al, 2009). It is also encouraging to note that participants are aware that a physical appearance of wellness does not guarantee an HIV negative status. Further, it appears that some of them recognise the futility of being in denial about their status, hence their receptivity to the projects HCT services. Their sensible attitudes towards HTC and HIV suggest prior exposure to communication messages related to these issues (Scalway 2010). Due to this, it can be inferred that the projects HTC facility re-enforces the base of information that participants appear to have amassed, which further “increases its educational effects” (Singhal and Rogers 1999:211). It can also be gathered from the responses that young women’s efficacy beliefs regarding the management of their HIV statuses are high (Bandura 1995; 2004). Through the projects provision of HTC, they are given the opportunity to exercise their agency in maintaining them (Bandura 1995; 2004 ;). In this way, the project realises its vision of empowering young women with information that can help them to preserve their health.

One of the major objectives of this study was to find out young women’s reaction to this service because there was concern that offering HIV services would change people’s outlook of the FB project. Management at the project were apprehensive that the women may be stigmatised as HIV positive by simply visiting the project, thus ostracising them. Or the project could possibly be branded as an HIV centre. Although their concerns were understandable, participants indicated that they were unnecessary because they considered the FB project clinic as the “Bilharzia clinic” and not an “HIV clinic. When the question was posed to them however, participants responded thus:

D: So how does that make you feel? Do you feel like this is now an “HIV” clinic?

I: No, we felt like this was a normal place where they teach us and give us knowledge.
We did not feel like it was that “HIV” place, Uh-uh (Interview, 20 May 2012).

Project management were also concerned that potential stigma could affect the quality of the relationships participants have with males. They feared that males would not want to associate with them any longer after learning that they had visited a so-called “HIV clinic”. Participants had the following to say on the matter:

D: If you had a boyfriend would you tell him that you were coming to this clinic to test for HIV?

I: I tell him. He knows. I don’t hide it from him. I don’t hide anything from him. I tell him whenever I go then I remind him that he can also go to the clinic. Even when I go
to the local clinic I let him know that I went to check for this you also need to go. (Interview 29 Aug 2012).

I: Yes because if you are dating someone they become like your friend. So it doesn’t help to hide things from them. Tell them where you are going so that they will know what you are going to do there. That way you can even take them along and say let’s go and get tested. (Interview, 29 Aug 2012).

Participants’ responses indicate that instead of alienating them from the males in their lives, the open disclosure about visiting the clinic to get HIV tests strengthens the relationships they have with them. The HIV tests appear to have helped the participants to revive the trust they had established in their relationships. Further, by consenting to the tests, they were modelling the type of behaviour that they wanted their boyfriends to emulate. According to Bandura (1995) modelling positive behaviour is one of the most effective ways of encouraging others to adopt it. This suggests that through their willingness to know their HIV status, the participants motivated their boyfriends to do the same. Essentially, this indicates that by offering the HIV counselling services, the FB project does not taint participants in any way. Instead, they empower them by giving them the opportunity to be in control of their relationships (Servaes 1996-2008). Also, this demonstration of agency is indicative of high efficacy beliefs amongst the participants. As mentioned earlier, it was previously thought that participants had a low sense of self efficacy. Findings such as these further demonstrate that in their communication campaign the project needs to focus on maintaining high efficacy beliefs where HTC is concerned because its importance is understood by them. Further, literature reveals that “scaled-up testing is increasingly advocated both as a gateway to treatment and prevention and as a way to “normalize and destigmatize HIV” (Makhlouf Obermeyer and Osborn 2007:1762). This suggests that HTC is one of the projects powerful communication tools that can be used in order to raise further awareness about HIV, encourage the afflicted to seek treatment and to control the creation of stigma.

Project HIV facility as a support structure

Other reactions to questions about the projects clinic being branded as a solely HIV clinic garnered the following reactions:

I: For the first time I didn’t know there was counselling. I just thought they tested.

D: So now that you know how you do feel about that?
I: Ya, I feel alright because we get to share things that we wouldn’t be able to share with our friends. Also, when you get here you know that you will find someone different. It’s easier to share things with someone you don’t know because when you come here on different days they won’t remember you because there are lots of us who come here. And they won’t point you out and say “that’s the girl”. (Interview 04 Sept 2012).

I: I don’t think it’s bad because they help you by referring you to a clinic close to you afterwards.

D: They do that? Even I didn’t know that.

I: What I mean is that they test you and then you are able to get treatment closer to home. (Interview, 30 Aug 2012).

Each of these responses indicates that the HIV facility at the project is regarded as a pillar of support amongst participants. The first participant seems to value the level of anonymity it guarantees her. Seemingly, during the HIV counselling participants can vent about private issues without the fear of being recognised or judged at a later stage. Furthermore, participants seem to feel that during the counselling they can get reliable information about HIV. This is an important attribute of the projects HIV clinic. Another important accomplishment is the fact that participants are aware that the clinic can establish a support system in their vicinity in the event of their HIV status being positive. This sends the message that the organisation sincerely cares about the participants thus strengthening their trust in it (Wynia 2007). It indicates that it is willing to take measures to ensure that participants can cope with the burden of this disease in their everyday environment where it matters most. In this way, participants are convinced of their value to the project (Kincaid and Figueroa 2009).

Conclusion

This chapter has provided a comprehensive presentation of perceptions regarding different aspects of the FB projects existing communication strategy. The bulk of this discussion comprised of young women’s opinions. However, since their participation is sometimes influenced by other stakeholders, their reception of the projects communication was factored in as well. Instead of being a mechanical presentation of data, this chapter attempted to interpret it in an engaging manner so as to expose even the most subtle details. Overall however, there is a fair amount of positivity as well as criticism towards existing
communication from the project. Academically based considerations that could address some of these challenges are discussed next.
Chapter Six: Additional Analytical Deductions

As stated previously this chapter is a continuation of the findings analysis. As a student who respects academic conventions, it is important to re-iterate that I am cognisant of the fact that recommendations do not typically feature in academic works. However, as explained in Chapter 4, the funders of this study required that I do so. Through the examination of the problems and consequences of applying a suggested intervention, they could get a sense of its viability and applicability to the FB project. In order not to overstep academic boundaries, the suggested interventions are supported by scholarly literature.

This chapter further reveals the FB project’s strong communication aspects, as well as areas that need to be amended. Additionally, this extended discussion encompasses interventions that may be useful during the development of the projects health campaign. As discussed earlier there were various responses that suggest that by entrenching itself into the Ugu District community, the FB project became the focus of great speculation. Many embraced it whilst others were (initially) uncertain about its motives for being in the community. This is evidenced in the ensuing discussion:

Improving Reception of the FB Project

Trustworthiness of the Project: Supportive Parents

At school meetings that were scheduled in order to introduce the project to parents and address their concerns, the reactions were generally favourable. At the end of these meetings when all their queries had been addressed, parents welcomed the project into the community. Observations via field notes of the parents who instantly approved of the project were captured below:

Towards the end of the meeting Prof emphasised the issue of receiving consent from the parents before the study commenced. When the school teacher asked them all if they consented to their children participating in the project, they agreed unanimously. She then encouraged parents with questions to ask them. Their enquiries were as follows:

Questions from parents:

15 In addition to the talks, parents were also provided with written, factual information such as ‘parent’s blessing’ letters with contact information.
16 Professor of medicine within the project who requested her name be with held
- Is the project designed exclusively for children with Bilharzia?

- Is the project open to adults who have suffered from Bilharzia previously or is it exclusively for children?

- Are menstrual pains associated with Bilharzia? If a child experiences them is she more vulnerable to Bilharzia?

- If a young boy suffers from chronic abdominal pains and nausea is it possible that they are caused by Bilharzia and what steps can be taken to help him? (Field Notes, “G” High School, 21 Feb 2012).

