COMMUNICATION AND INTERACTION IN THE CONTEXT OF ROUTINE PROVIDER INITIATED HIV TESTING AND COUNSELLING FOR HIV: THE CASE OF KENYA

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ABSTRACT

Background: The global policy focus of today's HIV efforts and strategies is to reverse the spread of HIV/AIDS and provide care, treatment and support. A key component of this strategy is to increase individual HIV status awareness through expansion of HIV testing and counselling (HTC). However, the numbers tested still remain low and evidence suggests that there are significant missed opportunities for HIV testing in clinical settings. One key strategy to expand HTC in clinical settings has been to implement a policy of 'provider initiated counselling and testing' (PITC) in which all patients accessing health facilities for treatment are routinely offered a HIV test.

The introduction of PITC has brought with it a 'dilution' of the previously lengthy and stringent testing process by doing away with signed informed consent and extensive pre and post test counselling. The previous process was recognised as a barrier to public health gains of HIV testing expansion, particularly as it differentiated an HIV test from other routine medical tests resulting in a sense of HIV exceptionalism. In its place, the PITC policy recommends an opt-out approach and replaces the extensive pre test counselling with an information giving session placing more emphasis on post test counselling in cases where the result is positive. This change has given rise to debates about the potential for PITC to infringe patients' rights to informed consent and counselling especially in developing countries.

Emerging evidence from the exploration of the PITC process within antenatal settings in the Sub Saharan Africa has revealed some of the complexities of implementing PITC guidelines in different cultural and healthcare contexts. These studies suggest that information giving and consent are difficult to apply in contexts characterized by healthcare worker dominance, lack of sufficient resources and time constraints. This study aimed to specifically investigate how patients and counsellors co-construct informed consent and perform counselling during the PITC consultation. It examined 'real time' patient-counsellor interaction within hospital outpatient and inpatient settings in Kenya, explored the patient's experience of a routine HIV test and evaluated how stigma and patient – provider interaction norms influence the PITC process in this context.

Methods: In order to explore the context of the routine testing consultation and the way the interaction played out, a qualitative research approach was adopted, utilizing multiple data collection methods (interviews, observations and audio recording of consultations). The study was carried out in two government run health facilities in Kenya's capital, Nairobi. The intention was to follow patients through the PITC process, i.e. before testing, during the HIV test and (whenever possible) after the HIV test. To get a broader picture of the events during the routine HIV testing consultation, additional interviews were conducted with five nurse-counsellors whose consultations had been observed. Ethical approval was obtained from the Kenya National Research Council, Kenya Medical Research Institute and the Aga Khan University Ethics Committee. The data were analysed using Charmaz's constructivist grounded theory approach which allowed for a systematic yet flexible approach to analysis. This method facilitated immersion and engagement with the data, and

provided a means of managing the different data sets in the study and undertaking a process of constant comparison within and between data sets.

Findings: Results from the study suggest that HIV remains a highly stigmatised illness in Kenyan society and is associated with death and immorality. This is still the case in spite of years of health promotion and high profile media campaigns raising awareness about HIV and the availability and effectiveness of treatment. The context of stigma shaped the consultation so that both patients and counsellors worked together to help patients to maintain a 'moral face'. Patients tended to withhold information on risky sexual behaviour whilst the counsellors avoided inquiring into this domain. The PITC consultation was characterised by a counsellor dominated approach to communication and health promotion. Counsellor inputs were generic, highly scripted and didactic rather than patient-centred. As a result, the counsellors' style of communication allowed little space for personalised risk assessment or for patients to ask questions or to express concerns. The findings suggest that informed consent enabling explicit refusal of the test offer was difficult to achieve in an environment where the HIV test was not framed as a choice and patients came to the health facility expecting to be told what to do. Nevertheless, in spite of the obvious lack of explicit informed consent and the counsellor dominated interaction, post test interviews revealed that patients were satisfied with the nature of the interaction.

The study concludes that there is a considerable distance between the policy recommendations and their implementation on the ground due to the complexity of real world practice. Lay constructions about HIV (HIV stigma) and the existing norms of patient-provider interaction that are characterised by a passive patient and a dominant health care provider shape the way the consultation unfolds. PITC training programs and manuals need to include skills and strategies that can support counsellors manage an uncomfortable interaction and emphasis the need to ensure an individualized post test counselling is carried out.

The thesis makes several contributions to knowledge. The study pays attention to the operationalization of PITC recommendations thus illuminating how the PITC policy is translated into practice within a developing country like Kenya. It informs the existing debates on how informed consent and counselling should be implemented. The study findings suggest that in spite of the global debates on what constitutes ideal informed consent and counselling, in practice, sociocultural norms shape how these issues are translated and implemented. However, the study indicates that diversion from the PITC policy recommendations does not necessarily constitute a disregard for the recommendations but, rather, is an attempt to adapt to the prevailing environment. The study methodology enabled unique insights to be gained on how counselling and consent are constructed and managed in the PITC setting through the use of observations / audio recording to examine 'real time' interactions. The research study has been able to illuminate barriers that are posed by sociocultural and organisational structures in the real world implementation of the PITC policy. Therefore, my study suggests that the national PITC policy needs to consider the practical problems faced on the ground in developing contextually appropriate recommendations for the conduct of PITC and implementation of key guidelines.

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ABBREVIATIONS

ARCAN	African Regional Capacity Building Network for HIV/AIDS
ART	Antiretroviral Therapy
EMTCT	Elimination of Mother to Child Transmission
ECSACON	East, Central and Southern Africa College of Nursing
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
IDU	Injection Drug Users (IDUs)
NACC	National AIDS Control Council
PLHIV	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PITC	Provider Initiated Counselling Testing
PrEP	Pre-Exposure Prophylaxis
STTI	Sigma Theta Tau International
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

DEFINITION OF KEY TERMS

Client-initiated HIV testing and counselling (also called Voluntary Counselling and Testing, or VCT) involves individuals actively seeking HIV testing and counselling at a facility that offers these services.

Key populations: defined as groups who die to specific higher-risk behavior, are at risk of HIV irrespective of the epidemic type and local context. In Kenya these include men who have sex with men, injection drug users and sex workers.

"Opt-in" approaches, patients must affirmatively agree to the test being performed after pre test information has been received.

"Opt-out" approaches, individuals must specifically decline the HIV test after receiving pre test information if they do not want the test to be performed.

Provider-initiated HIV testing and counselling refers to HIV testing and counselling which is recommended by health care providers to persons attending health care facilities as a standard component of medical care

Vulnerable populations: populations whose social contexts increase their vulnerability e.g. young girls and women, people in prisons, fishing communities, truck drivers, migrant populations especially those in humanitarian crisis and mobile workers, people with disabilities, children and pregnant women living with HIV and people living with HIV.

1 CHAPTER ONE: INTRODUCTION

1.1 Introduction

The face of HIV, its management and prevention has been transformed by increased use and access to antiretroviral therapy drugs (ART). Currently, attention is on a test-and-treat strategy in a bid to eliminate HIV infections in countries with particularly high HIV prevalence (Schwartlander et al., 2011; WHO, 2012a, 2013a). The test-and-treat strategy aims to provide regular testing to entire populations followed by immediate ART for all persons diagnosed with HIV. Early and timely HIV diagnosis is the gateway to prompt initiation of ART in order stop disease progression and reduce the risk of onward transmission for those diagnosed with the infection (WHO, 2012h, 2013a, 2013k). It also facilitates prevention of HIV infection by enabling discussions about pre-exposure prophylaxis (PrEP) and modification of risky behavior for those who are HIV negative (Baggaley, Doherty, Ball, Nathan, & Gottfried, 2015; WHO, 2013a).

In spite of the vital role of HIV testing and counselling (HTC) in improving HIV treatment and prevention outcomes, the numbers tested have remained relatively low (UNAIDS, 2014). This is the case particularly in low and medium income countries, especially in the Sub Saharan Africa region, which also bear the brunt of a high HIV prevalence rate (UNAIDS, 2014 ; WHO, 2014). Whereas the number of people who are aware of their HIV status worldwide has increased in the recent past, only about 48% of people who are infected with HIV know their status globally (UNAIDS, 2014). Further on, in the Sub Saharan region only a half of the adult population know their HIV status. This HIV testing need is prevailing

against a backdrop of increased access to ART and reported benefits of early and prompt initiation of ART. For instance in the Sub Saharan region 87% of people living with HIV (PLHIV) who know their status are on ART, 76% of whom have achieved viral suppression and are unlikely to infect their sexual partner (UNAIDS, 2014).

For PLHIV to fully benefit from ART they need to know their status early, be linked to care, commence and adhere to ART with the aim of achieving viral suppression in what is known as the HIV treatment cascade (Gardner, McLees, Steiner, del Rio, & Burman, 2011). HIV testing is the first step of the HIV treatment cascade. Early HIV testing and subsequent initiation to ART treatment has been shown to improve the overall quality of life and prevent spread of new infections (Cohen et al., 2011; Karim et al., 2010; Schwartlander et al., 2011). This evidence has changed the approach to HIV management with ART now playing a treatment and prevention role i.e. treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP) (WHO, 2012a). TasP involves providing ART to people diagnosed with HIV as early as possible irrespective of their CD4 count with the aim of halting disease progression and reducing risk of onward transmission of HIV to uninfected sexual partner(s) (WHO, 2012a). Low uptake of HTC has been a hindrance to these milestones in HIV treatment and prevention (UNAIDS, 2014).

Previous HIV testing approaches have been found inadequate in meeting the testing needs of the population identified by policy makers and professionals (WHO, 2012h; WHO/UNAIDS, 2007). In the past, HIV testing has been framed within a patient's rights discourse which emphasized on a

comprehensive counselling and informed consent process to protect patients from coercive testing practices (National AIDS and STD Control Programme, 2006; WHO/UNAIDS, 2007). The intention was to ensure human rights protection in a situation where due to limitations of treatment effectiveness, poor access to treatment and negative perceptions about HIV, patients diagnosed with HIV were prone to poor quality of life and stigmatization (Bayer & Fairchild, 2004; Rennie & Behets, 2006). As a result the HIV testing process constituted a detailed pre test counselling about HIV, its transmission, exploration of risky behavior, the decision to test and the importance of disclosure. This was followed by a distinct consent process requiring an active decision and an affirmative acceptance of the HIV test before it is done in what is known as an opt-in approach to consent (WHO/UNAIDS, 2007). Finally indepth post test counselling was carried out. It addressed the importance of disclosure, behavior modification information and referral to relevant HIV services depending on the HIV test results.

This comprehensive counselling and consent process has been identified as a barrier to HTC expansion initiatives (Bayer & Edington, 2009; De Cock, Bunnell, & Mermin, 2006). The process was considered a hindrance largely because it distinguished the HIV test from other medical tests; contributing to increased stigma and discrimination and associated fear of uptake of HIV testing (WHO/UNAIDS, 2007). On the other hand, client initiated testing models such voluntary counselling and testing (VCT), had not adequately met the testing needs due to lack of accessibility and poor individual risk assessment to self-refer for HTC (Byamugisha et al., 2010). At the same time, a number of studies had indicated that there are many

missed opportunities to diagnose HIV during routine hospital visits in the East African countries (Gichangi, Estambale, Bwayo, Rogo, Ojwang, Njugunas et al., 2006; Nakanjako, Kamya, Kyabayinze, Mayanja-Kizza, Freers, Whalen et al., 2007; Wanyenze, Nawavvu, Namale, Mayanja, Bunnell, Abang et al., 2008). There was therefore a need to change the HIV testing approach so as to increase access and coverage of the HIV test by routinizing the HIV testing process and integrating it to everyday clinical practice (WHO, 2012h; WHO/UNAIDS, 2007).

In a bid to make the HIV test more accessible and in order to optimize on the patient provider encounter during routine health care visits , the World Health Organization (WHO) called for the implementation of Provider Initiated Testing Counselling (PITC) (WHO, 2012h; WHO/UNAIDS, 2007). PITC seeks to increase uptake of HIV testing through routinely offering a HIV test to **all** patients seeking treatment in clinical settings irrespective of the reason for coming to the hospital (WHO, 2012h; WHO/UNAIDS, 2007). At the time of its implementation in 2007, PITC was recommended in areas with high HIV prevalence rates. Over time PITC has also been adopted in regions that have not previously reported a generalized high HIV prevalence such as UK and US in certain contexts such as antenatal settings (Phillips et al., 2013).

Divergent from the past comprehensive HIV testing process described earlier, the PITC process seeks to normalize the HIV test through 'dilution' of the testing process. The policy recommends a modified counselling process by reducing the detailed pre test counselling session to a brief information giving session, laying emphasis instead on the post-

counselling session. It also does away with the distinct (often signed) informed consent replacing it with an opt-out approach to consent in which patients are routinely offered a HIV test and tested unless they explicitly decline. The change in the process was expected to expand HIV testing. Indeed, evidence began to show an increased uptake of HTC with PITC models as compared to VCT models of testing (Dalal et al., 2011; Matovu & Makumbi, 2007). In spite of the evidence of increased uptake of PITC, there was concern about the impact of the diluted testing process on the patient's rights to information and informed consent.

Tension exists between the need to expand HTC in view of the prevention and treatment benefits by normalizing the testing process on the one hand, and the need to maintain patient's rights through intense counselling and consent on the other hand. The change in the HIV testing approach has raised concerns about the possible risk for infringement of patients' rights through coercive testing practices and potential for stigma and violence with disclosure of HIV results for those found to be HIV positive (Rennie & Behets, 2006; UNAIDS Reference Group on HIV and Human Rights, 2007). Yet at the same time, offering a HIV test becomes a key component of standard of care as it provides people with opportunities to access HIV related services that they would otherwise miss (WHO, 2012h). This tension will be unpacked in the subsequent sections.

1.2 Setting the scene: PITC as a normalization strategy

Previously HIV has been viewed as an exceptional disease requiring specific guidelines and policies which provide a practice and legal framework for its diagnosis, treatment and prevention in what is known as

HIV exceptionalism (Bayer & Fairchild, 2004, 2006). In particular, the HIV testing process required a specialized testing process in which counselling and consent are clearly delineated. This exceptionalist view originated from the nature of the initial HIV epidemic which was confined to vulnerable minority groups such as men who have sex with men (MSM), injection drug users (IDU) and commercial sex workers (Bennett & Erin, 1999). These groups of people were already marginalized and stigmatized by virtue of their perceived 'immoral' lifestyle (Bayer & Edington, 2009; Bennett & Erin, 1999). A HIV positive diagnosis thus added to their vulnerability through fear of stigma, exclusion and helplessness where knowing your HIV status did not lead to clinical benefits or improved wellbeing.

HIV exceptionalism was mirrored in the HIV policy and guidelines at the time which reflected a human rights discourse that emphasized the patient's right to comprehensive counselling and informed consent and confidentiality (UNAIDS, 2000). The spread of the HIV epidemic in the last fifteen years from designated groups to the general population and the effectiveness of ART in the management of HIV, signalled the end of HIV exceptionalism and the onset of normalization.

Normalization of HIV refers to the process of treating HIV just like any other illness by doing away with the specialized requirements for its diagnosis and treatment (De Cock et al., 2006; UNAIDS Reference Group on HIV and Human Rights, 2007; WHO/UNAIDS, 2007). This is done partly through integrating HIV testing within the existing health care system and routinizing its management. In normalization of HIV, the focus is on

expanding HIV testing of patients in order to reduce stigma which has been blamed for hindering HIV prevention and treatment strategies. Further on, improved access and effectiveness of ART improves the overall quality of life and turns HIV into a manageable chronic illness. In that case, seeking a HIV test becomes a key step in facilitating equitable access to ART and positive outcomes following a HIV positive diagnosis. This is reflected in the current HIV testing policy and guidelines which now focus on a public health discourse with little emphasis on a comprehensive testing process (National AIDS and STD Control Programme, 2010; National AIDS Control Council, 2014; WHO, 2012h; WHO/UNAIDS, 2007). This discourse denotes an emphasis on expansion of HIV testing to the majority of the population in order to maximize HIV prevention and treatment efforts. For that reason offering HIV testing and counselling by the health care provider becomes part of the normal standard of care in health care practice (WHO/UNAIDS, 2007, p. 7).

It would be problematic to presume that viewing HIV as a chronic illness effectively deals with the concerns that characterized the initial HIV epidemic and led to its exceptionalism. The reality is that even as a chronic disease, PLHIV will have to go through the course of the disease which is often uncertain, depend on the health care system to manage their illness and struggle with maintaining a normal life in spite of being infected with HIV (McGrath et al., 2014; Moyer & Hardon, 2014; Philbin, 2013). The health care system particularly in African settings is still struggling with mainstreaming the normalization discourse as PLHIV have to continuously access HIV clinics whilst those who are HIV negative deal with apprehension about testing for HIV due to HIV stigma (Moyer &

Hardon, 2014). In everyday life, HIV still continues to be viewed through the lens of its exceptional history which was shrouded by negative perceptions and stigma due to its association with immorality and promiscuity (De Jesus, Carrete, Maine, & Nalls, 2015; Persson et al., 2014).

Contextual differences may affect the normalization of HIV. Drawing from two qualitative studies carried out in Uganda, McGrath et al. (2014) suggest that in resource constrained settings, the construction of HIV within the paradigm of normalcy differs due to the economic burden of treatment, and the population's struggle with the social realities of daily life and stigma. Nonetheless, similar situations have been reported in developed countries which do not necessarily face resource limitations (De Jesus et al., 2015; Persson et al., 2014). Normalization of HIV still proves difficult as it becomes impracticable to disconnect from the long standing negative perceptions about HIV and associated stigma and discrimination (Persson et al., 2014). It would appear that normalization of HIV may be somewhat challenging and difficult to mainstream in light of the enduring negative perceptions about HIV. Consequently, it is possible that the long standing negative perceptions about HIV in diverse settings may influence translation and implementation of counselling and consent within the PITC approach to testing.

Normalization of the HIV test through PITC has raised concerns about potential infringement of human rights during HTC. The question of how patients' rights to informed consent and counselling will be maintained in diverse settings has been central to debates about its implementation

(Bayer & Edington, 2009; Hardon et al., 2011; UNAIDS Reference Group on HIV and Human Rights, 2007). The feasibility of implementing a person-centered and ethical process in settings where few health workers are expected to deal with an added workload of PITC has been in question (Evans & Ndirangu, 2009a, 2009d, 2009h). Moreover, an increase in the number of tested individuals requiring additional HIV treatment and prevention services places an added strain on the resource constrained health care systems.

The PITC model has generated debate on how best to expand and implement it in light of the potential of violation of rights to informed consent and counselling (Bayer & Edington, 2009; Obermeyer, 2007; UNAIDS Reference Group on HIV and Human Rights, 2007). It is argued that a provider routinely offering a HIV test to patients would potentially leave little or no room for consent and undermine voluntary informed consent (Obermeyer, et al., 2013). This is because a routine HIV offer by a health care provider may result in patients feeling under pressure to accept the HIV test thus undermining the possibility of consent being free and informed. Indeed a study from Kenya suggests that counselling may be compromised and the routine HIV test offer perceived as compulsory (Njeru, Blystad, Shayo, Nyamongo, & Fylkesnes, 2011). Similar findings were reported in a qualitative study carried in Uganda among pregnant women attending antenatal clinics where PITC was offered (Rujumba, Neema, Tumwine, Tylleskar, & Heggenhougen, 2013).

Conversely, integrating HTC in clinical settings may lead to an increased workload for healthcare workers and potentially affect the implementation

of the PITC process negatively. The latter concern is crucial to the Sub Saharan region which already faces resource constraints, high levels of HIV related stigma and an inadequate human resource for health which can pose a challenge in ensuring a quality testing process within PITC (Asante, 2007; Obermeyer, et al., 2013; Obermeyer, Neuman et al., 2013).

In spite of concerns about the operationalization of consent and counselling, available studies have not examined actual PITC consultations in clinical settings. They have instead used self-reports of patient and counsellor experiences within the PITC consultation mostly in the context of antenatal clinics. Existing evidence of the PITC implementation from antenatal settings in African countries like Malawi, seems to suggest that the processes of information giving and consent are undermined by lack of resources, time constraints and health provider dominance (Angotti, 2010; Angotti, Dionne, & Gaydosh, 2011; Hardon et al., 2012). Perhaps indicating the complexity of the implementation of consent and counselling in certain contexts. The lack of studies on how PITC is operationalized in situations outside antenatal settings makes it difficult to understand how consent and counselling processes become part of an attempt to normalize HIV testing in clinical settings.

It is important to note that the terms 'counselling' and 'consent' are used in the same way in VCT and PITC testing guidelines yet the tasks and expectations are different [1]. For example, whilst in VCT guidelines

[1] An explanation of the process of consent and counselling in the VCT and PITC guidelines is included in page 3 - 5

counselling referred to a comprehensive pre and post test counselling sessions, in the PITC guidelines, counselling is used to refer to a brief information giving pre test session with an emphasis on post test counselling. There is a possibility that the inconsistency of meaning associated with the same terminology may influence how the HIV testing process is implemented as it may be interpreted differently in diverse contexts. It is important to carry out research to examine how consent and counselling can be operationalized within PITC to safeguard patients' rights whilst minimizing the bureaucracy around consent and counselling that characterized previous testing approaches (Evans et al., 2014).

1.3 Setting the scene – Personal reflections

My first encounter with HIV/AIDS was in 1999 during my first clinical placement as a first year undergraduate nursing student in a Kenyan rural faith based health facility in Nyanza[2] region. At the time ART was not widely available and the HIV positive patients I encountered were emaciated, the majority of whom died at the health facility. It was during this time that I had my first ever HIV test. The HIV test was done after I had volunteered to donate blood for a 10 year old leukemia patient who could not get blood from the majority of her relatives who were found to have HIV during the pre-blood donation HIV test. The HIV test was done in the laboratory using a capillus HIV rapid test kit without any counselling. I vividly recall being very anxious and scared about what the results would be as I considered the possible ways I would have been infected

[2] Nyanza had a disproportionately high HIV prevalence rate at the time. This have continued to be the case with the highest number of HIV infections being reported in counties in these region.

particularly in the course of taking care of HIV positive patients. HIV positive patients formed the bulk of inpatients in this particular hospital due to the high HIV prevalence rate in the Nyanza region. Looking back I realize that my focus was on the impending result and it never occurred to me that I needed any counselling. I am not even sure what role counselling would have played and whether I would have listened to it during that process.

Since then I have had a number of HIV tests done with the most recent one in 2014. Two HIV tests were in an antenatal setting (one in Kenya and another in the UK), one HIV test was done as a requirement for employment, two HIV tests were carried out through VCT (with my spouse) and finally one HIV test was done as a requirement of marriage. In all these diverse testing experiences over the years, counselling was done only once during one of the VCT consultations. During this particular VCT session, counselling entailed the counsellor filling in a checklist with questions about risky behavior after which was followed by my spouse and I signing an informed consent form. These experiences were different to what was supposed to happen at the time based on the various guidelines and training manuals about counselling that were in operation at that time.

Following on my encounter with HIV, in 2003 after my BSc.N internship I volunteered in a HIV/AIDS program run by the Kenya Red Cross Society in my home town (Nakuru). The program entailed carrying out home visits to people living with HIV/AIDS in Salgaa, a truck driver stop over shopping center that had a high HIV prevalence rate. Although my purpose was to give my time to change another person's life, it marked a turning point for

me in how I viewed PLHIV. Whilst earlier I had dealt with patients who were massively emaciated with a high mortality rate, this time round the patients were on treatment and received food and nutrition supplementation. Hence they lived longer and did not have an emaciated frail physical appearance that defined a HIV positive diagnosis. Additionally, unlike earlier when I had only interacted with PLHIV in the hospital setting, the home visits in the Red Cross program gave me an opportunity to know the patients' 'story'. This was the first time I saw the 'human face' of HIV/AIDS. I began to understand that for PLHIV their physical (medical) wellbeing being was secondary to the difficulties they faced particularly related to the high levels of stigma and discrimination that were present then.

In 2004 when I registered for the Masters in Advanced Nursing Studies at the University of Nottingham, I undertook a dissertation exploring the psychosocial needs of African women living with HIV/AIDS in Nottingham (Ndirangu & Evans, 2007, 2009a). Engaging in the women's narratives taught me that their HIV status was secondary to their psychosocial needs which included, but not limited to, their immigration status. It was surprising for me to see how much the women valued a non-judgemental interaction with their providers and just how much something seemingly insignificant as a smile and a hallo during their hospital appointments meant so much to them. I also learned that in spite of the distance from Africa, the participants were extra vigilant about keeping their HIV positive status a secret particularly from people who came from their home countries. I was quite surprised that the participants were ready and willing to talk to me as long as I did not come from their home country.

This for me was quite telling about the level and significance of stigma and discrimination attached to HIV in the African region. The findings of this study have been disseminated in two peer reviewed journals (Ndirangu & Evans, 2009a, 2009c).

On completion of the masters program, I went back to Kenya where I started working as a lecturer at the Aga Khan University in 2006. The role involved teaching and program coordination of the African Regional Capacity Building Network for HIV/AIDS Prevention, Treatment and Care (ARCAN)[3]. ARCAN's focus was capacity building for various health care workers such as laboratory technicians, doctors and nurses who had found themselves taking up roles in various HIV prevention, care and support services often without any prior training. The program used a train the trainers (TOT) model to cascade knowledge and skills with the understanding that in limited resource settings capacity to individually train all health care workers is inadequate. This program provided an avenue for capacity building and experience sharing among nurses from a number of African countries namely Kenya, Tanzania, Zanzibar and Ethiopia.

In 2007 my MSc dissertation supervisor and I commenced a study exploring nurses' experiences with PITC which was at the time being piloted in government health facilities in Kenya (Evans & Ndirangu, 2009a). Whilst the findings of that study were useful in demonstrating the

[3] ARCAN is a World Bank funded program for training various health care workers as trainers of trainers (TOTs) in HIV/AIDS. Training of health care providers took place at the Aga Khan University (Kenya)

difficulties faced by nurses in the implementation of PITC in Sub Saharan countries and specifically Kenya, it was unmistakable that the patients' perspective on the PITC process was missing. In response to this finding, we published a critical review of the WHO guideline considering its implications for the nursing profession in Sub Saharan Africa (Evans & Ndirangu, 2009d). From this review it was apparent that most of the research on HIV testing was quantitative or relied upon health provider self-reports of the testing process. There were two key gaps in the knowledge base: the patient view was missing and there was a lack of understanding of how PITC was actually conducted in 'real time'. For this reason I chose to focus my PhD on the micro practices of informed consent and counselling in the milieu of PITC and normalization of the HTC process in respect of the sociocultural environment of HIV in Kenya.

1.4 Research aim and objectives

This study seeks to explore the implementation of PITC in public sector hospital facilities in Kenya. Using the discourse of normalization as a lens through which to understand and critique changes in HIV testing policy and practice, this study seeks to examine how the core components of PITC (consent and counselling) are understood and enacted in everyday practice. In this way, the study aims to provide important insights into: (i) the ways in which patients' rights and voices are (or are not) addressed through the current PITC process; (ii) the ways in which PITC processes can be operationally improved whilst maintaining high quality ethical practice.

The objectives of this research study are to:

1. Explore patients perspectives and understanding of HIV and HIV testing
2. Examine how patients' perceptions of HIV influence their communication and interaction with counsellors during the HIV testing consultation
3. Explore how the role of the counsellor is constructed by patients and health professionals, and how 'counselling' is performed during the PITC consultation
4. Explore how informed consent is understood by patients and counsellors, and how it is obtained during PITC

In order to address the above objectives there was need to investigate 'real time' PITC consultation and how the persons involved experience and make sense of the interaction. See figure one below for a summary of the aim, objectives and methods used.

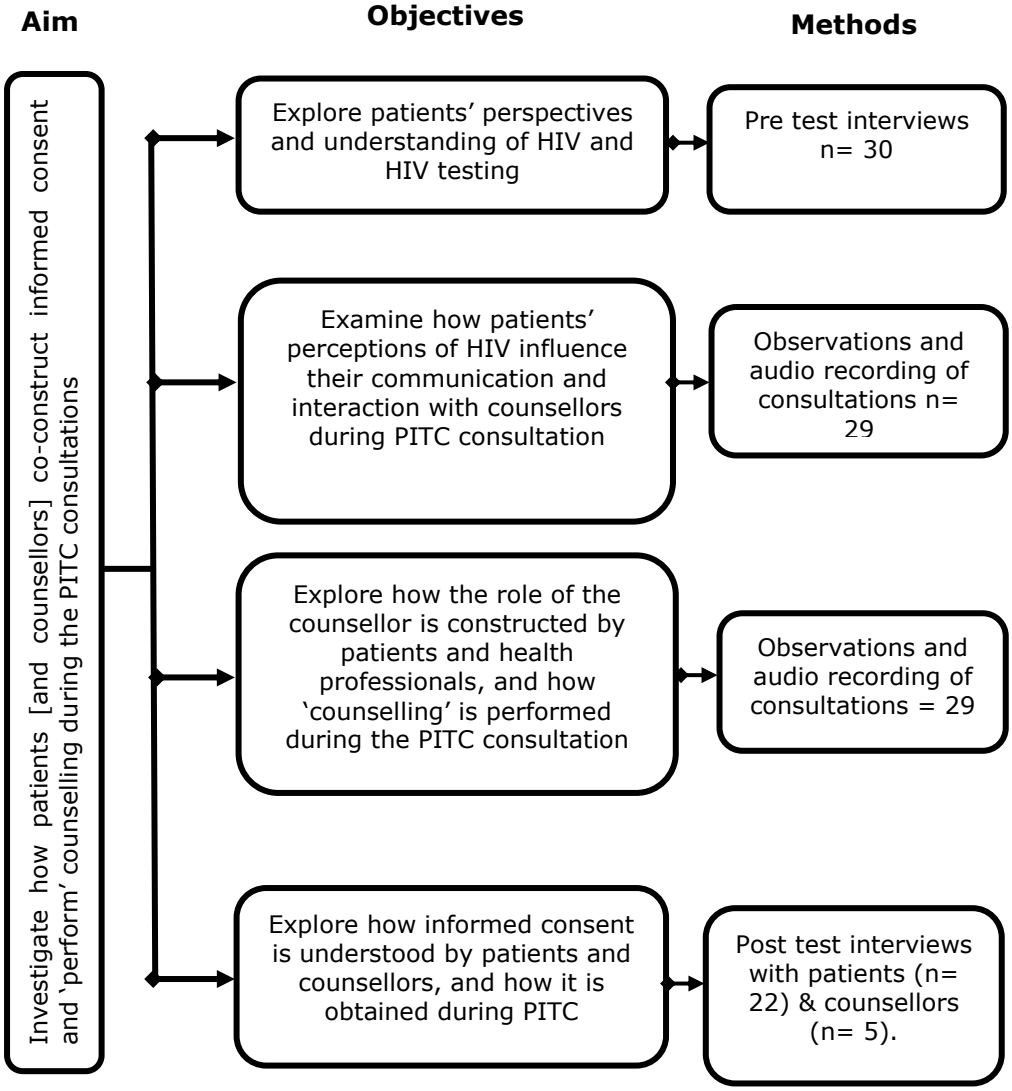


Figure 1: Summary of the aim, objectives and methods

Using a social constructionist approach, this study began with an indepth examination of the patients' perspectives about HIV and HIV testing using interviews prior to the PITC consultation. This was intended to appraise how existing sociocultural factors and perceptions about HIV shape PITC and, in particular, communication and interaction during the routine HIV testing consultation. The study then used observation and recording of the

consultations to examine how patients and counsellors 'perform' counselling and co-construct informed consent within the context of normalization of HIV. This also facilitated the exploration of how the patient and counsellor roles are constructed during the PITC consultation. Subsequently, indepth interviews were carried out with the patients after the routine HIV test to elicit their perspective of the PITC consultation. Counsellors whose consultations had been examined were interviewed to provide their perspectives of the events of the PITC consultations. Further explanations and details about the research methods used in this study are presented in chapter four.

1.5 Structure of the thesis

The purpose of this thesis is to present my doctoral research which set out to examine how the core components of PITC i.e. counselling and consent are understood, organized and implemented in every day practice. The thesis begins by setting the scene in chapter one with an overview of the study topic and its significance in policy and practice and a self-reflection of where my PhD journey started.