This extract illustrates the unfeigned interest many parents have regarding acquiring more knowledge about the projects work. The questions were specific and indicated their willingness to be involved. This demonstrates the level of trust that they are prepared to invest in the project (Wynia 2007; Kincaid and Figueroa 2009). By enquiring if adults with previous exposure to Bilharzia could receive treatment, their perceptions of susceptibility to it and their considerations of it as a health threat are communicated (Green and Witte 2006; Smith et al, 2007). Further, through their questions parents appear conscious of the fact that Bilharzia is not gender specific. This is a positive finding because as opinion leaders in their households, their progressive conceptions of this disease can be built on by the project for them to impart to their children (Lazarsfeld et al, 1948).

Based on observations it seems parents meetings are an ideal communication platform for the following reasons: First, they are an arena where queries can be addressed publicly. The community is addressed in its entirety which minimises “trickle-down effects” which can occur when segments of an audience receive information at different times (Panter-Brick et al, 2006:2811) (See Chapter 2). Secondly by verbalising their approval of the project at these meetings, to a minimal extent parents attain the status of participants. In these instances the type of participation exemplified is a combination of “participation by consultation [and] interactive participation” (Cornwall 2008:272). In the former participation occurs when people are notified of matters of interest within their communities. They can then interrogate aspects of it through questions until they are satisfied with the explanations (Cornwall 2008). In the latter they participate through joint analysis of the problems and consequences of supporting interventions in their communities (Cornwall 2008). Here, all perspectives are considered until a consensus is reached (Cornwall 2008). By so doing “participation is seen as a right, not just a means to achieve project goals” (Cornwall 2008:272). Based on this it
appears that not only does the project respect parents right to participation, it works hard to communicate their value to towards the realisation of its goals.

Secondly, during these meetings parents have the opportunity to reflect on the “compelling elements” of the projects work (Panter-Brick et al, 2006:2811) that may encourage them to accept it into their community. In this way their support of the project can be based on a fair evaluation of its merits or disadvantages. By so doing, parents’ agency is respected by the FB project despite being its indirect participants (Bandura 1995). According to Bandura (2004) the process of familiarising family members with a health ailment helps to convince them of its seriousness. From this we can infer that when parents understand the severity of FB, they can then be the support system that young women need during its prevention or treatment (Bandura 2004).Thus far it appears that the project adheres to Bandura’s (2004) recommendation through its collaborative communication with parents at meetings(Cornwall 2008, Melkote and Steeves 2001). Further, literature indicates that if potential participants in the project seek Bilharzia treatment with their parents’ approval, the likelihood of their self-efficacy being enhanced is high (Bandura 1995; 2004). The project encourages young women to communicate their participation in it to their parents at the onset. This suggests that attempts to increase young women’s efficacy beliefs begin in the early stages of their participation. Furthermore when the FB project discloses information to parents at meetings, their transparency improves their image as an authentic and therefore trustworthy organisation (Petraglia 2009; Wynia 2007). In sum, it appears that parents meetings are a positive aspect of the FB project’s existing communication strategy.

Misgivings about the FB Project

While the majority of parents’ perceptions of the FB project were positive, earlier findings revealed that others were tainted by suspicion. The responses from participants that suggest this include the following:

I: They [the parents] asked me where it was because they are afraid of the things that people say happen. But because I gave them the letter and it was something that was associated with school they trusted it. At first they were...but after I gave them the letter they were alright. (Interview, 07 June 2012).

From this response we can also surmise that rendering health services for free is a factor that helps to allay suspicion of the project. When no expense is incurred for a health service, the unspoken message that is sent out to the public is that no profit will be made by an
organisation at their expense (Wynia 2007). In this way the fact that their well-being is a priority is emphasised thus strengthening the relationship of trust between it and the community it works with (Wynia 2007). This excerpt is also an indication of the accuracy in Kincaid and Figueroa’s (2009) earlier claim that aligning an organisation with respected institutions in the community helps it to gain acceptance. This is another strength of the FB project’s present communication approach.

Conversely, the response illustrates the caution that some parents exercise regarding voicing their support of their children’s participation in the project. It seems they are apprehensive about trusting an unfamiliar organisation. The stories circulated by people about the consequences of trusting too easily appear to incite doubts about its credibility. However, it seems that perceptions of legitimacy can be established through print material that details the projects collaboration with schools. Print material can help to portray a project as a “trusted messenger” of a health message (Wynia 2007:6). Chapter 2 included a discussion by Plimpton and Root (1994:86) about how communication was the basis of “health promotion and disease prevention”. Parts of their work focus on print materials and how they contribute positively to health interventions (Plimpton and Root 1994). Based on the favourable reaction from some parents after reading a letter from the project, their findings seem accurate. From this we can deduce that some of the projects existing print material does improve communication between it and certain stakeholders [my emphasis]. As a result it may also be useful during its public health campaign.

Incorporating reading material

Based on the above findings it appears the distribution of reading material is a critical aspect of communication between the FB project and participants families. Due to the poor grasp of FB however, it appears not to meet the educational requirements of its primary targets. It is possible that the existing reading material is too dense and complex for teenagers to comprehend. Due to the strong oral practices that are a large part of our heritage, as South Africans we are not a strong reading nation [my emphasis] (Pretorius 2008). Reading avidly has yet to be fully immersed into our culture (Pretorius 2008). As a result of this perhaps the text should be replaced with graphics in order to be understood by the target audience. This is because properly designed graphics have been found to facilitate both the comprehension and recall of text (Rakes et al, 1995). Further, the reading material available at the project contains information only on Bilharzia. By distributing material that is solely about Bilharzia,
the project may be doing itself a disservice. It is compartmentalising itself into an exclusively Bilharzia oriented category. It offers various other health services to participants. However, it is denying itself the opportunity to publicise and declare its presence in the community as a future multi-faceted health project.

*Lack of access vs. free will*

At some schools particularly those in the rural areas the students were eager to participate in the FB projects study. However, Bilharzia was not the central reason for their participation as noted in participant observation:

“Stage 2 went very well. I spoke to approximately 6 girls individually about the project, the clinic, Bilharzia and the procedures that would happen should they agree to participate. All six girls agreed to come. The school was very rural and getting there was a difficult task. Most of them were very open and asked me some health related questions. These included concerns about vaginal discharge, itchiness, heavy periods and HIV Testing. I noticed that none of the questions were about FB at all. They did not request more information about how it is treated or even the possible side effects of treatment. They just seemed excited at the prospect of being treated for other infections. I was surprised by their openness given the fact that this was our first meeting...” (Field Notes, High School, 22 Feb 2012).

This excerpt is yet another demonstration of the inability to perceive Bilharzia as a genuine health threat (Green and Witte 2006; Smith *et al*, 2007). The interview excerpts revealed similar findings. However, whereas some women consented to participating due to trivial reasons, the observations suggest that others are forced by circumstances. It appears that access to proper gynaecological care is unavailable in some areas. Currently the FB project fulfills this health need and young women eagerly receive it. This is indicated by the nature of their questions and the instantaneous trust they invested in me despite it being our first encounter with each other. It is possible that they viewed the opportunity to come to the project as their sole chance to receive this type of health service. Based on their questions, it seems that education about sexual and reproductive health is needed. This is because this group of participants seemed to lack basic information about these matters. Before the FB project can expect to encourage its participants to be pro-active about maintaining their health, it needs to lay a proper foundation of facts. Before the FB project can expect to encourage its participants to be pro-active about maintaining their health, it needs to lay a proper foundation of facts. Evidently, some of their existing attempts at this are not as resonant as they could be. As a result perhaps a more interactive communication vehicle such as EE would yield better results (Panter-Brick *et al*, 2006;
Durden and Nduhura 2005). As discussed in preceding chapters EE can be advantageous in various ways (Durden and Nduhura 2005, Singhal and Rogers 1999). It is a powerful educational strategy that allows for information to be imprinted indelibly in its audience consciousness (Singhal and Rogers 1999). Further, in instances such as these, because of participatory nature it can transcend the socio-economic limitations and increase awareness about FB and general gynaecological health (Durden and Nduhura 2005). Also because of its oral nature it is an easily accessible and cost effective communication tool (Singhal and Rogers 1999; Durden and Nduhura 2005). These observations also demonstrate the accuracy in Hindin and Fatusi’s (2009) statements about some health issues eclipsing others during public awareness initiatives. The project treats various diseases; however its communication with potential participants focuses mainly on FB. While this is understandable because of the projects research focus, it sends the incorrect message that FB surpasses the other diseases it treats in terms of importance. As established earlier this limits the scope of its services in participants’ eyes. The project treats other diseases that can compromise women’s health.