Chapter two sets the scene of the study area (country) and topical issues related to the subject matter of this thesis. It introduces key debates and concerns related to the implementation of PITC. It highlights the unique Kenyan context vis-à-vis the health care system and how the existing system influences HIV prevention, treatment and management. An overview of HIV infection and the evolution policy and practice, including task shifting, in response to the HIV situation that has rendered itself over the years in Kenya is included. The chapter also provides an indepth

examination of the PITC policy guideline highlighting its impetus, process and limitations.

Chapter three explores existing literature relevant to this research study and expands on controversies surrounding PITC implementation introduced in chapter two. It specifically focuses on three broad areas: normalization of HIV and HIV testing, social construction of HIV, understanding patient-provider communication and the question of choice. Underlying theoretical issues related to informed consent and patient provider interaction are unpacked and explored. A critical analysis of key studies is included.

Chapter four outlines the research aim, objectives and the methodological choices made in this research study. In particular it highlights the epistemological assumptions underpinning this study, exploring how my social constructionist position informed the research design. Further, the chapter addresses the research design, the sample access and recruitment process, the research settings, data collection and analysis. The ethical considerations made in this study are also discussed.

Chapter five situates the findings by providing a brief overview of the participants recruited in this study and an overview of key themes from the data. Chapter six and seven present key themes arising from the study findings. Sub themes related to each theme are presented at length under each theme in each chapter. In chapter eight the findings are pulled together and discussed in the context of wider literature and the PITC policy in view of the context where this study took place. Finally the implications of this study and recommendations for training, practice,

research and policy are presented in chapter nine. The chapter also includes a self-reflection of my PhD journey and a reflection of the limitations of this study.

2 CHAPTER TWO: BACKGROUND

2.1 Introduction

The aim of this chapter is to provide the reader with background information necessary to understand the HIV situation in Sub-Saharan African and in Kenya where this study took place. To begin with, the chapter provides an overview of the Kenyan health care system. It then addresses the HIV and HIV testing situation in the region with a focus on Kenya in order to unpack the changing context of the disease and the corresponding evolving policy and practice response.

2.2 Kenya: Overview

In order to appreciate the scale up of HTC in Kenya, it is vital to understand the Kenyan situation and in particular the health care system in which HTC and other HIV/AIDS related services are offered. Kenya is one of the East African countries located in Sub-Saharan Africa. It borders two volatile countries (Sudan and Somalia) and is therefore a host to more than 650,000 refugees from these countries (United Nations High Commissioner for Refugees (UNHCR), 2015). This adds a strain to the limited health care resources available in Kenya which had since independence in 1963 been a classified as a low income country until 2014 when it was recognized to be a middle income country. Whereas the elevation into a middle income country is an indicator for potential growth with the right policies and good governance, it may also pose challenges. Kenya still has a low economic growth rate of 5.7% with four out of ten people living in extreme poverty on less than a dollar a day (World Bank, 2014). Moreover, there is potential for reduction in the amount of donor

funding received in a country that is highly dependent on donor funding in the running of key sectors like health, energy and infrastructure.

2.3 Health care system in Kenya since independence

Health care funding in Kenya comes from three main sources: private, public and donor sources. The government budgetary allocation for health is quite low ranging between 5% – 7% of the national budget which is below the Abuja declaration[4] recommendation of 15% and Kenya's own goal of 12% (Ministry of Health, 2011, 2013c). The available funds are not adequate to train, hire and retain the much needed health care workers. Additionally, the health care system has consistently struggled with a shortage of essential medications and medical supplies which hinders the provision of essential health care services (Ministry of Health, 2011, 2013c).

The Kenyan health system has undergone a number of major changes since independence in 1963 up to present. Soon after independence, the government augmented spending in health which led to the introduction of a 'free health for all' initiative which, together with a significant increase in the number of health facilities, led to improved trends in health (Mbatia & Bradshaw, 2003). However, rapid population growth, resurgence of tropical diseases like malaria and emergence of new ones like HIV/AIDS coupled with low economic growth led to a reversal of this upward trend in the late 1980s. Clearly, the government could no longer effectively manage to support the health system as it had done previously.

[4] In April 2001, heads of state of African Union countries met and pledged to set a target of allocating at least 15% of their annual budget to improve the health sector.

Subsequently, the World Bank under the structural adjustment programme compelled the government to reduce spending on health and impose user fees for health services. This meant that health care was no longer universally affordable to the general population. During this time, the Kenyan government also faced a reduction in donor funding for health care. This culminated in a range of new problems associated with poverty among the majority of Kenyans, making health care unaffordable and inaccessible to many. This, coupled with mismanagement of public funds due to corruption, exacerbated the debilitation of health services and health resources (Mbatia & Bradshaw, 2003). The deterioration of health care services led to the development of a number of health policies between 1994 to the present in a bid to tackle the health care challenges (see table one below).

Kenya Health Policy Framework (1994) The aim was to strengthen the central public policy role of the ministry of health and employ strategies to reduce disease burden and define costs of curative and preventive services
National Health Sector Strategic Plan 1999-2004 In 1999 there was a shift to decentralization and redistribution of health services to the rural areas and a shift of resources from preventive to curative services
National Health Sector Strategic Plan II 2005-2010 The aim is to reduce health inequalities and the downward trend of Kenya's health status through involvement of the population in decision making on health. This policy also takes into account other international health initiatives such as the millennium development goals (MDGs)
Kenya Health Sector Strategic and Investment Plan 2012-2017 The aim is to provide equitable and affordable quality health care to all with a shift from curative to preventive care. Unlike the previous health policies, this one places emphasis on a technology driven, evidence based and client-centered health systems.

(Ministry of Health, 1994, 2005a, 2006, 2013c)

Table 1: Kenya health policy development 1994 to present

2.3.1 Challenges and gaps in the Kenyan health care system

On the whole health care policies in Kenya have resulted in some improvement in health provision although this still faces a number of difficulties. These include high poverty levels which make health care unaffordable for many Kenyans, low budgetary allocation to health by the government, low prioritization of health at household level and unequal geographical distribution of health facilities (rural-urban divide) in terms of numbers and type of health services (Ministry of Health, 2013c). As a result, health care coverage still remains low in Kenya with a number of key health indicators such as maternal and under-fives mortality rates remaining relatively high. The maternal mortality stands at 488 deaths per 100,000 live births. Kenya is ranked the 39th country with the highest under-fives mortality with 180,000 deaths reported in 2012 (United Nations Children's Fund (UNICEF), 2013). The numbers of available health care workers in Kenya are rather small in view of the current health indicators.

The country faces a severe shortage of skilled health workers with, for example, 0.25 medical doctors per 10,000 population, 0.84 bachelor of science nurses per 10,000 population, 1.82 diploma nurses and 3.08 enrolled nurses (certificate) per 10,000 population (Ministry of Health, 2013c). Nurses form the backbone of the health care system in Kenya and are thus often the main health policy implementers particularly in public health facilities. Kenya is projected to have 1.44 health care workers per 1,000 population by 2015 which is much lower than the WHO minimum of

2.28 health care workers per 1,000 population (Scheffler, Bruckner, & Spetz, 2012).

A big proportion of the few available skilled health care workers are concentrated in urban areas in large health facilities (Ministry of Health, 2011). The rural and hard-to-reach areas where the lower level health facilities are located have very few trained health care workers. This is despite the fact that 80% of the population in Kenya resides in the rural and hard to reach areas. Consequently, rural areas suffer from a poor health care system infrastructure that has seen people travel for miles to access health care in facilities that lack drugs, equipment and qualified health care workers (World Health Organization, 2014). Kenya has made efforts to hire health care workers in the rural areas. Nonetheless, most decline or fail to turn up (Scheffler et al., 2012). This gap has partially been dealt with through the economic stimulus programme (donor funded) which seeks to hire health workers on 3-year contractual basis to work in specific rural areas. However, with devolution of health services, there has been a mix-up with this group of health care workers resulting in delayed or non-payment of their salaries.

Currently, health care in Kenya is provided by 7,795 health facilities made up of dispensaries, health centres and hospitals. About 50% (3,956) of health facilities are owned and run by the government while the rest are within the private sector (2,652), faith based organizations (881) and non-governmental organisations (NGOs) (306) (Ministry of Health, 2013c). The government health system is organised largely in a hierarchical structure. At the bottom level are primary care facilities (dispensaries and health

centres) which serve the grass root, sub-county and county referral hospitals in the middle level and finally two referral hospitals at the national level. This hierarchical organisation facilitates referral of cases from one level to a higher level and the implementation of health policies and directives from the ministry of health to the grass root. However, the different levels of health care services have vastly different capacities and resources with a variation of the type and quality of services offered across the health system (Ministry of Health, 2013c).

Health care in Kenya is offered to the general population at a fee which varies with the government charging the lowest and the private health facilities being the most expensive. Health care is unaffordable to the majority of the population due to high poverty levels with approximately 46% of the population living on less than one US dollar a day (United Nations Children's Fund (UNICEF), 2013). The income level in Kenya is quite low with a gross national income (GNI) [5] of $840 compared to $37,600 in the UK whilst the minimum pay per month is 3,043 Kenya shillings (KShs) in the rural areas and 6,130 KShs in urban centres i.e. approximately $38 and $76 respectively (Barasa, 2009; United Nations Children's Fund (UNICEF), 2007). There is a national health insurance fund (NHIF) through which people in permanent employment make monthly contributions. This provision can be used to access health care in all hospitals within the country when need arises (Ministry of Health, 2008).

[5] The gross national index (GNI) is the sum of value added by all resident producers. A GNI of less than $875 is considered of a low range while the high range is a GNI of more than $10,726

Nonetheless, this fund only caters for a fraction of the hospitalisation (in-patient) expenses, leaving it upon the user to cover the rest of the costs. It is also only available to a small fraction of the population: those in formal and permanent employment.

Access to a health facility is based on what is convenient and practical for the user which is shaped by the cost and affordability of services, perceptions about quality of care, personal preferences and distance to health facility among others (Mbatia & Bradshaw, 2003). There is no established pre booking system; instead patients go to a health facility of choice when they fall ill or require a particular health service. This open and uncoordinated access to care coupled with an undeveloped patient record system makes coordination of health access and follow up of patients difficult in most cases.

2.3.2 Towards bridging the gaps in health care: Vision 2030

The Constitution of Kenya includes a comprehensive bill of rights which compels the government to recognize the right to health for every Kenyan (The Republic of Kenya, 2010). The present health care policy and health sector strategic plan recognizes the inequalities in health care and their hindrance to making health care available to all Kenyans (Ministry of Health, 2013a). In particular, it takes into consideration the fact that the socioeconomic and political environment influence individual access and utilization of health care facilities. Hence the Government of Kenya has recently put into place a multi-sectorial plan known as Vision 2030 to guide policy and governance of the running of all aspects the nation including health care service provision. The current Kenyan health sector

strategic plan is guided by the overall Vision 2030 which aims at improving and evening quality of life (Ministry of Health, 2013a, 2013c). Notably, the Vision 2030 acts as a road map for the Kenya HIV/AIDS strategic plan which will be explored further below (Ministry of Health, 2014a).

HIV/AIDS services in Kenya, just like any other health related services, are delivered within the existing health care system. Therefore, the challenges and dilemmas faced in health planning and delivery in Kenya, such as the dilapidated quality of health services and the scarce human and material resources, also affect the nature of HIV interventions and services. HIV funding in Kenya is still largely dependent on international funding which meets 75% of HIV prevention, treatment and support services costs. It is these funds that sustain free HIV services including HIV testing, ART drugs and other HIV prevention, treatment and care services provided in public health facilities. This leads to a lot of uncertainty especially in instances where queries about corruption in the management of funds result in a threat to freeze or discontinue funding. Consequently, measures are being put in place to increase domestic funding for HIV/AIDS services through the implementation of a HIV trust fund (National AIDS Control Council & Ministry of Health, 2014). Nonetheless, these plans are still in their infancy and the HIV services in facilities remain few and disproportionately distributed. Further discussion on the HIV situation vis-à-vis health care services are presented further below.

2.4 The HIV epidemic: Global and Sub Saharan Africa situation

There was an estimated 35.5 million people living with HIV/AIDS globally in 2012 (UNAIDS, 2013). Recently gains have been seen globally with new infections declining by 33% since 2001 and AIDS related deaths declining from 2.3 million in 2005 to 1.6 million in 2012. The Sub-Saharan region continues to bear the brunt of HIV/AIDS accounting for over 70% (25 million) of PLHIV globally and 75% (1.2 million) of AIDS reported deaths in 2012 (UNAIDS, 2013). Further on, although the region has seen a 34% decline in new HIV infections between 2001 and 2012 it still accounted for 70% of the new HIV infections reported globally in 2012 (UNAIDS, 2013).

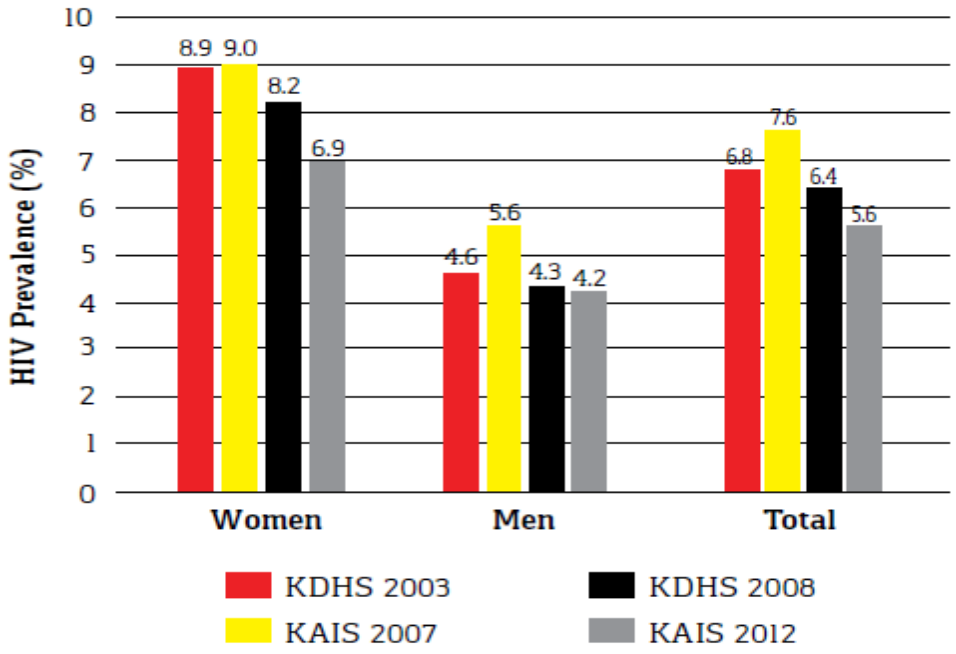
Likewise, although Antiretroviral (ARV) coverage has increased globally and in the Sub Saharan region, a large proportion of PLHIV who are eligible for ART are still not accessing these lifesaving drugs. For instance, in 2012, 9.7 million people in low and medium income countries were on ARVs, representing only 34% of people eligible for ARVs according to the latest WHO guidelines (UNAIDS, 2013; WHO, 2013a). There are variations in ARV coverage within the Sub-Saharan Africa. For example, whilst Botswana has an ARV coverage of more than 90%, in Kenya only about 38% - 45% of those in need of treatment are being reached at present (UNAIDS, 2013). The high ART coverage in Botswana has been attributed to the increased number of persons who are aware of their status with the introduction of PITC. The unmet treatment and support need is largely due to the high number of PLHIV who are unaware of their HIV status in the Sub-Saharan region.

Individuals infected with HIV/AIDS face debilitating symptoms often marked by progressive weight loss particularly in the absence of ARVs. Consequently, PLHIV are often left unable to engage in productive work resulting in poor income coupled by increased health care costs due to frequent hospitalization and treatment of opportunistic infections (UNAIDS, 2010). The effects of HIV/AIDS extend far and beyond the infected individual to the overall economic, social and health care system. Health care systems are strained due to high hospital admissions in a region with limited resources particularly human resources for health (HRH). Similarly, HIV prevention, treatment and care strategies require additional resources which are already constrained in the majority of countries in Sub-Saharan Africa including Kenya[6].

2.5 The HIV epidemic: Kenyan situation

Kenya is one of the Sub-Saharan countries that have suffered greatly from the HIV/AIDS epidemic but has equally seen improvements in HIV/AIDS trends in recent years. According to the most recent Kenya HIV estimates report, the HIV prevalence rate in Kenya dropped from 7.2% in 2007 to 6% in 2013 (National AIDS and STD Control Programme, 2014). Women are disproportionately more affected by HIV/AIDS in comparison to men (see figure two below) and are therefore a key priority in the HIV strategic plan (Ministry of Health, 2014a, 2014j).

[6] A discussion of the Kenyan health care system and human resource for health is provided in section 2.5 below



Source: Kenya Demographic Health Survey 2003 and Kenya AIDS Indicator survey 2007,2008 and 2012

Figure 2: HIV prevalence and gender

There are regional differences in HIV prevalence within Kenya. Homa Bay County has the highest HIV prevalence rate of 25.7% whilst Wajir has the lowest prevalence rate of 0.20%. The exceptionally high numbers in Homa Bay and the Nyanza region in general have been ascribed to the low rates of male circumcision and the practice of widow inheritance and sexual rituals (Amornkul et al., 2009; Perry et al., 2014). Nairobi County where this study was carried out reported a HIV prevalence of 6.8% in 2013 (National AIDS and STD Control Programme, 2014). The number of new infections reported in Kenya in 2013 was 88,620, a 15% decline from the 105,000 new cases reported in 2000. Presently there are 1.6 million Kenyans living with HIV/AIDS with about 760,000 in need of ART based on a CD4 count of <350 (National AIDS and STD Control Programme, 2014).

The epidemic in Kenya has two characteristics. It is generalized in some regions of the country, uncommon in others while in other regions there is a very high prevalence rate among key populations such as injection drug users (IDUs), men who have sex with men (MSM) and sex workers (Ministry of Health, 2014j). Consequently, HIV strategies must be tailored to address the mixed populations most affected by HIV in Kenya.

Overall, levels of HIV testing have increased with 72% of adults aged between 15 and 64 years in 2012 reporting having been tested for HIV - an increase from 34% reported in 2007 (National AIDS and STD Control Programme, 2013). Nonetheless, 53% of people found to be infected in 2012 were not aware of their HIV positive status (Ministry of Health, 2012). Presumably, being tested at one point in time does not mean that the HIV status remains unchanged subsequently. Thus, although the number of people reporting having tested has increased, the low percentage of reported HIV positive status awareness is a hindrance to uptake of HIV care services. HIV/AIDS is the leading cause of health related deaths in Kenya accounting for 29.3% of health related mortality (Ministry of Health, 2013c). The trend is expected to continue in the coming years. Even so, progress with the management of HIV/AIDS is evident in the reducing prevalence rates and increased coverage of critical HIV interventions such as use of ART, prevention of mother to child transmission (PMTCT) in some regions and condom use (Ministry of Health, 2013c; National AIDS and STD Control Programme, 2014).

2.5.1 Kenya's response to HIV/AIDS over the years

HIV was first diagnosed in Kenya in 1984 but it was not until 1996 that the first national HIV framework was developed although it was not accompanied by a national co-ordinated effort to deal with HIV. In 1999 a marked increase in the HIV prevalence rates resulted in a concerted effort by the government which declared HIV a national disaster. With this came the creation of the National AIDS Control Council (NACC), a body under the office of the president charged with the task of coordinating a single national HIV response strategy. NACC led the response towards HIV/AIDS through national HIV/AIDS strategic plans. The focus of the first Kenya National HIV/AIDS Strategic Plan was biomedical prevention, care and treatment of HIV (Ministry of Health, 2005c).

By the year 2000 the HIV prevalence rate in Kenya had increased to 13.5% with about 2.2 million PLHIV (Ministry of Health, 2005c). At this time ARTs were too expensive and not available in public hospitals or through public funding. HIV testing was through expensive laboratory based tests that took up to two weeks to get results. This posed a barrier in a failure to return for test results and unaffordability of the HIV test and treatment. At the same time HIV was highly stigmatised, AIDS patients were neglected and HIV messages focused on death (Ministry of Health, 2005c). Within health facilities, health workers lacked accurate information about HIV and HIV/AIDS was treated as a highly contagious illness (Ministry of Health, 2005c). The HIV response in the first decade of 2000 thus shifted its attention to social mobilization in order to de-

stigmatise HIV testing and impress upon the general population the importance of HIV status awareness.

In 2001 Kenya developed a national VCT guideline (National AIDS and STD Control Programme, 2001). VCT was initiated to meet the testing needs of people who were asymptomatic and wished to know their HIV status (Marum, Taegtmeyer, & Chebet, 2006). The guideline focused on pre test counselling, rapid HIV testing, post test counselling and anonymous coding with no written results to ensure confidentiality. The availability and government approval of simpler rapid HIV tests in Kenya allowed for results within 30 minutes or less. Rapid tests meant that patients could now be tested and receive test results within a short period of time in the same sitting. This aided in dealing with the challenge of failure to return for test results which had been reported across various settings.

For instance, a study undertaken in an antenatal clinic in Kenya, found that 31% of the women tested routinely failed to return for their results a big proportion of which were sero-positive for HIV (Kiarie, Nduati, Koigi, Musia, & John, 2000). Similarly in a VCT setting in Tanzania, 50.9% of the patients did not return for post test counselling thus failing to complete the VCT process (Mmbaga, Leyna, Mnyika, Hussain, & Klepp, 2009). Introduction and widespread use of rapid tests allowed an increase in the number of patients tested and receiving their HIV test results, particularly for those who are HIV positive and requiring referral to further treatment and care.

VCT services were further scaled up during this period in response to the 3 by 5 WHO initiative which was a drive by WHO to increase the number of

people receiving ART to three million by the year 2005 in low and middle income countries. This meant that ARTs were finally available in public health facilities in Kenya. Intensive mass media played a key role in increasing utilization of VCT services in the country, with studies showing an increase in uptake of VCT with increased use of mass media to create awareness and inform about VCT services (Marum, Morgan, Hightower, Ngare, & Taegtmeyer, 2008; Onsomu, Moore, Abuya, Valentine, & Duren-Winfield, 2013).

The VCT approach to testing has had a positive impact in the HIV/AIDS situation particularly in the Sub-Saharan context. It has provided an avenue for testing and subsequently increased HIV status awareness and access to relevant services. Noteworthy is the evidence showing the impact of uptake of VCT services on behaviour change such as reduction in high risk sexual behaviour, increased condom use and decrease in multiple sexual partners (Arthur et al., 2007; Mall, Middelkoop, Mark, Wood, & Bekker, 2013). This was evidence of the benefits of the counselling component of VCT which focuses on personal risk assessment and risky behaviour reduction strategies. In a survey done in South Africa to explore changes in stigma prior to and after the implementation of a VCT programme, stigma was seen to reduce in a community that had a high HIV prevalence as the uptake of VCT services increased (Mall et al., 2013). Reduction of stigma in that study was attributed to wide spread education campaign and normalization of HIV due to availability of ART.

However, despite the milestones achieved by VCT, the numbers tested in the first decade of 2000 in Kenya remained low with only 13% of women

and 14% of men reporting having tested and knowing their status in 2003 (Central Bureau of Statistics (CBS) [Kenya], Ministry of Health (MOH) [Kenya], & ORC Macro, 2004). Only 414,903 clients had visited VCT sites countrywide between the year 2001 and 2004, making it unlikely that this testing model would effectively reach the majority of the population as it was intended (Otwombe, Ndindi, Ajema, & Wanyungu, 2007). The low up take of VCT has been attributed to the far distance to testing centres, the existence of widespread stigma and discrimination which puts people off accessing testing services, dependence on the client's initiative to test and denial of personal risk to HIV (Maman, Groves, King, Pierce, & Wyckoff, 2008; Matovu & Makumbi, 2007; Mugo, Kibachio, & Njuguna, 2010; Obermeyer & Osborn, 2007).

Consequently, the need to expand access to VCT through mobile VCT, home based VCT, couple counselling testing, self-testing and routine HTC are key as a means of overcoming barriers to traditional VCT models was recognised (Matovu & Makumbi, 2007). At the same time evidence on access of VCT services in Kenya showed that women were less likely to test through this approach despite being disproportionately infected by HIV (Kimani & Ettarh, 2012; Ministry of Health, 2014a; Otwombe et al., 2007; Taegtmeyer, Kilonzo, Mung'ala, Morgan, & Theobald, 2006). A study carried out in Kenya using mixed methods found that the majority of women did not attend VCT as often as their male partners (Taegtmeyer et al., 2006). Further on, women were disempowered when it came to negotiating matters related to sex and their ability to make health promoting decisions. That study recommended that HIV testing services need to address gender disparities and barriers to testing.

The second decade of 2000 saw an increase in ART coverage leading to renewed emphasis on HIV status awareness to increase accessibility to these lifesaving drugs. It was during this time that WHO recommended routine HIV testing in antenatal settings to reduce vertical HIV transmission from mother and child. Kenya incorporated these recommendations and rolled out the PMTCT programme in health care facilities (National AIDS and STD Control Programme, 2002). However, these guideline often left male partners out leading to further amendments of the guidelines to emphasis male involvement in PITC within PITC settings.

In 2004, a hallmark guideline by the Ministry of Health in Kenya made a significant change in HTC through the initiation of diagnostic testing and counselling (DTC) (National AIDS and STD Control Programme, 2004). DTC was conducted on patients accessing health facilities who exhibited symptoms that were suggestive of a possible underlying HIV infection. DTC used an opt-out approach in which the identified patients were offered HTC by the health care worker and tested unless they explicitly declined. Noteworthy, this was the first time that HIV testing placed an emphasis on testing rather than counselling which was reflected in the word testing preceding counselling i.e. testing and counselling as opposed to counselling and testing (DTC and VCT respectively).

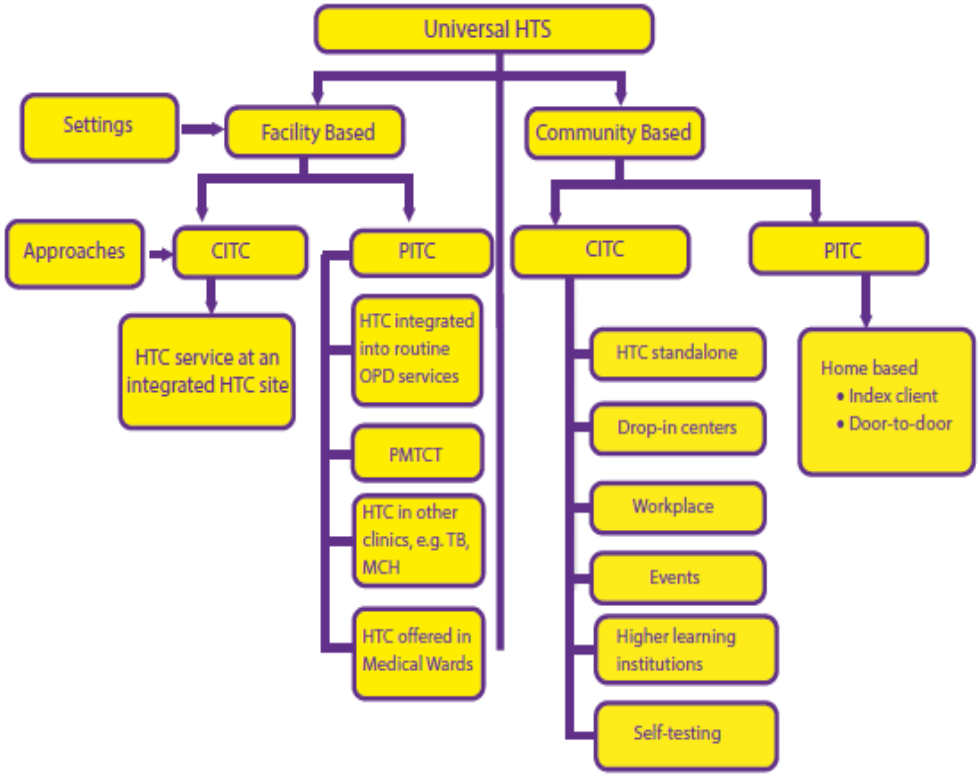
Later on in 2006, Kenya developed testing guidelines that addressed the need for testing beyond client centred VCT to addressing HIV testing as a tool for prevention in primarily healthy populations (National AIDS and STD Control Programme, 2002, 2006). These guidelines provided for

routine testing to all patients in tuberculosis (TB) clinics, sexually transmitted infections (STI) clinics, antenatal settings and in children. These expanded the routine HIV test offer beyond patients presenting with specific symptoms and those in antenatal settings. By 2007 provider initiated testing was expanded to other clinical settings in Kenya following the WHO/UNAIDS recommendations on PITC (WHO/UNAIDS, 2007). Kenya developed a guideline and policy document to provide guidance for routine HIV testing (National AIDS and STD Control Programme, 2008). These were the guiding policies at the time of undertaking this study. A detailed description of PITC is given below.

Following this, the focus on universal access to HIV testing in Kenya continued. The Kenya national testing guidelines recommended a combination of several HIV testing models in diverse settings e.g. institutions, health facilities and the community (National AIDS and STD Control Programme, 2010). The testing models include VCT, PITC, home based counselling and testing (HBCT) and DTC which come under the umbrella of HTC. The Kenyan HTC guidelines have transformed HIV testing into a primary care intervention which is a gateway to appropriate HIV services. PITC is still one of the key components of HTS in clinical settings in Kenya. The PITC process is addressed in section 2.7 further below.

The current Kenyan HIV testing guideline changes its approach from HTC to HIV testing services (HTS) with an emphasis on consent, confidentiality counselling, correct results and linkage to care (National AIDS and STI Control Programme, 2015). A key change in the HTS guidelines is the need to integrate HIV testing to other services which is expected to

expand the roles of stand-alone HIV testing centers. In this regard, stand-alone testing centers will also offer other services such as sexual reproductive health, TB identification and treatment, drugs and substance abuse counselling and support as well as voluntary male medical circumcision among others. The HTS approach and settings are illustrated in the figure below:



(National AIDS and STI Control Programme, 2015, p. 5)

Figure 3: HIV testing and services approach and settings in Kenya

2.6 The PITC policy in Kenya

PITC is a key element in interventions geared towards increasing knowledge of HIV status and linkage to other services. The implementation of PITC has been viewed as vital in tackling the high

percentage of people who are unaware of their HIV status. At the onset of HIV testing in the mid-1980s, the purpose of the HIV test was solely for diagnosis i.e. DTC among those considered at risk and those who presented with symptoms suggestive of HIV infection. As the epidemic spread beyond the previously designated at risk groups, the need to expand HIV testing became apparent. Most importantly there was need to change the approach to testing from one that focused on diagnosis and treatment to one that focused on and facilitated HIV prevention as well as early detection so as to optimize treatment outcomes.

The Kenyan government recognized the central role HTC plays in prevention of HIV, especially its role in providing a gateway to HIV services (Ministry of Health, 2014a, 2014j; National AIDS and STD Control Programme, 2012). Hence the current HIV strategic plan utilizes a rights based approach to testing in line with the goals of the Vision 2030 to provide equitable HIV services to all Kenyans across the geographical and socioeconomic divide (Ministry of Health, 2014a).

2.6.1 Quality assurance systems for PITC

Quality assurance in HTC in Kenya is defined as "the degree to which testing and counselling services meet or exceed established professional standards or user expectations" (Mwangi et al., 2012, p. 15). National and international guidelines emphasize the need to ensure that the HIV testing process is accurate irrespective of the testing approach used in all settings where HTC is offered (National AIDS and STI Control Programme, 2015; WHO, 2015). Concerns about the quality of the HTC process have been reported in many settings particularly in low and middle income countries.

These concerns have been linked to the expansion of testing services and centers which have made it difficult to sustain the quality assurance systems that had been established at the implementation of rapid HIV testing (Mwangi et al., 2012).