Therefore, its communication messages need to reflect this because at this point they are partial to FB.

**Conflicting messages**

Drawing from the interview excerpts another factor that contributes to the occasional poor reception of some information from the project is the gynaecological aspect of its work. In their research on steps health programs can implement to reduce the effects of stigma, Guttman and Salmon (2004) state that the incomprehensibility of a message could offend the sensibilities of the people it was designed for. I argue that the FB project has done this inadvertently. Although the males are not its targets, their reception of communication about FB does affect the relations participants have with them afterwards. As a result it appears that ensuring that information is received appropriately by both sexes is important. When it visits schools and informs the student body that Bilharzia is a serious disease that affects everyone, the message encourages both genders to seek treatment [my emphasis]. It seems that by removing the males from the discussions about the gynaecological portion of the talks, it sends a contradictory message that Bilharzia is more of a female problem [my emphasis]. In fairness limited resources such as sponsorships from donors necessitate FB to be the primary communication focus of the project. As a result the other services that the project offers such as sexual and reproductive services and HIV counselling become secondary priorities. However, there are other cost effective options such as EE that the project can explore.
so doing, the authenticity of the original message about the risks of Bilharzia is diluted (Petraglia 2009). In this way the males are deterred from viewing it as a threat to them.

Later attempts to involve them are possibly interpreted as a direct challenge to their manhood because they had accepted that bilharzia is a female concern. The project can address this lapse in communication by explaining how Bilharzia manifests itself in the body. Providing young people with correct information is the first step towards convincing them of the value of adhering to an advocated behaviour (Aggleton and Campbell 2000). Further, both genders need to be present when it is explained that both males and females are susceptible and can experience its long term effects such as infertility (Kjetland et al., 2012). By so doing the applicability of the projects cautionary messages to them may be understood better instead of being “fossilized in memory with little connection to application” (Petraglia 2009:176). One solid message of commitment to erasing the Bilharzia problem needs to be communicated to young people at schools instead of inconsistent messages that may confuse them.

Additionally, although it might be uncomfortable, perhaps a more open and inclusive approach through dialogue is best (Kincaid and Figueroa 2009). Perhaps male teachers and boys need to be present for the segment of the talks about gynaecological exams. This might normalise the procedure and alter inaccurate perceptions of it. When people have a proper understanding of a sensitive issue, the knowledge is empowering because it promotes an atmosphere of acceptance of it known as “convergence” (Kincaid and Figueroa 2009:1313). It stops being something foreign and shameful and is instead integrated into the social fabric. For instance, for many, the issue of menstruation was uncomfortable to discuss (Harrel 1981). For a long time it was shrouded by a veil of secrecy. However, through forthright discussion in public spaces, it is gradually being acknowledged and accepted as a normal part of life (Oinas 1999).

*Tension between rural and urban participants*

Participants indicated that occasionally there was tension between young women from the rural and peri-urban schools. Although the number who indicated this is not high, it is valid because it has affected the quality of the hospitable environment the FB project works diligently to create. The following was said on this issue:

D: Did you all get along with the other girls?

I: No.
D: Why not?

I: Not really cuz “school Y” is known as a...ok well let me talk about “school X”. It’s known as a high-class school. So “school Y” is known as a school with bullies and so on. So “school X” know that they are snobs and we don’t like them. (Interview 20 May 2012).

D: Did you get along well with the school?

I: [Laughs] No we did not get along.

D: Why not?

I: I don’t know. I got here and it was very quiet. The kids were quiet and those who were talking a lot were the ones from our school. I don’t know why but maybe it was because it was a primary school with a high school (Interview, 04 Sept 2012).

This animosity between participants appears to stem from the perception of Bilharzia as a social class disease (Schall 1995). It seems that those participants from the peri-urban areas make those from the rural areas self-conscious whilst in the project’s waiting area. Although slight tension amongst teenagers is not uncommon, at a deeper level it indicates how some of the stigma related to FB develops. The perception of Bilharzia as a disease that is restricted to people in rural areas that lack proper sanitation is incorrect (Schall 1995). However, it seems extremely widespread. To minimise the creation of stigma being attached to people, scholars who have examined this issue at length suggest the following:

When raising awareness about a potentially stigmatising disease, it might be best to recruit those who are at “moderate risk” of contracting it first (Guttman and Salmon 2004: 536). By encouraging them to “adopt risk reducing-practices” (Guttman and Salmon 2004:536) they can be role models to those who are at a higher risk. In the long term this “may promote values of solidarity and reduce the likelihood of stigmatisation and labelling of those considered at ‘high risk’ (Guttman and Salmon 2004:536). Perhaps as part of its public health campaign, the FB project could consider targeting a larger sample of young women from peri-urban areas. This might reduce the association of Bilharzia with social class and instead draw attention to its riskiness. It might also create a positive atmosphere amongst participants at the project. Positive encounters between participants are fertile ground for the development of “strong inter-personal relationships” (Speer and Hughey 1995 in Melkote and Steeves 2001:358). These relationships may simplify the process of uniting young women and encouraging them to act against the threat of FB.
Project responsibilities to participants

Encouraging self-management

The seemingly reciprocal relationship between the project and its participants’ uncovered issues that I believe need to be addressed through communication. I believe that doing so would be fulfilling many of its obligations to participants. Further, rectifying these concerns now can prevent them from impacting negatively on the public campaign. As discussed earlier, generally, participants have a positive impression of the FB project and its staff. However some responses indicated that at this stage the FB project has yet to fully imprint the value of managing their health independently. This assertion is motivated based on the works of scholars from within the participatory paradigm who claim that true empowerment manifests itself through self-management (Servaes and Malikhao 2005; Kincaid and Figueroa 2009). Responses that suggest the escalating complacent attitude of some participants include the following:

I: Maybe some of the staff who works here could come and ask me if they can talk to me. Some of them live in my neighbourhood and they avoid coming over to talk to me because they think I might be afraid. So maybe it’s for the best if they ask me if I want to talk to them... they are like nurses. If she lives in my neighbourhood I can go to her and say “it’s like this now”, what is wrong? And she can explain to me. Maybe if I know that the person is a nice person who is not judgemental, I could go and talk to them and tell them that I have this and that. If it’s something that she also does not know she can come here and ask, then come back and tell me and make me understand. Now if I’m wary of going to the clinic or it’s full and the clinic and its far here, I can stay with something and it turns out to be something big because I am scared that she lives in my neighbourhood. It’s for the best if they ask us if it’s fine if people we know can interview us. If we say no, then we say no. (Interview, 20 May 2012).

This response highlights the following: firstly, there seems to be a problem with the fact that project staff from the same neighbourhoods as participants are advised not to interact with them while they are at the project. This rule was implemented by project as an attempt to protect young women from feeling exposed in front of people who are also members of their community. It was believed that upon recognition of a familiar staff member, they would feel self-conscious. In this way the quality of their experience at the project as well as the long term relationship being built with them would be affected.
This participant’s response contradicts this belief. It indicates that she feels she should have been consulted and had her choice in the matter being considered. Essentially this indicates the need by some participants to be included at every level of decision making (Melkote and Steeves 2001; Servaes 2008). Furthermore, the excerpt suggests that in some instances participants discomfort is presumed and not confirmed. The fact that some participants’ equate the research assistants (RA) to nurses indicates that the degree of confidence in their health expertise is high. However, the need for their availability outside the project is cause for concern [my emphasis]. This particular participant saw no issue in an RA sharing the expertise that is restricted to the professional project environment in a social one. Although her concern for her health is commendable, she did not consider that it might disrupt the pattern of the RA’s life outside the confines of the FB project. By expecting an RA to search for solutions to her health problems and then consult her, she is confusing their job description with that of a community health worker. In order to remedy this, the extent of the RA’s responsibilities needs to be properly delineated. It has to be communicated to young women that although their participation is invaluable, it should not translate into their resigning themselves to the role of being passive recipients of knowledge from project staff (Freire 1990; 1990). This would contradict the core tenets of the participatory paradigm and the values the project is working to impress upon them (Melkote and Steeves 2001; Mohan 2001; Servaes 2008). The agency to either seek more information regarding their health queries once they leave the project or to visit clinics in their vicinity needs to originate from them (Bandura 1995). It should not be expected from RA’s. True participation involves a willingness on beneficiaries’ part to solve problems on their own (Cornwall 2008). This is the “transformative” aspect of participation (Cornwall 2008:273).