An audit carried out in three countries namely Democratic Republic of Congo, Burundi and Ethiopia reported false positive results of 10%, 2.6% and 4.7% respectively (Shanks, Klarkowski, & O'Brien, 2013). False HIV positive results have detrimental consequences such as commencing persons who are HIV negative on ART needlessly and the psychological impact of receiving a diagnosis for an illness one does not have (Shanks et al., 2013). Quality control concerns are rife with the expansion of HIV testing to other settings and other cadres. Reports of inaccurate results are higher in non-laboratory staff as opposed to laboratory staff in some settings (Mwangala, Musonda, Monze, Musukwa, & Fylkesnes, 2016). This is key finding in view of the expansion of HTC and task shifting to other medical and none medical (lay) persons.

Several strategies are recommended for ensuring quality of the HIV testing process. These include support supervision of counsellors to improve quality of the counselling process, accurate record keeping, timely procurement, ensuring psychological wellbeing of counsellors, validation of testing process and accurate HIV test results (Mwangi et al., 2012; WHO, 2015). The Kenyan HIV testing guideline discusses the need to include client satisfaction surveys and observed practice of the HTC consultation (National AIDS and STI Control Programme, 2015). However, the parameters for assessment of quality of the consultation are limited to

adherence to the necessary steps and protocol laid down in the HTC guidelines. Arguably the strategies for quality assurance in HTC appear biased towards the accuracy of the test results, following specific steps and record keeping with little emphasis on the intricacies of construction of consent and counselling in the Kenyan context.

Quality assurance and management of HTC faces various challenges (Mwangi et al., 2012; WHO, 2015). Firstly there is a heavy reliance on donor funding for some of the quality assurance activities such as counsellor supervision and these are difficult to sustain due to resource constraints. Secondly, the expansion of HTC to settings like VCT, PITC and outreach testing services, has seen HIV testing remain poorly monitored in all testing centers. Finally, procurement of the testing kits and other essential commodities required for HIV testing is a challenge in resource constrained countries. Mwangi et al. (2012) recommend the need to carry out operational research to increase efficiency, effectiveness and quality of HIV testing services by providers in various settings.

2.6.2 Training for PITC

Training is a key component in ensuring a quality HTC process (WHO, 2015). Training and adherence to national testing algorithms has been associated with increased accuracy of HIV test results (Mwangala et al., 2016). Training for PITC is officially run by National AIDS and STI Control Programme (NASCOP) which has developed course handbooks and reference manuals for trainees and trainers (National AIDS and STD Control Programme, 2007d, 2007i). The goal of the training is to build capacity in the provision of PITC to ensure quality PITC services. The

course is designed to run for five days during which classroom and practical sessions are carried out to meet various objectives as summarized in table two below.

The PITC participant training learning objectives are:
1. To provide the participants with the knowledge and skills needed to provide patients with information on the basic management of HIV infection 2. To provide the participants with basic counselling skills to enable them carry out a pre test and a post test counselling session 3. To provide the participants with knowledge and skills needed to correctly conduct and interpret a rapid HIV test 4. Identify the need to make appropriate referrals for those who test HIV positive so as to ensure that they access medical and psychological support services 5. To influence the participants positively on need to maintain accurate and detailed records of PITC activities (National AIDS and STD Control Programme, 2007d, p. 9)

Table 2: PITC participant training learning objectives

The objectives above appear somewhat involving for a five day course especially in view of the key counselling and communication skills that the trainers may need to acquire so as to effectively engage in an otherwise difficult interaction such as exploration of risky sexual behaviour and breaking bad news. During the training, competency evaluation is done through role plays and checklists while knowledge is evaluated through pre and post course questionnaires (National AIDS and STD Control Programme, 2007d). The training manual is silent on ongoing refresher training for those who are already trained for PITC.

2.7 The PITC process

The PITC process specifies three basic steps which must be present: the pre test session, the HIV test itself and post test counselling (National AIDS and STD Control Programme, 2010; WHO, 2013a). The pre test session involves giving basic information about HIV to either individuals or groups in which case every individual is accorded the opportunity to ask questions and give consent before receiving a HIV test. This information includes benefits of knowing one's status, benefits of couple testing, an explanation of the testing process and the need for consent for the HIV test. However, this information should be tailored to the unique needs of the client and the setting where the routine test is being offered. Due to the increased awareness and widespread availability of HIV information, the guidelines recommend a reduction in the amount of time spent in the pre test counselling and instead lays emphasis on the post test counselling. Once consent is obtained, the HIV test is done using a rapid test kit which produces the results within 10-15 minutes and does not require sending of the sample to a laboratory.

It is recommended that when the HIV test result is positive, a second confirmatory test should be done either using a different rapid test kit or using laboratory tests like the ELISA and Western Blot[7]. When giving the results, the health care provider is expected to offer post test counselling to the patients, the content of which will be determined by whether the test result is positive or negative. However, the general post test

[7] ELISA and Western Blots are antibody HIV tests that are carried out in well-equipped laboratory. The results take about 10-14 days and hence the patient is required to come back for the confirmatory results at a later date not at the point of testing.

counselling should include risk reduction information, emotional support and referral to appropriate services based on the needs of the clients. See figure four below for a summary of the process.

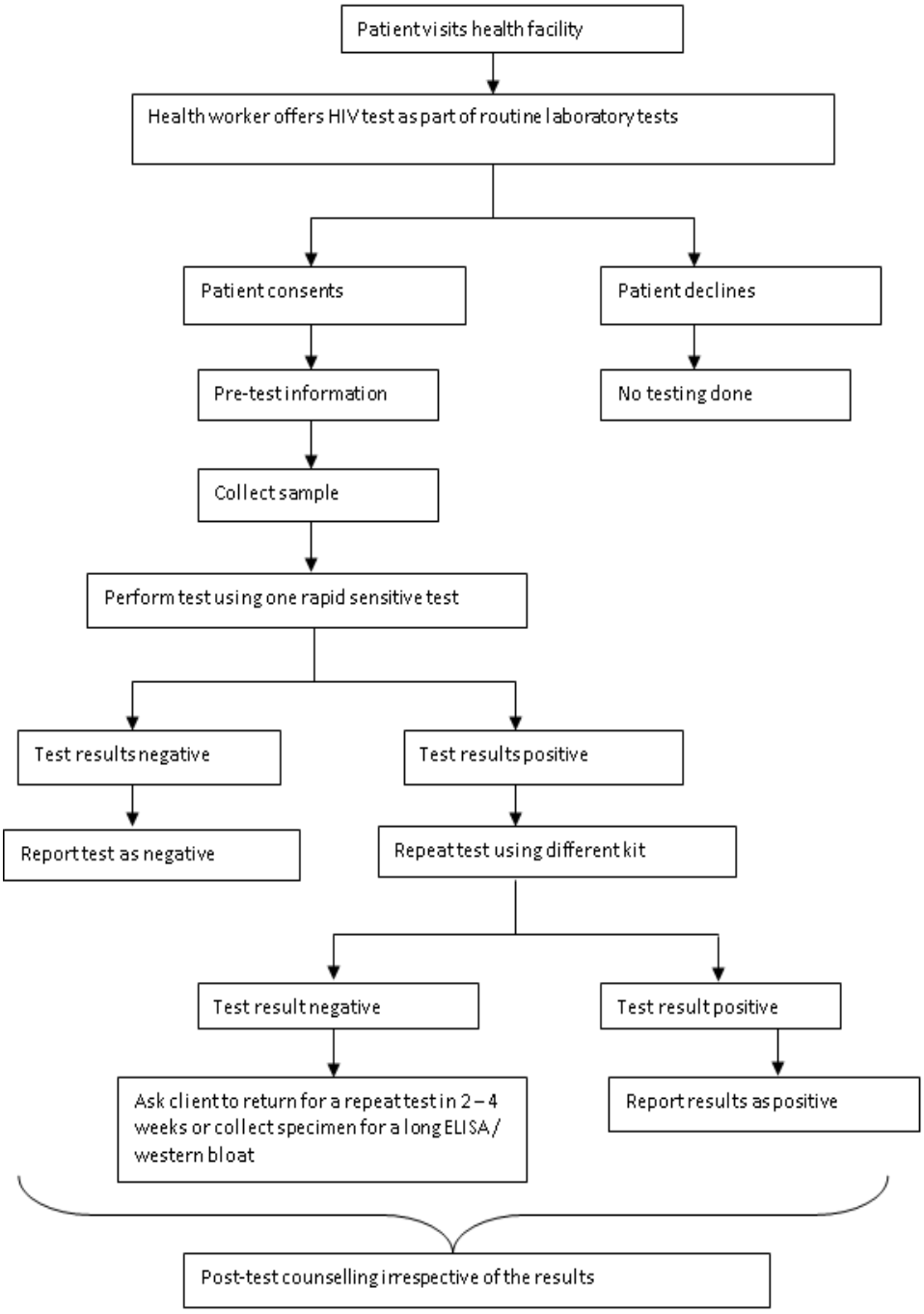


Figure 4: Flow chart of the PITC process

2.7.1 Acceptability of PITC

Studies on PITC show that there is a general high acceptance on routine testing in a number of African countries (Moyer et al., 2008; Nakanjako et al., 2007; Wanyenze et al., 2008). However, there are marked differences in testing acceptance rates (Roura, Watson-Jones, Kahawita, Ferguson, & Ross, 2013) ranging from as low as 20.2% (Pope et al., 2008) in some settings to more than 90% in other settings (Gichangi et al., 2006; Nakanjako et al., 2007; Wanyenze et al., 2008). These differences could perhaps be due to the variations in the length of counselling, differences in resources available and the conditions under which counselling and testing are undertaken (Minnie, van der Walt, & Klopper, 2009). It has been suggested that high acceptance rates tend to be reported in clinical settings which are donor funded. These health facilities are well resourced with sufficient health workers and well established support networks which is not reflective of the majority of health services in African countries where most people seek treatment from (Evans & Ndirangu, 2009d; Pope et al., 2008).

Nevertheless, acceptance and willingness to test does not necessarily equate to uptake of a HIV test. In a study done in Ethiopia acceptability to HIV testing reduced at different phases of the testing process whereby 73% of the patients were willing to be tested when initially offered a HIV test while only 35% took the test in the end (Jerene, Endale, & Lindtjorn, 2007). A similar mismatch in the willingness to test versus uptake of test has been reported in VCT settings (Bwambale, Ssali, Byaruhanga, Kalyango, & Karamagi, 2008; Iliyasu, Abubakar, Kabir, & Aliyu, 2006;

Karim et al., 2008). For instance in a VCT context in Nigeria, Iliyasu et al., (2006) found that although 72% of people said that they were willing to be tested, only 1% had sought VCT services while in a South African study, only 28% of the patients had been tested (Karim et al., 2008).

Reasons for unwillingness to test included association of a HIV positive results with impending death, fear of rejection by others due to widespread stigma and discrimination, lack of knowledge about the importance of testing and uncertainties about confidentiality of the test results (Bwambale et al., 2008; Iliyasu et al., 2006; Karim et al., 2008). Even in cases where high levels of knowledge on the importance of a HIV test are apparent, unwillingness to test due to negative perceptions of HIV is still significantly present (Chivonivoni, Ehlers, & Roos, 2008). As a result it is important for research to go beyond investigating the numbers of people accepting a test to addressing the perceptions that come into play in the process of HIV testing, not just at the point of offering a test, but also after the test when the patient is referred to follow up services.

2.7.2 Impetus for PITC

Routine HIV tests offered in antenatal settings have informed the extension of routine testing in other clinical settings. Evidence from PMTCT had shown increased uptake of HTC which has led to early diagnosis of a HIV positive status and a subsequent reduction in the number of children born of HIV positive mothers who seroconvert (WHO, 2014). A systematic review aimed at assessing the contribution of PITC towards universal testing of pregnant women in various settings indicates that introduction of PITC significantly reduces missed opportunities for HTC in clinical

settings (Hensen et al., 2012). Another systematic review found an increase in uptake of HIV testing rates by large amounts in HIV testing strategies utilizing a PITC approach (Kennedy et al., 2013). However, PMTCT faced the challenge of involving the men in HTC resulting in women being disproportionately tested (Angotti et al., 2011). Kenya continues to report lower levels of HIV testing among men in comparison to women (Kenya Demographic Health Survey (KDHS), 2015). Subsequently, there is need for expansion of facility based testing to other clinical settings where men seek health care services. The successful use of rapid tests in antenatal settings and the high number of patients receiving their test results has also positively impacted on the expansion of PITC to other clinical settings (WHO, 2014).

Presently approaches towards reducing vertical transmission of HIV from mother to child have moved towards elimination of mother to child transmission (EMTCT) by 2015 (Ministry of Health & National AIDS and STD Control Programme, 2012). This is aimed at reducing the risk of mother to infant transmission by 5% through reduction of HIV infection in women, use of ART, addressing unmet family planning needs and reduction in HIV related maternal mortality. This mirrors the prevailing move towards zero new HIV infections by 2015. The starting point of EMTCT is expansion of PITC in antenatal settings.

The PITC approach is critical in bridging the gaps of access to care. Whereas VCT was a key strategy in increasing uptake of HIV testing, the fact that it served the 'worried well' who were not necessarily those at risk of HIV infection meant that those who were likely to be HIV positive did

not take up the opportunity to learn their status (Waxman, Merchant, Celada, & Clark, 2013). PITC provides an opportunity for persons who would not ordinarily seek a HIV test to become aware of their status (Matovu & Makumbi, 2007; Topp et al., 2011). Its introduction in clinical settings has also been associated with higher testing rates (Kayigamba et al., 2015; Silvestri et al., 2011). Silvestri et al. (2011), in a comparative study between PITC and standard testing models in rural Zambia, reported an increase in the number of patients tested by three times per practitioner when a PITC approach was utilized.

Evidence suggests that VCT is likely to target individuals with higher education level and higher social economic status leaving out the majority of the population in developing countries (Obermeyer, Neuman, et al., 2013). Further on, individuals of lower socioeconomic status are more likely to test in integrated facilities through provider initiated approaches (Kimani & Ettarh, 2012; Obermeyer, Neuman, et al., 2013). PITC approaches can increase HTC in low resource settings and to the socioeconomically disadvantaged populations than VCT (Obermeyer, Neuman, et al., 2013). In Kenya there is a recognition that HIV testing services are inequitably accessed with less the disadvantaged and those living in rural areas less likely to test (Kimani & Ettarh, 2012; Ministry of Health, 2014a). Consequently, scaling up of PITC is vital in ensuring universal access to comprehensive HIV prevention, treatment and care in Kenya (Kimani & Ettarh, 2012; Ministry of Health, 2014a, 2014j).

The changes in ART use and initiation from its use in the late stages of HIV for treatment to its use as treatment for prevention in a public health

approach is a key rationale for implementation of PITC (WHO, 2013k). Previously ART was primarily used as a treatment intervention in PLHIV who had been diagnosed with HIV and had a CD4 count of ≤200 cells/mm^3. In low income countries one in four people often start ART treatment with a CD4 count of ≤100 cells/mm^3 resulting in high mortality and morbidity for PLHIV (WHO, 2013a, 2013k). Evidence began to emerge on the dual advantage of earlier initiation of ART in keeping PLHIV alive healthier for longer and dramatically reducing risk of HIV transmission to others (Cohen et al., 2011). At the same time early initiation of ART with a CD4 count of $\underline{\geq}$500 cells/mm^3 has been associated with improved CD4 count recovery (Le et al., 2013).

Consequently the 2010 WHO guidelines recommended the initiation of ART at ≤350 cells/mm^3 and later at ≤500 cells/mm^3 for all individuals who test HIV positive irrespective of their WHO clinical staging (WHO, 2013a, 2013k). For specific groups of HIV positive people i.e. pregnant women, breastfeeding mothers, children under five, and patients with TB and hepatitis, ART should be initiated as soon as HIV is diagnosed irrespective of their CD count (WHO, 2013a, 2013k). A big step is the use of ART treatment for prevention where ART is used to reduce the viral load of a HIV infected person which in turn improves the health of PLHIV and reduces risk of onward transmission of HIV (WHO, 2013a, 2014). Thus overcoming barriers to HTC uptake becomes key to successful HIV management.

2.7.3 Limitations of PITC

Although PITC played a big role in increasing the number of people who have tested for HIV particularly in Kenya to 72% in 2012 and the percentage of those who have received their results, it has a number of limitations (National AIDS and STD Control Programme, 2013; WHO, 2012h, 2013k).