**Nursing Staff Involvement**

While the project’s RA’s appear competent at working with participants, they are not trained as health professionals. However, the project does have qualified nurses with vast experience in their field and are thus credible sources of health information. Encouraging them to be more pro-active about giving participants health advice may be a viable communication strategy for the project to consider. The nursing staff are valuable communication assets for the project. Teaching them to share their health expertise with participants could be advantageous because it prevents possible over-reliance on RA’s and through information shared; the facts of FB are re-enforced.
Protecting participants from peer mockery

As part of honouring its responsibility to the participants, the FB project works hard to protect them from “unintentional adverse effects” (Guttman and Salmon 2004:534) that come as a result of their involvement with them. These effects include stigma which has been a constant topic throughout this study. The sources of stigma appeared to be misconceptions stemming from misguided social beliefs and lack of knowledge. The literature examined throughout this dissertation indicated that more aggressive, culturally relevant educational tactics could possibly remedy these problems (Panter-Brick et al, 2006; Servaes 2007). However, in some instances I believe that circumstances within the project’s control interrupt communication between it and participants. The excerpt below suggests this:

I spoke to a girl under a tree due to a lack of space and in order to maintain privacy. Also it was very hot. I felt extremely uncomfortable because I felt like I was isolating the young girl and drawing unnecessary attention to her. The fact that we arrived on time got, delayed by the teachers and then had to speak to the girls during the lunch break complicated things further. While we were under the tree I kept getting distracted by the groups of boys who grabbed their chairs and sat a few feet away from us. Occasionally they would laugh and yell “Isichenene” (Bilharzia) in our direction. They were the same group that followed us from the classroom and did some minor yet irritating things to get us to notice their presence. The girls who are part of the school’s feeding scheme and the teachers were doing their best to pretend like they were ignoring us. However, the curious glances in our direction gave them away. The giggles from other girls did not ease the discomfort. The girl I interviewed was introverted yet she listened and agreed to participate in the study. She mentioned that the clinic was far and she was happy to come with us. (Field Notes, “S” High School, 20 January 2012).

This extract indicates that the major communication impediment, that may also generate stigma, is the synchronisation of schedules between the schools and the FB project. These conflicting schedules seem to be the root cause of stigma which is one of the “unintended adverse effects” the project aims to protect participants from (Guttman and Salmon 2004:534). The first encounter between potential participants and project staff is of vital importance because it influences their decision to participate. Privacy is needed in order to explain the fundamental aspects of the projects work and for the young woman to make enquiries and subsequently an informed decision. Being interviewed in a public space with teachers and the rest of the student body watching renders participants vulnerable. This
interaction between myself and the participant is an indication of how inadequate spaces restrict dialogue and obstruct what Cornwall refers to as “effective” participation (2000:275). In this instance the supportive structures that can “nurture [an individual’s] voice” were missing (Cornwall 2000:275). As a result I sensed that the participant may have felt coerced into consenting. The excessive attention from her peers may have led to her hastily deciding to participate in order to avoid the public scrutiny. If the schedules had been properly co-ordinated the participant would not have been subjected to scrutiny which could erode her self-esteem.

_Dealing with disgruntled teachers_

Despite prior arrangements with the teachers, at some schools the projects actual presence on the premises was received poorly. Judging from both the interview sessions and observations the FB project did nothing to warrant the unenthusiastic reception from teachers. However, the findings also indicated that teachers affect participants’ willingness to participate and their reception of information from the project. Due to this I believe it is part of the projects responsibility to alter teachers’ mindsets about it through communication. Further evidence that highlights the need for this is documented below:

The teachers received us coldly, yet politely...they seemed very irate and I got the sense that they were reluctantly going through the motions of accommodating us. They continuously enquired about the amount of time we would need and repeatedly mentioned that we had come during the lunch break when students had to eat. Although it was unspoken, I got the impression that they were anxious for us to leave...From the learners I felt that they were teenagers with a lot of discipline problems. I gathered that they would have a negative attitude towards treatment. Not because of side effects but because they feel the need to demonstrate that their indifference to the project. (Field Notes, 17 May 2012, “Z” High School).

This extract illustrates how the negative reaction of teachers impedes effective communication between the FB project and filters down to participants. It appears that they grudgingly tolerate the project despite regarding it as an obstruction to the routines of their schools. Teachers are part of the social environment that influences participants’ attitudes and behaviour (Bandura 1995; 2004). Therefore they can be powerful role model whose attitudes towards Bilharzia can be easily altered for their learners to imitate (Bandura 1995). Drawing from the literature, a possible strategy for changing these negative attitudes is to structure informational talks in a manner that communicates the import of teachers support (Bandura
2004). It needs to be communicated to teachers that their goals of empowering their learners are shared by the FB project (Kincaid and Figueroa 2009). Therefore by co-operating with it and not regarding it as an imposition these goals can be realised within a shorter time.

Secondly, in order for a health intervention to be successful it needs to be “in the school but not of the school” (Bandura 2004:158). The FB project operates according to this rule; however, it may not have communicated this explicitly to teachers at schools, hence their perception of it as an obligation that requires their involvement. Their lack of knowledge about the value of their assistance as well as FB manifests itself as irritation. Kincaid and Figueroa (2009) believe that once all stakeholders are convinced of the significance of their roles to a project their support of it increases. From this we can infer that the project can counter this unfriendly reception from teachers by bringing them to the realisation that they too are integral towards maintaining the health of their students (Kincaid and Figueroa 2009). By supporting the project’s work and encouraging students to listen or participate, they afford them the opportunity to acquire health lessons they can carry into adulthood.

**Community expectations from the project**

*Demands for donations*

Throughout the research period it became clear that members of the broader Ugu District community where the FB project works had different expectation of it. Many of them were realistic whilst others appeared opportunistic and unfeasible. There were some parties who were convinced that their co-operation with the project needed to be rewarded. I believe that at a deeper level such beliefs are symptomatic of a lack of trust of the FB project. As a result, making unrealistic demands is regarded as compensation in the event that they are exploited by it. At a rural school, a principal demonstrated his mistrust of the project’s intentions thus:

The Principal Mr. M.J.N.... eventually joined us and the first thing he asked about was something that Professor “T” who was accompanying us had promised him. Apparently at an earlier point in the project’s work at his school, he had asked her if she could donate desks to the school. She had told him she could try and find out if a certain institution had old ones that they could give to his school. He seemed to regard her inability to locate the desks as a betrayal or a lie that had been told to gain entry into the school.... The principal then repeatedly asked about what the school would benefit as a result of their co-operation. He explicitly told the team that the project needed his school to work in; therefore they should get something in return. He asked
if project team could bring something to donate to the whole school. He related a story about how in the previous year members of the project had promised to bring the school cake. They then brought a box of *Choice Assorted* biscuits and one cake that they left at the Staffroom. He then said: “Mxim [expression of annoyance] that was not enough for the whole school (Field Notes, “KB” High School, 26 January 2012).

This excerpt as well as others, demonstrates miscommunications that can occur partially because of resistant gatekeepers (Lazarsfeld *et al*, 1948). They need to be addressed by the project before they escalate. Firstly, although the project requires the approval of school principals before they can work with students, it is treating a legitimate health issue (WHO 2011) and is not compelled to submit to unrelated demands. It can be argued that schools that are selected are privileged because the treatment is available at no expense to them (WHO 2011). Further, the on-going research might yield results that will be beneficial to young women throughout their adulthood (Kjetland *et al*, 2012). Secondly, the exchange of items between the project and teachers is not mandatory. It is a gesture of goodwill that is intended to signify that their co-operation is appreciated (Kincaid and Figueroa 2009). In essence doing so is an exercise that is intended to strengthen the relationship of trust between the project and its community of stakeholders (Kincaid and Figueroa 2009). Third, it appears that the fact that the FB project is a non-governmental organisation (NGO) that has limited funding and consequently limited resources is not understood. Due to this, it cannot accommodate requests for desks and other shortages of supplies at schools. Doing so would translate into the deduction of finances from other important sectors of the organisation. Furthermore, if these charitable requests could be met, there would be guidelines to follow and channels to go through in order for them to be distributed equitably.

This incident seems to corroborate earlier findings about people having a limited understanding of the research process. This was demonstrated by the statement that the project “needed” to make a donation since they were working with students from his school. In research it is not uncommon to have incentives in order to appease the study participants. The FB project offers several incentives. They utilise their own resources to ensure that free treatment is delivered to participants in exchange for their participation. They have the option of free contraceptive services for three months. Participants also receive free treatment for other related illnesses such as sexually transmitted diseases and an optional HIV test. During their visit to the project, they are treated to a free meal. These incentives are substantial and at both a moral and logical level demands for more are unwarranted.
It needs to be expressed that the project has clearly defined goals and is not obligated to resolve every social ill. Furthermore, if an influential opinion leader (who also acts as a gatekeeper) such as a school headmaster can make these demands, it demonstrates how the conditioning of young people into entitled “welfare recipients” occurs (Freire 1990:48). It is in this way that patterns of dependency on development initiatives originate (Servaes 2008).

The opinions of influential community members can affect the rest of the people within it (Lazarsfeld et al, 1948; Melkote and Steeves 2001). This means that the likelihood of their magnified expectations of the FB project acting upon potential participants is high. This is problematic because it interferes with its efforts to empower and encourage them to be self-reliant (White 2004, Servaes 2008; Melkote and Steeves 2001). In sum, it appears that the project’s current communication strategy has not adequately conveyed its function in the community to all authoritative figures within it. As a result, they have inflated expectations that it cannot meet which leads to their reluctance to work together with it.

**Exploring appropriate communication tools**

One of the chief goals of this study was to establish whether the manner in which the FB project communicates was suitable for young women from both rural and peri-urban areas. When asked to suggest ways in which the project could improve its current communication strategy, participants unanimously favoured targeted methods instead of amplifying ones. By this I mean they seemed to prefer small scale communication options that reach small groups as opposed to those that reach massive audiences. The different mediums that they suggested and the possible problems or consequences of the FB project adopting them as part of their communication approach will be discussed next.

**Word of Mouth**

Through their responses participants indicated that the power of word of mouth is a powerful tool that should not be under-estimated by the project:

I: What made me want to come back is...... [Long pause] What is it really? What made me want to come back is that I heard some of the girls at my school saying they felt as if here [she gestured at her abdomen] something had been removed and they felt great. So when the lady from here called me-was it yesterday- and asked me if I was coming to the clinic and that I had to be in agreement with my parent about it. So my mother said ok and I told myself that I also want to get cured because I had heard those kids. So I agreed to come (Interview, 31 May 2012).
D: Wait—the girls who had been here before were telling you who had not been here not to come?

I: Yes.

D: Why?

I: I asked if it was painful they said no it was not. I asked if you were forced to do it, they said no if you don’t want to you don’t have to. So I asked them why they didn’t refuse. Then they said they wanted to experience it. So I told them that I also wanted to experience it. I also told them that they were here to play but I wasn’t because I knew that I had a problem. (Interview, 29 Aug 2012).

Both responses illustrate that word of mouth can be a powerful tool for creating perceptions about an organisation. The first response indicates that word of mouth can accelerate the diffusion of information about the positive contribution an organisation makes within a community. The second response is a demonstration of how word of mouth can perpetuate a myth. Following the positive experience that the first participant’s peers had at the project, through word of mouth, they became unwitting “core agents of change” (Tufte 2005:165). They became a vehicle that disseminated accurate information (Tufte 2005) and challenged misperceptions that may have been a cause for young women in their school to fear the FB project. In so doing, the group of participants whose efficacy beliefs regarding FB were magnified following their visit to the project became a catalyst for others to start being accountable for their health (Smith et al, 2007). To this end, I assert that enlisting participants who have visited the project to be agents of change that raise awareness about FB could serve it in good stead for the public campaign (Tufte 2005). There were participants who were willing to assume this responsibility because they believed that word of mouth can be used as a tool to equip other young women like themselves with information about FB:

I: Yes. They could ask us to volunteer plus I live with many people, I have many friends and throughout my neighbourhood there are different groups that I know. You might find that there are people who might want to be involved in something like that but they do not say it. So we could try and go to people in their own neighbourhoods to talk to them. (Interview, 20 May 2012)

This response suggests that the participant was empowered by the project to the extent that she is willing to become an ambassador of sorts and go out into her community to educate others. She indicates that there are other young women within her community who would welcome the opportunity to act as representatives of the FB project. Based on the excerpt we
can presume that the project has successfully gathered a niche group of loyal female supporters. To a degree, the project’s existing communication strategy has managed to secure the trust needed to make “co-operative action” between itself and the young women it was initiated for possible (Kincaid and Figueroa 2009:1323). This accomplishment may simplify the complicated process of recruiting former participants willing to work on the public health campaign. Other advantages of utilising former project participants are discussed below:

They are from the community therefore they understand intricacies that even an experienced researcher cannot [my emphasis] (Servaes 1996). Due to this inherent knowledge, they can foresee possible predicaments that can affect the reception the campaign receive (Servaes 1996). For instance, they can suggest the best way to approach minor actions such as the development of appropriate phrasing of slogans and inoffensive imagery. In addition, their involvement enhances the credibility of the FB project (Wynia 2007). It is difficult to completely erase people’s doubts about an exogenous organisation that enters their community (Servaes 1996; Melkote and Steeves 2001). Earlier findings indicated that these misgivings are amplified due to factors such as the miscomprehension of the scientific aspect of the project. However, the literature examined in different chapters of this study suggests that these suspicions can be subverted gradually once locals become involved.

Evidence of young women being vocal about FB as a health issue that affects them is virtually non-existent. This is especially true in conservative social settings. Therefore, I believe that the novelty of young females taking this initiative can draw attention to the Bilharzia topic. Furthermore, if females in the community are exposed to other females who speak openly about the health issues that affect them, this may have a stronger impact on their attitudes and behaviours. This is because the strongest role models are those whose lives mimic that of those observing them (Bandura 1995; Singhal and Rogers 1999).

To a small extent the involvement of former participants addresses the unemployment problem. Although this is not the direct concern of the FB project, it is an inescapable social ill in the community where it is based. The fact that participants of this study volunteered themselves and their friends in their neighbourhoods to assist the project in its endeavours is ample evidence of this. Therefore, minor attempts to give unemployed young women a purpose by enlisting their help in the development of a campaign can rectify it slightly. The monotony of unemployment can be tempered by their participation in a health campaign that could reach thousands of young women like themselves. In addition to the sense of agency of
being a part of a massive initiative, these volunteers could circulate positive information via word of mouth. The findings revealed the power that lies in word of mouth. However, positive word of mouth could possibly undo the damage caused by prevailing myths. This will enhance the image of the project to the wider community and re-enforce the trust relationship it had developed thus far. An added advantage of working with former participants is that anything positive they say about the FB project can be considered a testimonial. Their personal accounts about proceedings at the project clinic for instance can be used as evidence that nothing sinister occurs there. The gynaecological examination was one of the controversial procedures according to the findings. However, a testimonial by a young woman who has undergone it can be a potent endorsement for it. Other suggestions were as follows:

*Inclusion of Bilharzia into school syllabuses*

I: I think they should add Bilharzia into L.O. [Life Orientation school syllabus] so that we can get an understanding of what it is. It’s just that LO educates about a lot of other diseases but I have never heard of Bilharzia. (Interview, 04 Sept 2012).