PITC is limited to patients who are accessing health facilities for treatment, leaving out those who do not have access to health facilities. In particular, with the implementation of PITC in antenatal settings, men are disproportionately less likely to test for HIV in comparison to women. This has been attributed to lower utilization of health services by men hence fewer opportunities for them to test and receive early HIV treatment and care (Obermeyer, Bott, et al., 2013). Expansion of HTC into other settings in the community, institutions and through national testing campaigns is expected to address this limitation (Ministry of Health, 2014j; National AIDS and STD Control Programme, 2010; WHO, 2013a).

Efforts to include men have led to implementation of a couple counselling approach in all settings which not only provides opportunities for men to test but also facilitates disclosure of HIV test results between partners (Musheke, Bond, & Merten, 2013; WHO, 2012d, 2015). However, couple counselling faces various challenges to the female partner such as verbal abuse, cessation of sexual relationships, and abandonment. At the same time some men may feel forced and trapped to test since they thought that a refusal to consent would negatively affect their partners' access to antenatal services (Musheke, et al., 2013). This may often arouse

concerns about the voluntariness of HIV testing in couple counselling and testing especially in PITC done in antenatal settings. Even so, PITC remains a key testing strategy in the expansion of HTC (WHO, 2015).

In Kenya there have been reports of unavailability of testing kits which means patients accessing health facilities do not always get an opportunity to test through PITC (Ministry of Health, 2014a, 2014j). Closely related to this is the reluctance of health care workers to offer a HIV test routinely because this has an impact on their workload in an environment that has marked low numbers of skilled health care workers (WHO, 2012h). Offering a HIV test then becomes an additional task that 'interferes' with the other tasks required leading to disagreeable effects like lengthy queues and long hospital waiting times.

Although HIV testing is a key starting point in the HIV treatment cascade, poor linkages to care and low retention in treatment undermines benefits of increased uptake of PITC (Gardner et al., 2011; Waxman et al., 2013). It is imperative that patients who are tested are effectively started on treatment and retained in it to ensure the ultimate benefits of ART are achieved. However, there are suggestions that PITC does not necessarily facilitate early referral, uptake and retention in essential clinical serves in even well-established HIV treatment programmes (Topp et al., 2012).

Survey data from a large maternity hospital in Nairobi Kenya found that in resource constrained situations PITC within antenatal settings was faced with challenges such as late presentation, reduced antenatal visits, low screening rates for opportunistic infections, limited contraception counselling and lack of disclosure to partners (du Plessis et al., 2014).

Similarly, in a systematic review of literature on PITC in various settings Kennedy et al. (2013), found that despite an increase in uptake of HIV testing in PITC, there was a mixed outcome regarding the effect of HTC. After receiving PITC rates of condom use, uptake of niverapine, HIV disclosure and uptake of HIV testing among partners did not significantly differ between opt-in and opt-out approaches. This may be attributed to poor linkages of care following PITC. The referenced review concludes that, in spite of the mixed outcomes with PITC, there is a need to continue rolling out this approach since PITC appears to generally lead to as much behavior change as client initiated testing and counselling (CITC) approaches (Kennedy et al., 2013).

Conversely, there are concerns that the quality of the PITC encounter may have an impact on linkages to care. For example, if the encounter is well managed and the patient receives none discriminative and empathetic care, presumably, the patient may be more likely to follow up care. Whilst a discriminative unpleasant encounter may act as a deterrent towards the uptake of follow up services as patients may be apprehensive about possible stigmatization. A systematic review by Hensen et al. (2012) highlights the inconsistencies and differences in the intensity of the PITC process. These differences make it difficult to make comparisons of the process across different contexts. Further on, the review concludes that there is a gap in the examination of quality of counselling and testing in the literature. They recommend that further research examining the quality of the components of PITC (counselling and consent) is required in order to provide evidence on the process of PITC (Hensen et al., 2012).

Loss to follow up has also been attributed to PITC diagnosed patients being less psychologically ready for HIV treatment (Topp et al., 2012). Additionally lack of centralized electronic patient record systems in Sub Saharan countries may make it difficult to track patients who receive a HIV positive to safeguard take up relevant services (Topp et al., 2011). A recently released HTC guideline by WHO identifies poor linkages to care as a key challenge in HIV testing expansion (WHO, 2015). Providing access to HIV testing where there are poor linkages to care has limited benefits for those found to have HIV (WHO, 2015, p. 10). This adds to the concerns about the ethics of expanding HTC in resource limited contexts where those who test positive may not have access to the much needed treatment. At the same time the quality of the PITC process and in particular how it may influence linkages to care is central to addressing concerns about the uptake of follow up services.

Finally, there are concerns about the consent and counselling process due to fears of possible coercion and compromise of the HTC consultation in different settings. However, PITC is based on a public health approach which in essence shifts focus from the human rights issues of voluntarism and informed consent to obligatory uptake of HTC. The question then becomes how to normalize HIV testing whilst still respecting human rights, and how to balance the rights of the individual against those of the wider society. This shift is aimed at normalizing and routinizing HTC. This study examined the process and role of consent and counselling in normalization of HTC.

2.8 Task sharing in PITC

Task shifting is important in a region where shortage of human resources for health care is an issue due to the low patient to nurse ratio, few skilled health workers and the high disease burden that characterizes countries in this region. In the Sub Saharan region resources are limited and health services are highly overstretched with a high disease burden. The region carries 24% of the global disease burden with only 3% of the world's health worker population available to deal with it yet the area accounts for only just over 10% of the world population (WHO, 2006 p.1). It is this small number of health workers, in the midst of high healthcare demands, that is expected to take up the additional role of implementing routine PITC.

This situation is intensified by the HIV/AIDS pandemic which affects health workers themselves as well as raising additional roles and tasks required in the prevention, treatment, care and support of HIV/AIDS. Task shifting in HIV/AIDS prevention, care, support and treatment is largely practiced across African countries (Arem et al., 2011; Callaghan, Ford, & Schneider, 2010; Lehmann, Van Damme, Barten, & Sanders, 2009; Zachariah et al., 2009). Whilst the initial task shifting happened from a higher cadre to a lower one e.g. doctors to nurses, task shifting has also been observed between trained professionals and lay workers (Chiambe et al., 2009; Rohleder & Schwartz, 2005). Task shifting has been seen as an avenue of substantially increasing access to HIV/AIDS services particularly in areas where the shortage of trained health workers is a hindrance in provision of key health services. The challenge of scarce trained health care personnel

in HIV testing has been dealt with through the scaling down the role of testing and counselling from medical to none medical staff (also known as lay counsellors). In Kenya, task shifting in HIV testing was first employed with the implementation of VCT which used rapid testing kits that did not require specialized training to implement (National AIDS and STD Control Programme, 2001).

A qualitative study which sought to explore health resource implications of scaling up of HIV testing and counselling in Kenya demonstrated the impact of the introduction of lay counsellors and their authorization to use rapid diagnostic tests (Taegtmeyer et al., 2011). It found that task shifting to lay persons and lower cadres of health workers was facilitated by the introduction and use of rapid diagnostic tests that did not require specialised laboratory skills and technologies. There were, however, concerns about the quality of the process in view of the length of training required for lower cadres and lay persons and the sustainability of this training in the event funds were not available. In spite of these the study concluded that task shifting strengthened HIV testing rather than undermining it and also facilitated the increased workload with the expansion of HIV testing (Taegtmeyer et al., 2011). Whilst this study was carried out prior to the implementation of PITC, its findings are important in light of the increased demand for counsellors in view of the high number of persons requiring HIV testing and counselling through PITC. In particular, it shows that in a context of limited human resource, task shifting provides a viable solution to meeting HTC expansion needs.

Similar gains in the use of lay counsellors have been reported within PITC. Topp et al. (2011) in a study examining coverage and uptake of PITC in Zambia when using lay counsellors reported increased coverage of PITC. Using lay workers in that setting helped to maximize the number of individuals tested. Consequently this increased the acceptance of PITC from 52% to 83% in a period of three months with the introduction of lay workers. The need for task shifting in PITC emanates from the practice difficulties faced by nurses offering PITC in addition to their day to day duties. A critical review of the WHO guideline and the limited literature on PITC from the Sub Saharan region by Evans & Ndirangu (2009d) demonstrates some of the situational challenges faced by nurses in the implementation of PITC that are perhaps distinctive to countries in this region. These include health system constraints such as lack of time and space which impede on the capacity of the staff to provide adequate counselling.

This situation is expressed in a study conducted among nurses working in medical and surgical wards where PITC is being implemented in Kenya (Evans & Ndirangu, 2009a). The nurses in that study indicated that the high workload and high number of clients requiring PITC diminished the time they spent in counselling. At the same time the lack of space (a private room) to do the counselling and testing impeded their efforts to maintain confidentiality. In addition, the organisational objectives of testing as many people as possible within a given period of time placed great pressure on the nurses which they felt affected the mode of delivery of counselling. That study brings to light some of the organisational

related difficulties faced in maintaining quality during routine PITC in a human resource constrained situation.

Another study was carried out in Namibia using observational and qualitative methods to explore opportunities for strengthening PITC (Davyduke, Pietersen, Lowrance, Amwaama, & Taegtmeyer, 2015). It found that shared counselling rooms did not accord patients confidentiality whilst the available designated counselling rooms which were clearly marked with bio hazardous signs were stigmatizing. At the same time, nurses reported that they did not see PITC as an integral part of their current role and they felt inadequately trained and supported (Davyduke et al., 2015).

A systematic review examining the nurse and midwife views and experiences with PITC found that whilst in a number of studies nurses were supportive of PITC, in some instances they had reservations about PITC (Evans et al., 2016). These were associated with concerns about lack of privacy and limited infrastructure and human resources. This review recommended the need to undertake research to evaluate different approaches to PITC in terms of staff skill mix.

Questions have been raised about the quality of HTC in instances where testing and counselling is done by lay counsellors. A systematic review seeking to answer the question of whether trained lay providers should be used to provide HTC using rapid diagnostic tests indicates an increased uptake in HIV testing services with lay providers (Kennedy & Fonner, 2015). Additionally, the review reported a marginal difference in the quality of HIV test between lay counsellors and professional providers.

However, the review was based on literature drawn from different contexts which may not be comparable. Moreover, the systematic review was constructed from only five studies and may not necessarily be representative of the diverse environments in which HTC takes place.

Task sharing to lay providers is a key recommendation in the most recent HTS guideline (WHO, 2015). It recommends that lay providers who are trained and supervised can conduct safe and effective tests using rapid diagnostic tests (WHO, 2015, p. 44). Further on, it suggests that lay counsellors are peers who can act as role models by providing none judgemental support which can help in reducing stigma associated with HIV in the community. However, there are concerns that people may be wary of having a HIV test done by someone who comes from their community due to fear of breech of confidentially (Kennedy & Fonner, 2015).

Even so, there is emphasis on a long training for lay providers which should include medical ethics examining consent and confidentiality accompanied by mentoring and ongoing support (WHO, 2015). In practice there have been concerns about the extent and content of the training of counsellors as well as the quality of HTC even when professional providers are involved (Evans & Ndirangu, 2011). This perhaps raises questions about how, with the inclusion of lay providers, the quality of the PITC process would be maintained and monitored.

2.9 Conclusion

To sum up Kenya is one of the Sub Saharan African countries, which like most countries in this region, faces a high burden of HIV/AIDS. Kenya has

been on the forefront in its response towards HIV/AIDS through expansion of HIV testing by being among the first countries to initiate DTC and PITC globally. Although Kenya has made significant milestones in its response towards HIV/AIDS, there is still a lot more to be done to increase HIV testing coverage, uptake of services and improve HIV management. HIV prevention, management and treatment in Kenya faces challenges largely related to the poor health care infrastructure, scarcity of trained health care workers and limitations of resources required to provide adequate, quality health care services. Additionally, there is disproportionate distribution of resources leading to a huge rural urban divide with health care resources mainly concentrated in the urban areas. The prevailing health care situation may have an effect on the implementation of PITC policy recommendations.

The PITC guidelines by and large leave it upon individual health institutions to operationalise its implementation (WHO, 2012h). There are particular questions on what a quality testing process entails and especially how a routinized and normalized HIV testing process is implemented in diverse settings (WHO, 2012h). Moreover, the operationalization of informed consent and counselling within a context where obvious power differences are inherent in patient-provider consultations has not been adequately addressed. Arguably, although the PITC process is presented as beginning at the time of offering the test, it is possible that the environment outside the testing setting such as perceptions and in particular beliefs about HIV could potentially influence what takes place during and after testing including uptake of follow up services. These issues surrounding normalization of HIV testing, informed

consent and counselling form the three core issues underlying the conceptual framework on which this thesis is based and are discussed in the literature review chapter.

3 CHAPTER THREE: LITERATURE REVIEW

3.1 Introduction

The previous chapters have discussed the background of the PITC model and introduced some of the controversies surrounding its implementation. The controversies centre on how an ethical HIV testing process can be implemented in the face of normalization of the HTC process. It has alluded, albeit briefly, to the challenges of operationalization of PITC policy's recommendations on consent and counselling in the milieu of expanding HTC in resource constrained settings. The challenges related to scarce resources related to health care particularly in Kenya and the unequal distribution of resources have been discussed. The current chapter will seek to expand on these issues by providing a detailed discussion of the existing literature on routine HIV testing. In particular, it explores issues arising from its implementation and contextual factors that may influence the testing process, specifically consent and counselling, in the Sub Saharan and Kenyan context.

The chapter considers research from PITC in clinical settings and antenatal settings as well as other testing models such as VCT and how this literature informs the PITC situation. It also deliberates on theoretical aspects of the concepts under scrutiny such as informed consent and patient provider communication. This review identifies and evaluates available literature providing a brief critique of the main studies identified. Finally, this section identifies key gaps which will provide the rationale for this study. The chapter is divided into four distinct subsections: 1) Normalizing HIV and HIV testing 2) Social construction of HIV and HIV

testing 3) Understanding lay and professional interaction in the PITC consultation and 4) The question of choice

3.2 Normalizing HIV and HIV testing

A change in the testing approach and discourse has been largely driven by the need to normalize HIV and the testing process. This need arises from the understanding that treating HIV differently from other medical conditions is a key barrier to expansion of HIV testing and uptake of HIV services. However, the processes involved in HIV testing are in part a response to the prevailing social stigma and are necessary to protect people from discrimination.

Normalization of HIV is not a distinct discourse per se but the consequence of changes in the care and management of HIV due to availability and effectiveness of ART which have not only improved quality of life but also increased the life expectancy of PLHIV. The significance of this is that PLHIV will live longer and need long term care. Changes in ART use have also led to new models of care such as treatment as prevention which require a public health approach to expand HTC and maximize uptake of essential treatment. The net result of this is more people requiring prevention, care and treatment services which would strain the available specialist HIV services. To curb this, it becomes necessary to normalize HIV related services by integrating them to the existing health care systems. Normalization and integration facilitates linkages to care following a HIV test, bridging the gap between HIV testing and uptake of relevant services (WHO, 2015).

The normalization narrative in HIV is problematic within social and clinical settings. Normalization is driven by developments in the biomedical field but the response may be socially constructed by those involved. Socially reframing a disease narrative is difficult for a condition that has a long standing history of negative perceptions that are ingrained in the social environment (Nguyen, 2013). For instance whilst PLHIV will routinely seek services such as CD4 count and ART in clinical settings, they have to live and spend time in the community and with their families where HIV is shrouded by negative perceptions (Moyer & Hardon, 2014).

HIV's association with sexual immorality and stigma and discrimination may lead to anxiety for PLHIV who have to work exceptionally hard to keep their HIV status a secret (Mazanderani & Paparini, 2015; McGrath et al., 2014). Hardon and Posel (2012), illustrate the contradiction inherent in the normalization narrative between the social constructs of secrecy versus the biomedical constructs of secrecy. From a biomedical perspective, disclosure equals normalization, improved quality of life, access to treatment and reduced stigma. From a social perspective, disclosure may lead to discrimination and therefore, normalization is maintained through non-disclosure and keeping one's HIV diagnosis a secret (Hardon & Posel, 2012). These factors may make it difficult for PLHIV to identify with the normalcy narrative of HIV in their everyday life.