This may be a viable suggestion because when a health issue is incorporated into the school syllabus its credibility as enhanced. All the relevant facts that need to be communicated to young people about it are repeated on a regular basis which accelerates the rate at which they are remembered (Singhal and Rogers 1999). Furthermore, teachers are influential figures of authority (Freire 1985; 1990) who could successfully address the misconceptions about Bilharzia and facilitate the process of normalising it amongst both sexes. Earlier in this dissertation the discussion highlighted how participants related how teacher mocked her for her involvement with the project. If teachers were knowledgeable about with Bilharzia, they could assist in curbing the stigma surrounding it. Also, if the Bilharzia issue is integrated into the school system it is guaranteed longevity. Students and teachers will always be exposed to it and have access to correct information about it that they can pass on. In this way a constantly evolving cycle of knowledge sharing ensues. This approach will also garner free publicity for the FB project. In this way the public health campaign can supplement existing information about Bilharzia.

*Community level communication*

Most of the participants suggested generating publicity using smaller avenues first before embarking on a massive public health campaign:
I: They could put up pamphlets on streetlights, on bus stops or in places where they know that people will be there. People will read them and probably understand. Some might not understand but they will find other people who will understand and explain it to them. They will definitely find lots of people in the community (Interview, 29 Aug 2012)

I: I think they can have containers that operate on weekends where people can go to get help.

D: What?

I: Containers where people can go and get help during the weekends.

D: Oh! You mean like mobile clinics? (Interview 31 May 2012)

I: Maybe it would be better if they go to the clinic closer to their homes (Interview, 30 Aug 2012)

The first suggestion of creating pamphlets and posting them in areas that people frequent in their communities such as bus stops is feasible. Not only is it cost effective, it acquaints people with the issue being publicised and stimulates dialogue about it which enhances understanding of it. The second idea of having mobile clinics is worth further consideration because the concept of “mobile clinic” is one that people from every location are familiar with. Secondly, people have easy access to a structure embedded in their communities that provides them with accurate information. This idea could be implemented as part of the long term communication strategy of the project due to the cost of initiating, staffing and maintaining a mobile clinic. In the future it could serve as an extension of the actual FB project clinic. The third suggestion of targeting local clinics is good because it legitimises the FB clinic in the eyes of the broader community and not just the project participants. It also challenges the notion of the project as a replacement for local clinics and instead assists it to assert its position as a research facility that collaborates with these clinics in treating Bilharzia. Also, at local clinics community members generally gather there in large numbers thus making mass bilharzia communication easier. Further, if local nurses can be relied on to provide FB information to those who seek it, possible dependence on the project’s research assistant could be diverted.

**Consequences of using print mediums**

There were mixed reactions regarding the usage of print media such as newspapers to communicate about FB:
When it comes to newspapers I don’t want to lie, I only look at the picture or if there is a heading that entices me I will only read half. Newspapers are not my thing. I look at the picture only, ONLY. (Interview 30 Aug 2012).

I: I actually read magazines...

D: Newspapers?

I: I only read them if there is something exciting (Interview, 20 May 2012).

These excerpts are representative of most of the interviewed participants’ stance on reading newspapers. It seems that these young women prefer light, leisure reading as opposed to reading purposefully for enlightenment about issues. The newspapers that are available to participants are mainly the subscription free types that are circulated throughout their localities. They include *Ugu Eyethu* and *South Coast Fever*. A small group indicated having access to regional newspapers such as *Ilanga* and *Isolenze*. If newspapers were to be incorporated into the projects communication campaign, the following would need to be considered: While newspapers are readily available to young women the challenge lies in encouraging them to read. Secondly, if they are not the target market for hard hitting news, their parents might be. Therefore, communication via newspapers can be a platform for interacting with parents. Participants were also asked to discuss whether they found the print material issued by the project such as pamphlets helpful. They said the following:

I: Well, they had already explained them to us and we understood. So we thought that for sure what they were explaining to us was the same as what was written in the papers. So we didn’t read them (Interview, 20 May 2012)

I: Yes we read them. At first there was someone who read them for us and explained what this and that meant. They read the whole thing and explained it and then told us to answer the questions, Ya. [on the forms]. (Interview, 07 June 2012)

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18One of the eight weekly newspapers under the Eyethu brand. They are distributed throughout Kwa Zulu Natal and readership is approximated to be 1.4 million weekly. Available at: [http://www.bizcommunity.com/Article/19690/65615.html](http://www.bizcommunity.com/Article/19690/65615.html) Accessed: 12 November 2012


Both responses suggest that participants felt the talks at the schools explained the Bilharzia issue to their satisfaction and the pamphlets were merely re-enforcing what had been said. It seems as if after the talks, participants browsed the pamphlets briefly. However, they are an important component of the current communication approach because participants keep them. In this way they have the option of sharing them with their families or referring to them when they need clarification at a later stage.

**Television and radio**

Based on the participants responses, it seems both television and radio are used more as an entertainment than educational medium by participants:

I: TV is what I watch a lot and it’s usually movies.

D: And the news?

I: I don’t want to lie but when its half past seven and it’s time for the news I switch to *Scandal* and then at eight I switch to *Generations*....

D: And the radio?

I: Like I said it’s not my thing. Even on my phone I just put my earphones on and listen to music that I chose to put on my memory card. The radio...ayi. (Interview 29 August 2012)

I: *Generations, Scandal*, and the news at half past seven.

D: And the news?

I: Yes because it’s my way of making sure that *Generations* does not pass me by.

(Interview, 25 August 2012)

These excerpts were selected from the overwhelming majority who reported that they were selective television viewers. What was gleaned from their responses is that they have an avid interest in both local and international soap operas. The most popular of these seem to be the locally produced *Generations* and *Scandal* and the international favourite was *Days of* ...

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22 Rated as South Africa’s “most popular prime TV” programme with an audience of 7 million watching daily. Available at: [http://www.thenewage.co.za/59287SABC_soapie_Generations_a_hit_with_Mzansi_viewers](http://www.thenewage.co.za/59287SABC_soapie_Generations_a_hit_with_Mzansi_viewers)

Accessed: 08 November 2012

Our Lives\textsuperscript{24}. For the participants, the \textit{format} in which an issue is presented to them is crucial \textit{[my emphasis]}. With the soap opera for instance current issues are discussed regularly and they seem to succeed in engaging them because there is an entertainment aspect to it. In sum, for most participants the television is a gathering place where they seek temporary entertainment or escapism through movies and soap operas. A small sample of the participants reported listening to the radio to inform themselves about pertinent affairs. uKhozi \textit{fm} which is the continents biggest radio station\textsuperscript{25} that broadcasts in Zulu was named as the station participants listened to regularly. However, for many of them, they listened due to the station being favoured by their families because of its sophisticated programming. Most of the participants preferred \textit{Gagasi fm}\textsuperscript{26} which is a regional station that seems to cater predominantly to the youth market. Their programming content is comprised mainly of popular music. \textit{East Coast Radio} was also mentioned and recommended for the quality of the music it plays. Based on interview responses UKhozi \textit{fm} may be the only radio option. It has an extensive reach and is unanimously considered to be a reliable source of important information. Essentially, both these mediums are used for recreational purposes hence the uncertainty about their suitability as part of the projects communication strategy.