Likewise, within clinical settings, it has been suggested that health care systems may not be ready for integration and normalization of HIV (Moyer & Hardon, 2014). To begin with health care providers may be unable to delink from the historical framing of HIV as an exceptional disease

(Persson et al., 2014). At the same time, whilst PITC seeks to dilute the counselling and consent process, HIV still remains the only condition that has a distinct testing process requiring counselling and informed consent in health facilities. It is therefore likely that both patients and professionals may have to navigate the contradictions associated with normalization of HIV in the course of HIV testing and subsequent uptake of HIV related services. This may influence how they construct and co-construct the routine HIV testing consultation. For this reason it is important to understand the complexity of the social construction of HIV and how this social construction of HIV impacts of the PITC process. The section below examines how construction of HIV influences HIV and HIV testing.

3.3 Social construction of HIV and HIV testing

HIV/AIDS, just like other illnesses in society, is explained and defined in relation to existing social norms. This section examines the social construction of HIV and HIV testing in a bid to highlight the complex social terrain in which the PITC policy recommendations are implemented. PITC was originally introduced as a public health measure to increase HTC but is now part of an effort to normalize and integrate HIV to existing health services (WHO, 2015). The section problematizes the nuance of normalization of HTC by illuminating the key role of social constructs of HIV in informing and shaping lay, and by extension professional, views about HIV. This influence is vital as it may affect how PITC policy recommendations are translated within the existing social terrain.

3.3.1 Lay construction of illness and health

Every society develops cultural systems of explanation for particular misfortunes and why and how they happen to a particular person at a particular time. These explanations are extended to include occurrences of health and illness. For example, in a UK study about heart disease by Davison, Smith, & Frankel (1991), lay people were shown to use information obtained mainly from their own experiences or what they had heard from other people to decide who is likely to suffer from heart disease and evaluate their personal risk. Lay people utilise a number of factors including individual lifestyle to explain the occurrence of heart disease or predict who is likely to suffer from heart disease. This creates a concept of 'candidacy' which the authors refer to as a manifestation of lay epidemiology.

The concept of lay epidemiology reveals the significance of lay knowledge and personal experiences and the part they play in influencing perceptions about health and illness. Lay knowledge is also drawn from scientific / professional knowledge which, together with lay experiences and observations, creates a complex web of knowledge. Lay persons work with the different repertoires of knowledge (lay experiences, observations and professional knowledge) to make sense of illness and health (Kleinman, 1978). Similarly health professionals may also combine biomedical and lay knowledge in their day to day activities. It is not entirely possible to separate lay knowledge and scientific knowledge because lay people tend to draw on both interchangeably depending on the situation at hand (Davison, Frankel, & Smith, 1992; Davison et al., 1991).

Similarly, the idea of candidacy has been in use in the context of HIV. HIV has over time been associated with people who are seen as immoral and promiscuous (Roura et al., 2008). This is in spite of extensive mass health promotion campaigns aimed at changing negative perceptions towards HIV and PLHIV. In many countries, from a normative lay perspective, a HIV positive 'candidate' continues to be seen as one who has engaged in risky sexual behaviour contrary to expected social norms and is thus culpable for getting infected with HIV/AIDS (ActionAid International Kenya, 2009). It is this perception about how HIV is spread and the loss of moral standing of the infected person that has seen stigma and discrimination continue to be a key feature in HIV/AIDS (Hamra, Ross, Orrs, & D'Agostino, 2006; Roura et al., 2008).

3.3.2 HIV stigma

The genesis of HIV/AIDS related stigma is its historic connection with behaviour and social groups that were considered immoral and unacceptable such as prostitution, homosexuality, drug use and promiscuity.

The definition of stigma remains unclear across the literature although for the most part it is based on Goffman's view of deviance and difference. Stigma is an attribute, behaviour or reputation which is socially discrediting in a particular way (Goffman, 1963). Goffman (1963) explains that stigma disqualifies the stigmatized person from full social acceptance because of their perceived deviance. He further noted that stigma is not a fixed attribute of an individual but rather the experience and meaning of difference. Consequently, for the stigmatised person, social interactions

become a process of managing a spoilt identity through various ways such as controlling information shared with others (Goffman, 1963, 1969).

Stigma originates from the social conceptualisation of 'difference' or 'deviance' which is applied to individuals or groups meeting particular criteria (Malcolm et al., 1998; Scambler, 2006). Stigmatising people through creating a feeling of 'otherness' and 'difference' gives others a feeling of comfort and personal invulnerability towards a particular risk or disease (Crawford, 1994). Literature draws a distinction between perceived (felt) and actual (enacted) stigma (Goffman, 1963; Lekas, Siegel, & Leider, 2011; Sandelowski, Lambe, & Barroso, 2004). Perceived or felt stigma refers to a situation where patients internalise the negative views and comments about HIV and thus begin to consider themselves as inferior even in the absence of real discriminating actions towards them. Actual or enacted stigma occurs when PLHIV become recipients of real negative behaviour from others on the basis of their HIV positive status. However, it is sometimes difficult to draw a distinction between the two since both felt and enacted stigma result in feelings of difference and otherness from within and from others respectively (Lekas et al., 2011; Sandelowski et al., 2004).

Scambler, (2006), explores the relationship between stigma and culpability and deviance. In his argument, people who are stigmatised are seen as imperfect with presumed defects which are beyond their control to correct. However, deviance comes into play when the defect is seen as a result of individual choice and thus people are seen as being morally responsible for their defects or illness. HIV stigma is characterized by

deviance (a HIV positive person has consciously transgressed acceptable social norms by being promiscuous) and culpability (the infected person deserves the negative consequences / punishment for his transgression). A number of studies have shown that HIV is often deemed as a punishment and evidence of wrong doing that the infected person may have engaged in (ActionAid International Kenya, 2009; Campbell, Foulis, Maimane, & Sibiya, 2005; Hamra et al., 2006; Roura et al., 2008; Winskell, Hill, & Obyerodhyambo, 2013).

A qualitative research study carried out in three districts in Kenya found that 70% percentage of the respondents felt that people with HIV were promiscuous and 74.7% reported that HIV was a punishment for bad behavior (ActionAid International Kenya, 2009). Contrary to these findings, a quantitative study drawn from the Kenya Demographic and Health Survey, reported relatively high levels of accepting attitudes towards PLHIV at 60-89% (Chiao, Mishra, & Sambisa, 2009). The difference in the findings can be accounted for by the use of self-reported measures of attitude and the quantitative methodology in the later study may have hampered the uncovering of the deep social layers of attitudes towards PLHIV which is possible in qualitative investigation.

HIV stigma is complex in how it is expressed (or not) which may account for the conflicting evidence in spite of different methodological approaches. The complexity of stigma is addressed by Gausset, Mogensen, Yameogo, Berthe, & Konate (2012) in their qualitative research study to examine causes of stigma in Burkina Faso. This study involved semi-structured interviews with PLHIV, heads of community based organizations (CBOs),

people in charge of HIV programmes and employees and volunteers working with CBOs. The study found that stigma in HIV was often associated with immorality and an associated moral discourse as opposed to concerns about the physical contagion of the infection. This would mean that when asked about stigma in terms of physical contagion responses were likely to show low or no stigma, whereas if examined within social constructs of immorality, responses were likely to show stigma is present or high. Gausset et al. (2012) reported that stigma is an ambiguous term in which there is no clear response to what stigmatizing an individual entails.

A cluster randomized control trial on the effect of home based counselling and testing on HIV stigma found that self-reported stigma declined over time (Jürgensen, Sandøy, Michelo, & Fylkesnes, 2013). However, it reported mixed findings between felt and perceived stigma whereby there was a reduction in individual symbolic stigma but not in perceived stigma. Hence it follows that the body of evidence about HIV stigma may not necessarily reveal the same picture even when research is done within the same context. It would be problematic to assume a uniformity of perception and expression of stigma across different contexts and between individuals (Knight et al., 2014).

Meanings attached to health and illness are created and sustained through social interactions and influenced by the sociocultural context such as experiences of others with an illness and the community's perceptions about a particular disease (Obermeyer & Osborn, 2007; Steward et al., 2008). Likewise, stigma is developed and experienced within established

social, economic, cultural and religious structures and as such may be widespread even with the availability of information to alter this negative view. A systematic review of interventions to reduce HIV related stigma and discrimination found considerable progress in stigma reduction from 2002 to 2013 (Stangl, Lloyd, Brady, Holland, & Baral, 2013). However, this systematic review found that there were gaps in the integration of stigma and discrimination in national AIDS response strategies in most countries. Failing to include stigma in AIDS responses has created a hindrance to uptake and adherence of key HIV strategies and interventions including HTC (Stangl et al., 2013).

3.3.3 Stigma and HIV testing

The relationship between stigma and HIV testing is a reciprocal one. Stigma impedes HIV test uptake due to fear of negative consequences in the event of an HIV positive diagnosis (Musheke, Ntalasha, et al., 2013). At the same time, high HIV status awareness has been associated with low levels of stigma (Castro & Farmer, 2005; Mall et al., 2013). This has been attributed to information given during the course of HIV testing that may positively influence negative perceptions about HIV (Mall et al., 2013). For this reason, PITC which does not rely on an individual initiating the HIV test, is considered crucial in overcoming barriers to HIV test uptake and subsequently reducing HIV stigma (WHO, 2012h).

In a cluster randomized evaluation of home based counselling and testing (HBCT), the researchers found high rates of testing in areas reporting high stigma hence reaching people who would not ordinarily test on their own. HBCT uses a PITC approach within the community setting (Low et al.,

2013). Similarly, Kabiru, Beguy, Crichton, and Zulu (2011) found that the routine offer of an HIV test in a health facility increased the number of youth who received an HIV test in a Kenyan urban informal settlement in spite of existing stigma. PITC is considered a key HIV testing strategy in an environment characterised by negative HIV perceptions. This is a key rationale for the implementation and expansion of PITC throughout the country.

3.3.4 Stigma and disclosure following a HIV test

Fear of testing due to apprehension about a HIV positive diagnosis is associated with the stigmatizing treatment one is likely to get. In a context where morality and social acceptance are the essence of everyday life, a judgment of moral transgression has far reaching consequences to individuals who are found to be HIV positive. There have been reports of negative effects of stigma such as violence, denial of treatment and rejection from family and friends (Campbell et al., 2005; Nyblade et al., 2003; Stansbury & Sierra, 2004). Exclusion from community and family activities due to one's perceived immorality means a loss of social connection which is the corner stone of individual existence in the African context. This results in a need to keep one's HIV positive status a secret which leads to low disclosure and a subsequent hindrance to accessing medical care and social support for PLHIV.

Anthropological and social research illustrates the dilemma associated with disclosure in a situation where HIV stigma is deep rooted (Hardon & Posel, 2012; Lugalla, Yoder, Sigalla, & Madihi, 2012; Moyer, 2012). Patients have to constantly weigh the medical benefits of disclosure versus the negative

experiences of disclosure they are likely to face in the communities where they live. In most instances patients may chose not to break their silence about their HIV positive status. Disclosure of a HIV positive status is perceived as tantamount to accepting that one has engaged in a risky sexual encounter. Consequently, one may feel the need to conceal this information in a bid to maintain their moral and social standing (Moyer, 2012).

Moyer (2012) argues that silence is not always due to fear of stigma, but rather a way of maintaining social relationships and honour in what she refers to as 'respectful concealment'. In her paper, Moyer (2012) explores the contradiction of disclosure among HIV/AIDS activists who willingly disclose their HIV status in public but are silent about their HIV status in their everyday discussions to avoid shame and maintain a semblance of normalcy. This suggests that disclosure entails a process of managing and controlling information whereby certain information may be disclosed in certain circumstances but not in others. Similarly, a qualitative research study carried out in Tanzania found that although the rates of disclosure had increased, disclosure was selectively done and not always to sexual partners (Lugalla et al., 2012). The researchers suggest the need to address disclosure particularly between sexual partners, in a socially appropriate manner during the HIV testing consultation. This acts as a good rationale for expansion of couple testing and counselling which in itself aids in easing disclosure between sexual partners.

Whilst across the literature negative consequences of disclosure of a HIV positive status have been reported, there are also instances where a

patient's expectations of a detrimental response following disclosure have been met by increased support from family and friends (Castro & Farmer, 2005; Greeff et al., 2008). In a study conducted in Nigeria, the researchers found that whilst half of the study population reported negative experiences with disclosure, the other half reported positive feedback on disclosure such as increased access to family care and improved social and financial support (Ezegwui, Nwogu-Ikojo, Enwereji, & Dim, 2009). In line with this, some research has pointed to the fact that a considerable proportion of expressed stigmatising experiences stem from perceived (felt) rather than actual (enacted) stigma experiences [8] (Sandelowski et al., 2004). In Kenya, perceived stigma affects the quality of life of HIV positive people and their access to care as much as enacted stigma does (Hamra, Ross, Karuri, Orrs, & D'Agostino, 2005; Yebei, Fortenberry, & Ayuku, 2008).

In sum, stigma cannot be ignored when examining any aspect of HIV prevention, care and support. Additionally, the complexity of stigma in the Sub-Saharan region means that a consideration of its effects is vital in understanding operationalization of PITC in Kenya. Present evidence appears to pay attention to stigma's effect on uptake of HIV testing and uptake of services after a HIV test. There is a gap of evidence on the impact of stigma on the HIV testing process itself and in particular the implementation of the counselling and informed consent. For instance negative perceptions about HIV may inevitably affect how patients talk about their risky behaviour (or not) and how providers present HTC as

[8] Perceived or felt stigma and actual or enacted stigma has been addressed in pages 68.

they try to overcome barriers to HIV testing associated with stigma. It is therefore important to examine actual provider patient interaction within HTC in light of the existing stigma associated with HIV.

3.4 Understanding lay and professional interaction in the PITC consultation

An important component of HIV testing is the counselling session. As alluded to in the previous chapter, HIV testing has evolved over time from a detailed pre and post counselling to a pre-information session with emphasis on post test counselling. In this evolution, the term 'counselling' has been used to refer to a consultation with different expectations over time. Consequently, counselling may be operationalized in varied ways in diverse settings depending on the local translation of PITC policy recommendation on counselling, staff training, resources and infrastructure. For instance, observations of PITC in Namibia showed that the counsellors used a full VCT protocol (detailed pre and post test counselling) rather than the abbreviated PITC process (Davyduke et al., 2015). These differences make it difficult to determine what constitutes an ideal PITC counselling session without examining the actual consultation in the milieu of the prevailing environment.

Far and beyond the challenge of possible [mis]interpretation of the term counselling, the PITC consultation necessitates a discussion of sexual matters in the midst of a myriad of activities. These include blood sample collection, carrying out the HIV test, disclosure of tests results and obtaining consent. The multiple tasks that require to be accomplished during the PITC consultation and the nature of talk that is expected to

take place makes this particular patient-provider encounter a sensitive and potentially challenging one. It is necessary to examine how these new tasks are integrated into the pre-existing patient-provider consultations. This section seeks to tease out key issues and theoretical arguments related to patient provider communication in PITC. The focus will be on the nature of patient provider interaction and the management of difficult consultations. Informed consent will be explored in details in section 3.5.

3.4.1 Nature of patient – provider communication within health care settings

Most of the theoretical and empirical work on patient – provider communication has come from different cultural and health care contexts with very little done in Kenya. Communication in health settings is a social process that is influenced by social behaviour, social status and power relations between the patient and the health care provider (Crawford, Brown, & Nolan, 1998). Although as represented in official discourse, the patient-provider interaction is expected to be empowering and balanced in practice, often patients adopt a passive role whilst the providers dominate the consultation (Barry, Bradley, Britten, Stevenson, & Barber, 2000; Maynard, 1991; Mol, 2008; Alison Pilnick & Dingwall, 2011; Vaga, Moland, Evjen-Olsen, Leshabari, & Blystad, 2012). Communication is affected by the language used, rules or laws of social behaviour, social status and power relations of participants and the kinds of roles they have adopted (Crawford, Brown, & Bonham, 2006). Despite the persistent focus on doing away with the paternalistic nature of health communication (Crawford et al., 2006), asymmetry in health consultations still persists

(Mol, 2008). Health professionals exert their power when communicating in clinical settings through their ability to interrupt, decide on what will be discussed, use closed questions and decide what should be talked about (Crawford et al., 2006; Maynard, 1991).