\textit{Cellphones and social networks}

Participants had the following to say regarding cell phone and social network communication:

\textbf{D:} Are you on Facebook\textsuperscript{27} or Mxit\textsuperscript{28}? \\
\textbf{I:} No, I don’t use those things. \\
\textbf{D:} At all? \\
\textbf{I:} Maybe another thing that could be responsible for that is that I don’t have a phone that has those things. Maybe if I did, I might be on those things. (Interview 29 Aug 2012)

\textsuperscript{24}International TV soap opera series syndicated in many countries including South Africa. Information available at: http://www.imdb.com/title/tt0058796/ Accessed: 08 November 2012 \\
\textsuperscript{25}Listenership is estimated at 7.2 million people. Statistics available at: http://www.ukhozifm.co.za/portal/site/ukhozifm/aboutus Accessed 08 November 2012 \\
\textsuperscript{26}Radio station that targets “Funky Young Black Adults of urban Kwazulu-Natal”. It has a listenership of 1.8 million. Statistics Available at: http://www.radmark.co.za/pwb_gagasifm.php Accessed 08 November 2012 \\
\textsuperscript{27}Popular international social network. \\
\textsuperscript{28}Social network that is popular particularly amongst teenagers.
I: And also on Facebook. We won’t talk about Mxit because that’s for children. Even Facebook is better.

D: Really?

I: Even Facebook is better because we see important things there (Interview, 29 Aug 2012)

These uninterested reactions suggest that incorporating cell phones and social networks into the FB projects communication strategy could possibly be premature. Instead of enhancing communication between the project and participants, these two mediums may exclude some participants. The first response indicates that for some participants the availability of cell phones that have applications that grant them access to social networks is limited. This is a significant limitation because the prevailing assumption is that technological innovations [such as the cellphone] are fundamental to successful health communication (Bandura 2004). Granted Bandura’s (2004:149) observation that technological mediums have an interactive component that increases “the scope and impact of health promotion programs” is accurate. However, the findings indicate that for this particular group of young women and at this phase in the projects development, they are not a realistic option. The participants’ economic background (which was briefly discussed in Chapter 1) may be responsible for their lack of access to advanced cell-phones. For this community of young women cost-effective methods of communication might be a better option. A participant suggested the following:

I: Well I think maybe if they had a show that can explain-something like a drama you know? Something like that. (Interview, 06 June 2012).

The merits of using EE methods such as drama to facilitate discussions of important issues were examined in chapters two and three. Unlike technological devices this option allows for more personal levels of interaction. Were technological tools to be considered for future inclusion into the project, deciding on an appropriate social network would be a challenge. Prevailing beliefs about which networks are “for children” and which are regarded as promoting the discussion of “important things” would need to be considered. In sum, judging from these findings, extensive use of cell phones and social networks are premature at this stage of the projects development. It is evident that there are numerous considerations that need to be made before they can qualify as a practical option that can meaningfully contribute to the FB projects communication strategy.
Conclusion

This chapter has offered further insight regarding the reception of communication from the FB project. In addition it integrated theoretically driven considerations for the project to explore for a possible forthcoming public health campaign. Following the discussion in the chapter it is evident that there are various constraints impeding effective reciprocal communication between the project and its intended target. However, it is encouraging to note that there are measures that can be implemented in order to build on the positive aspects of its existing communication strategy. In sum, the project has achieved various communication successes and this chapter has provided evidence that the areas that need adjustment can be altered successfully.
Conclusion

This dissertation sought clarity on three key areas of effective communication between the FB project and its participants. To summarise, the issues under investigation were firstly the identification of strengths and weaknesses of the FB project. The second was assessing whether the FB project addressed the communication needs of its participants/target group from both the rural and peri-urban urban social contexts. Thirdly, it explored appropriate options the project could utilise in order to communicate about HIV and other sensitive subjects. Following an inductive approach, possible strategic communication interventions to emerge from this study as ‘lessons learnt’ could then be implemented into a future public health campaign by the project. In order to provide a balanced overview regarding whether or not the study fulfilled its original goals, each key research question will be evaluated individually.

Firstly, following this study we can surmise that the FB project has an almost equal proportion of strengths and weaknesses. The findings indicated that it has attained a balanced share of both. With regards to communication successes, it appears to have raised awareness about the importance of managing gynaecological health. It was discovered that many of the young women who participate in the project lack access to gynaecological healthcare. Conversations with them revealed that at different points in their lives they have been afflicted by gynaecological ailments yet had no recourse. The FB project has availed treatment and initiated communication about these socially overlooked health issues. Young women now have a reliable structure within their community, although its permanence depends on the research being funded, which facilitates learning about the prevention, management and treatment of these issues.

Secondly, the FB project actively transcends prevailing social obstacles in order to give young women the opportunity to be in control of their health. For example there are numerous social constraints to the effective management of their sexual and reproductive health within the community. These include pervasive yet misguided modern myths as well as allegations of repressive attitudes amongst local health staff. This study, has established that the project’s communication strategy has succeeded in communicating information about sexual and reproductive health in a social-context appropriate manner. Although the conscientisation of its participants is not absolute, it appears that gradually, it may increase (Freire 1985; 1990). This is indicated by some young women volunteering themselves to
teach others in their communities about these health issues, thus initiating a cycle of knowledge sharing. Another important achievement is that its communication efforts appear to resonate with parents who are a vital source of support to young women. As a result the basic health knowledge acquired via the project can be re-enforced by the parents thus enhancing their self-efficacy beliefs (Bandura 1995; 2004). Also important to note is that the projects HIV testing and counselling facility appears to add value to its participant’s lives. The study revealed that it is considered by many of them to be a trustworthy structure in the community that supplements the reserves of knowledge they have about HIV. Further, it appears to strengthen the relationship between them and their partners by indirectly facilitating dialogue about HIV. Young women appear to appreciate the availability of this service greatly.

Conversely, this study has revealed that the FB projects current communication has yet to fully imprint the severity of FB in young women. As a result of this different communication options that may rectify this have been explored. Presently they appear not to regard it as the potentially detrimental disease that it is. It can be inferred that due to their brief exposure to it at different points in their lives, they have become anaesthetised to its possible health risks. Furthermore, like other studies within the FB area, this dissertation indicated that there is a reluctance regarding seeking FB treatment because of the social stigmas attached to doing so. The most pervasive of these stigmas appears to be that receptiveness to FB health warnings connotes poverty (Schall 1995). As a result, it was deduced that the educational aspects of the projects communication need to be modified to clear these misconceptions.

Further, the study indicated that communication from the project is received differently in diverse social contexts. In the peri-urban areas it appears not to generate as positive an impact as in the rural contexts which could be due to barriers such as perceptions related to social class and the easy access to basic amenities. In the rural areas an obstacle that appears to limit the depth of impact in communication with young women are the stringent values that are upheld by individuals in authoritative positions. These include demonstrating respect by abiding to the rules stipulated by these authoritative figures even if they interrupt the quality of the reception of critical health information. It was established that at this point communication by the project has no mechanisms in place that can overcome these unanticipated social impediments. Additionally, this study indicated that the initial stages of interaction with its participants may expose them to peer mockery should it become known that a young woman visits the FB clinic etc. Measures that can be implemented by the project
in order to rectify this oversight were examined. These included adopting a more open and inclusive approach towards communicating the facts about FB in order to encourage an atmosphere of social acceptance of it.

A primary objective of this study was to give young women the opportunity to speak their minds about a health matter that affects them. The logic behind this was to empower them by giving them a platform to tell their own stories in their own words (Melkote and Steeves 2001). Further, their feedback could be utilised to improve the quality of the services at the project. It has attempted to abide by this original mandate by presenting their thoughts and accompanying them with theoretically based interpretations. Although the number of participants that were interviewed is small, the issues that were unearthed are legitimate and may be applicable to a large segment of the young women the projects works with.

In future the FB project could expand on the findings that were uncovered through this study by working with a larger sample of young women. Interviewing those young women who declined FB treatment and gynaecological examinations may be a beneficial experiment that could yield rich results. The project could also enlist development students in order to further examine the external limitations confronting it, such as resistant opinion leaders/gatekeepers in the community as well as other ways to combat stigma. Interviewing teachers, parents and project staff could also generate new information.

Overall this dissertation has been an exploration of how a bio-medical initiative like the FB project can empower and subsequently improve the health of young women using communication as a tool (Scalway 2010). I believe it has demonstrated that the union of both the bio-medical and communication fields can produce innovative ways of approaching the process of public health improvement. It is demonstrated that both fields can complement each other for the betterment of public health.
Bibliography

Primary references


Interviews: Rural Participants, 20 May-30 August 2012, FB Project Offices.


Secondary references


**Internet Sources**


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**Unspecified Websites**


Appendices

Appendix A: Map Depicting the Ugu District 2012
Appendix B: Ethical Approval

UNIVERSITY OF KWAZULU-NATAL

16 June 2012

Ms. Duwuelle Jwene (209526409)
School of Applied Human Sciences

Dear Ms. Jwene,

Protocol reference number: HSS/0483/0/1.251
Project title: Assessing Perceptions/Addressing (Ns)complaints: The construction of a communication strategy to address the health needs of female teenagers affected by HIV/AIDS.

In response to your application dated 16 May 2012, the Humanities & Social Sciences Research Ethics Committee has consented to the above mentioned application and the protocol has been granted FULL APPROVAL.

Any alterations to the approved research protocol i.e. questionnaire/interview schedule, informed consent form, title of the project, location of the study, Research Approval and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you every success of the best with your study.

Yours Faithfully,

[Signature]
Professor Steven Collins (Chair)
Humanities & Social Science Research Ethics Committee

cc Supervisors: Dr. Laureen Syl-Mikkelsen and Dr. Kristine Lila
cc Academic Leader: Professor M. Guntenach
cc Ms. Alice Pathi 209526409

Professor S Collins (Chair)
Humanities & Social Science Research Ethics Committee
Wollville Campus, Governor Matabeli Building
Postal Address: P.O. Bag 214001 Durban 4010, South Africa
Telephone: +27 031 269-1111 Extension: +27 (0)31 269-4828 Email: hssreethics@ukzn.ac.za

Inspirant: Greatness

130
Appendix C: Informed Consent

INFORMED CONSENT FORM

Dear Participant

I, Duduzile Zwane am doing a study entitled: Assessing Conceptions-Addressing (Mis) conceptions-The exploration of interventions of interventions to address the health needs of female teenagers affected by Bilharzia. The goal is to find a better way for the Bilharzia Project to communicate with you. You have been chosen because you are a teenager and you determine the success of the whole project. You deserve the opportunity to be heard and I intend to do that.

Your participation in this study entails consenting to an in depth interview. Each interview will run for approximately 15 minutes and will be documented using a tape recorder. With your permission, a silent observer might be present in the room to take down notes. At a later stage, the notes will be transcribed.

Only girls aged 16 years and older can be interviewed and strict confidentiality will be followed. The data will be stored in a safe location and false names will be used in order to protect your identity. Furthermore, although your participation will be highly appreciated, it can be withdrawn at any stage and no negative consequences will be experienced by you as a result of your withdrawal.

The study has been granted permission by the University of Kwa Zulu Natal (UKZN), Oslo University Hospital in Norway and the Bilharzia Project. Although your willingness to be interviewed is appreciated you will not receive any financial incentives. However, you will not incur any expenses either. The researcher undertakes to cover the cost of your transport to the clinic as well as food for the duration of the interview.
Name of Investigator: Duduzile Zwane

Contact Details: 079 953 6963 (cell)

zwaneduduzile1@gmail.com (email)

Qualification for Project: M.A. (Full Research)

School: Applied Human Sciences

Faculty: Humanities, Development and Social Sciences

University: University of KwaZulu Natal

Project Supervisor: Lauryn Dyll-Myklebust

Contact Details:

ladyll@hotmail.com (email)

I……………………………………………………………………………

 (Full name of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

 I understand that I have the right to request that certain information disclosed during the group discussions remain confidential.

 I understand that I am assured of anonymity.

Please sign next to whether you want to use your real name or false names.

The investigator may use my real name……………………………………...

I request that my real name be withheld ……………………………………...

 I understand that I am liberty to withdraw from the project at any time, should I desire so.

 SIGNATURE OF PARTICIPANT DATE
Appendix D: Informed Consent Zulu

Incwadi yoku qinisikisa ukuchazeleka kwakho ngalolu cwaningo

Ngiya kubingelela


Lolucwaningo imvumo luyithole kwisikhungo semfundo ephakeme i University of Kwa Zulu Natal (UKZN), ibambisene ne Oslo University Hospital Ezweni lase Norway kanye ne Bilharzia Project. Ngingakuthokozela kakhulu ukuthi ubeyingxenye yalolucwaningo kodwa awukho umuholo ozowuzuza. Kepha ngiyathembisa ukuthi uhambo lwakho uza kumtholampilo wale Project kuzoba mahhala. Futhi kukhona okuncane okuya ngase thunjini ukukubonga ngokungi phakamela kwakho.
Igama lowenza ucwaningo: Duduzile Zwane

Imininingwane yami: 079 953 6963 (cell)

zwaneduduzile1@gmail.com (email)

Iziqu ezizo zuzwa nga lolucwaningo : Master of Social Science (Full Research)

Isikole: Applied Human Sciences

Umnywango: Humanities, Development and Social Sciences

iNyuvesi: University of KwaZulu Natal

Umphathi womucwaningi: Lauren Dyll-Myklebust

Iminini ngwane yakhe:

ladyll@hotmail.com (email)

Mina……………………………………………………………………………………………………………………

- (Igama) ngiya qinisekisa ukuthi ngiyazwisisa konke okubhaliwe kuleli dokodo kanye nakho konke okupathelene nalolucwaningo, futhi ngiyavuma ukubayingxenye yalo.

- Ngiyaqinisa ukuthi ngiyazi ukuthi nginelungelo lokucela ukuthi eminye imininingwano engizoyiveza hlale iyimfihlo.

- Ngiyaqinisekisa ukuthi ngiyazi ukuthi ngi thembisiwe ukuthi yonke imininingwane engazisayo izohlala iyimfihlo.

Ngicela usayine lapha uma kuwukuthi ufuna kusebenziswe igama lakholangempela noma ozozakhela lona

Umucwaningi angalisebenzisa igama lami langempela ………………………………………

Bengicela umucwaningi angali sebenzisi igama lami langempela…………………………

- Ngiyaqinisekisa ukuthi ngiyazi ukuthi ngi vumelekile ukuluyeka ucwaningo umangabe ngifisa

- SAYINDA                          USUKU
Appendix E: Personal Interview Guide

Interview Question Guide:

- How did you first hear about the Bilharzia Project?
- Had you ever heard of Bilharzia prior to the Bilharzia Project explaining what is was? Please elaborate.
- How would you describe the series of talks held by Bilharzia Project informative?
- How the print material helpful?
- Why do you prefer: print material or talks?
- How would you like the talks to be given: small groups, the whole school, girls only or both girls & boys?
- Did you feel pressured into agreeing to participate?
- What were your expectations after you gave your consent?
- How did you feel about the selection process (i.e. did it embarrass you etc)
- Were you ridiculed/discriminated against after agreeing to participate in the project?
- Was every step of your involvement properly explained to you? (i.e. the urine, blood, collection and gynaecological examination)
- Describe how donating each sample made you feel?
- How was the collection of the samples handled in your opinion?
- Was the procedure of sample collection and their uses properly explained to you?
- Was the process of releasing the results properly explained to you?
- How did you feel about the questionnaire?
- How did you feel about the gynaecological exams?
- How would you describe your interaction with the gynaecologists?
- What are your thoughts on some of the other services offered at the clinic e.g. free contraceptives?
- Can you explain/Do you understand the connection between FB&HIV
- How would your boyfriend react if you told him you had FB/HIV?
- How would you describe the environment at the clinic?
- Do you feel that you were safe sharing your private information?
- How would you describe the interaction between co-pupils whilst they wait to be examined?
- What made you consent to participating in the project for a second time?
- How often do you listen to the radio/watch TV/read newspapers?
- When you were contacted by cell-phone was that ok?
- If you could change anything about the manner in which the project communicates with you, what would it be?