In his examination of clinical discourse Maynard (1991) provides an interesting perspective on the patient-provider interaction drawn from an examination of clinical encounters involving parents and their children with disability. I will draw on key issues he raises in his paper that are pertinent to my research study. Maynard found that the interaction was asymmetrical with a passive patient and a dominant provider. The asymmetry was interactionally achieved rather than imposed on the patients by the provider. This was interactionally achieved through the patient adopting a passive role whilst the provider dominated the interaction. One reason for this is because doctors possessed cultural authority and there was in reality a difference in authority between the patient and the provider. Hence, challenging official discourse that infers an empowered patient who should be an equal active partner in health consultations.

Another interesting issue arising from Maynard (1991) is the rigidity of the sequence of interaction which made the patient – provider interaction predictable. This is noteworthy in view of the fact that patients attending an interaction are likely to have diverse needs and specific expectations about how the encounter will go. Hence, one would expect that the structure of the interaction would vary from patient to patient. A similar finding was reported in a controlled trial conducted in South Africa which

found that counsellors used a fairly formulaic structure of giving HIV information even when this was not necessary during the counselling session (Leon, Lewin, & Mathews, 2013).

A final key point of interest in Maynard's study (1991) is the fact that clinicians shaped the communication into a biomedical interaction which was devoid of patients' emotional concerns and lay understandings. It is noteworthy that the findings from Maynard (1991) are drawn from the US in the early 1990s, which presents a different time and context from the present one. Nonetheless, the issues raised by Maynard (1991) are reflected in more recent studies carried out in a number of clinical settings (Barry et al., 2000; Vaga et al., 2012). These studies suggest that Maynard's findings remain relevant over an extended period of time as explored further on in this section.

Barry et al., (2000) and Britten et al., (2000) report on the same UK study which aimed at exploring the interaction that takes place between the patient and the general practitioner during the consultation process. The researchers used a qualitative research methodology that included semi structured interviews before and after the consultation, audio taping of the consultation and semi structured interviews with the general practitioners (GPs) after the consultation. This methodological approach allowed the researchers to compare patients' prior expectations with what transpired during the consultation. It also enabled an examination of the interaction as well as the views of the GP on the consultation itself.

The findings from these articles indicate that patients came to the consultation with expectations, agendas and questions which they planned

to bring up during the consultation process. However, in most cases the patients were not able to voice their agendas during the interaction with the GP (Barry et al., 2000). This is despite the fact that the patients had clearly articulated what they felt and wanted to say to the researchers but were not able to do this during the consultation. Barry et al. (2000) postulate that failure of patients to voice their needs during the consultation may affect health care. They therefore, recommend taking steps in daily clinical practice and research to encourage patients to voice their agenda (Barry et al., 2000).

The asymmetrical nature of the patient-provider interaction is also reported in African countries, although detailed research is lacking. In an ethnographic study conducted in Tanzania to examine how care is shaped and expressed by nurses, the researchers found that the interaction was strict, curt and generally paternalistic in nature (Vaga et al., 2012). The researchers reported that whilst the interactions within the health facility were paternalistic this changed when patients were treated in the home setting where patients were more assertive. The authors conclude that the quality nursing care needs to be explored within specific historical and social cultural contexts. However, the researchers in that study did not observe the interactions; the findings were based on self-reports about the interaction. Observations of the interactions would have provided further insights on the nature of the interaction in the context where that study was carried out.

It is worth noting that the findings about the asymmetrical nature of medical consultations in practice appear to be the same across time and in

different geographical and cultural settings. Evidently the ideal of the patient partnership model in medical consultations does not translate easily in practice. Whereas in some instances patients want to be involved in the interaction, in other instances patients may not wish to play a more assertive role during consultations and are rather more accepting of the traditional provider dominated, paternalistic interaction (Kumar et al., 2010). This is an interesting conclusion in view of the fact that the PITC policy recommendations and debates surrounding maintenance of informed consent and counselling during the HIV test are based on the assumption that the patient-provider interaction in practice is a symmetrical one.

The Kenyan PITC training manual defines counselling as:

> [9]"Counselling is the ***skilled and principled use of relationships***, which develop ***self-knowledge***, ***emotional acceptance*** and ***growth***, and ***personal resources***. The overall aim is to live more ***fully*** and ***satisfyingly***. Counselling may be concerned with addressing and ***resolving specific problems***, ***making decisions***, ***coping with crises***, ***working through feelings*** and ***inner conflict,*** or ***improving relationships*** with others. The counsellor's role is to ***facilitate*** the ***client's work*** in ways that ***respect*** the client's ***values***, ***personal resources***, and ***capacity for self-determination"*** (National AIDS and STD Control Programme, 2007a, p. 38)

The above definition suggests a client centred, engaging interaction in which a patient is empowered by the counsellor to make decisions or take certain actions. However, in light of the prevailing nature of patient provider interaction explored further above, counselling ideals may be

[9] Emphasis has been added to this extract

difficult to implement in practice. It would be useful to examine real time counselling to add insights to how the recommendations of counselling within PITC are implemented on the ground.

3.4.2 Evolution of counselling in HIV testing

'Counselling' is one of the key concerns raised about PITC. It emanates from fear that a condensed HIV testing session would negatively affect the content shared due to the limited time in which session is expected to take place. Whist initially counselling during HIV testing was characterized by detailed pre test and post test counselling sessions[10], in PITC counselling has been reframed as a short information session with longer counselling during the post test session and mainly if the patient receives a HIV positive result (WHO, 2012h, 2015). At the time of carrying out this study, individual risk assessment was recommended during the pre test information session. This has since then been removed as a requirement in the current HTC guideline (WHO, 2015).

Even as counselling has evolved in HIV testing, the lack of evidence drawn from real time counselling in various environments makes it difficult to understand how various counselling recommendations have been operationalized over time. There is no body of literature that has examined actual counselling in HIV testing beyond a check list evaluation of the content covered during a consultation. This use of checklists does not inform how counselling has been constructed in HIV testing to adequately inform and provide a platform for references for counselling

[10] The PITC consultation lasts approximately 15 – 20 minutes in comparison to the detailed counselling session that took approximately 45 minutes

within PITC. Even so questions abound on whether the re-framed counselling sessions in PITC are adequate or not.

In his exploration of HIV counselling in the UK in the pre-ART era, Silverman (1997) found that the interaction did not meet the criteria of a counselling session. He argues that the consultation in which HIV counselling takes place involves a number of other activities such as information giving, informed consent and the actual HIV test itself. Further on he argues that unlike counselling in normal settings, the HIV counselling is never initiated by a patient in spite of the patient having initiated the HIV test in a VCT setting. Consequently, the counsellors are often faced with the difficult task of engaging an otherwise passive patient to explore their personal circumstances which they had not intended to engage in from the start of the consultation.

The thin line between counselling and information giving emerged from the conversation analysis of the findings from which Silverman (1997) draws his discussions. He notes that a substantial component of HIV counselling is providing patients with information to increase knowledge about HIV together with health promotion. This was done at the time with the intention of helping patients to reach an informed decision about whether or not to have an HIV test. Additionally, he found that there was a lot of advice giving which differs from the client centred empowering interaction expected in counselling. Admittedly his study was carried out in the pre- ARV era when the focus of counselling was to empower PLHIV to deal with the diagnosis of an incurable infection. Nonetheless, counselling within healthcare consultations are usually driven by professional agendas

and are usually about helping people make decisions about medical actions. This has been the case even in PITC in various settings particularly within PMTCT where a number of studies examining the patient-provider interaction during a routine HIV test offer have been carried out (An et al., 2015; Gourlay et al., 2014).

A qualitative study carried out in Tanzania to examine how patient-provider interactions influence PMTCT services found few instances of shared decision-making (Gourlay et al., 2014). The majority of observed and self-reported experiences of consultations revealed power differences between the patient and provider (Gourlay et al., 2014). Patients in that study used phrases such as 'instructions', 'ordered' and 'directions' to describe information given by the providers. This reflected the didactic nature of the interaction during the HIV testing consultation in this setting. Interestingly, in spite of the obvious assertiveness of the providers, patients reported satisfaction with the PITC consultation. It is important to note that the study was carried out in a rural setting and the participants were all women to whom a routine HIV test offer was done during an antenatal visit. The researchers concluded that there is need to empower women to seek information about services as well as to place emphasis on ethics of care and communication to improve PMTCT services.

Leon et al. (2013) using a range of qualitative methods such as focus group discussions with providers, indepth interviews with patients and participant observations of clinical consultations demonstrated the challenge of integration of PITC within pre-existing services in an STI clinic. The researchers found that the providers tended to use an authoritative

role when providing information but had to shift to a patient centred approach when seeking consent. Consequently, the providers faced tension between provider and patient centred communication approaches even as they tried to integrate tasks associated with PITC and established tasks inherently done during an STI consultation (Leon et al., 2013). Even so the researchers noted a formulaic information giving session across different clients even when circumstances did not require one. The authors postulate that providers may face challenges meeting the clients' counselling needs in an environment where the providers have high workloads and increased stress levels. Nevertheless, in spite of these challenges, integration of PITC in STI clinics increased coverage and uptake of HIV testing and ensured a consistent performance across the clinics (Leon et al., 2013; Leon, Naidoo, Mathews, Lewin, & Lombard, 2010).

Negative and unsupportive relationships have also been reported during patient provider interactions during PITC. Instances of disrespect from providers as well as discrimination of HIV positive patients has been widely reported (An et al., 2015; Gourlay et al., 2014; Mbonye et al., 2013). Additionally, there have been concerns of potential breach of confidentiality resulting in a patient's HIV positive diagnosis becoming known at the health facility and wider community (An et al., 2015; Hardon et al., 2012; Våga, Moland, & Blystad, 2015).

A theoretical paper by Nguyen (2013) exploring the evolution of counselling technologies in Africa infers that counselling is linked with imperative talk about sex in order to change behaviour and prevent HIV.

He further explores the challenges posed by the empowerment model of counselling within African settings that constitutes self-exploration and self-awareness in order for one to take charge of their health and speak the truth about themselves. In his discussion, he illuminates that expression of self within the African context is culturally defined and this often interferes with the perceived empowerment expectation of a counselling session. He concludes that the future of counselling in the African context continues to be shaped by the expansion of HIV counselling within this context. This suggests that narratives associated with counselling within the Western world may not easily translate to the Kenyan context due cultural expectations and norms in the majority of the African settings.

The above challenge is illuminated in a study that aimed to explain when, how and why counsellors in rural Malawi adapt Western testing guidelines in light of the 3Cs (consent, counselling and informed consent) to deal with local needs (Angotti, 2010). Angotti (2010) argues that local national guidelines and the international guidelines from which they are derived undergo transformation from the international and national level to the point of implementation. In her view, counsellors are the ones charged with the duty of implementing guidelines which for the most part are not suited for the African context mainly due to its sociocultural variation from the Western countries where they originate. In any case there is a policy and practice gap which results in policy and guidelines being variably implemented globally (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). The findings of that study indicate that the counsellors are well aware of the importance of the 3Cs but the challenge of implementing these principles

force the counsellors to make adjustments when implementing the HIV testing policies. For example, counsellors faced the challenge of time, space and large queues of patients which affected how the counselling sessions unfolded. The counsellors are caught between strictly following the guidelines on the one hand and the reality of the situation on the ground on which application of the guidelines as packaged would be inappropriate at least from their perspectives (Angotti, 2010).

It would appear that recommendations about counselling are difficult to implement as it were in the African context in view of the existing norms of patient provider interaction, cultural expectations about expressing oneself and complexities of empowerment during counselling. However, far and beyond the challenge of translating recommendations about counselling within the pre-existing sociocultural environment, is the challenge of managing a difficult interaction that constitutes discussions about sex and death.

3.4.3 Managing difficult interactions

Counselling within PITC is complicated by discussions about issues considered a taboo in a number of environments particularly in the Sub-Saharan Africa region. In the African context, communication in HIV/AIDS presents a complex picture in light of the stigma and discrimination related to the disease and its direct association with matters concerning sex and death. Historical secrecy and ambivalence about overtly talking about matters of sexuality and, by extension, matters about HIV is still present in community and health care settings (Wood & Lambert, 2008). The PITC testing consultation is expected to contain information on risky sexual

behaviour, behaviour change, HIV transmission and prevention (National AIDS and STD Control Programme, 2010; WHO/UNAIDS, 2007). The counsellors and patients are faced with two competing repertories in the interaction: an institutionalised long tradition of not openly communicating about sex and HIV on the one hand and the policy recommendations of openly talking about these taboo topics. It is evidence of how the counsellors and patients are able to manage the difficult interaction and communication in this situation that is of interest in light of my research study.

The nature of HIV transmission and course of the infection guarantees that sex and the prospect of death become central to the provider-counsellor communication during the routine HIV testing consultation. Additionally, in the event of a positive test result the consultation requires/leads on to the breaking of bad news: a process that is difficult for both the patient and provider.

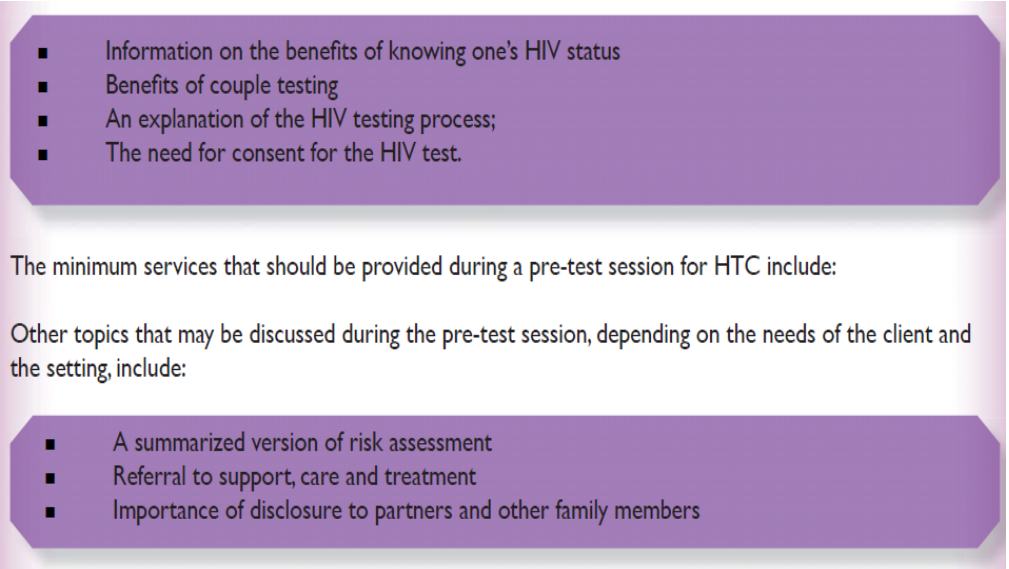
3.4.3.1 Navigating around taboo subjects

The information shared during the counselling session is sensitive because it centres on a patient's personal sexual behaviour - a topic considered a taboo in the African context. Wood & Lambert, (2008) in their study on the use of coded language in the context of HIV in South Africa examine the concept of the ''logic of linguistic avoidance'. They propose that in some settings avoiding talk about an issue is used as a means of dealing with taboo topics. Talking about a taboo topic is perceived as acceptance and tolerance of the frowned upon behaviour. For example, openly talking about risky sexual behaviour may mean one is engaging in it and

accepting negative consequences associated with the unacceptable behaviour. It is therefore expected that one maintains a verbal distance from taboo matters. The researchers therefore further argue that avoidance and denial of risky behaviour is not a mark of ignorance but a reflection of the underlying complex relationship between talk, experience and practice.

Metaphoric language has been a key feature in health promotion messages in Kenya where sexual transmission of HIV is implied using coded language and euphemisms. For example phrases like 'side arrangement" (*mpango wa kando*) are used to infer multiple sexual partners. Indeed, a recent attempt to make an explicit health promotion message led to a public outcry that led to withdrawal of a condom use campaign using the context of an extramarital affair (Mosoba, 2013). The public's notion was that the explicit health message on condom use encouraged immorality by explicitly asking people with multiple sexual partners to practice safe sex to protect their loved ones.

As things stand in the HIV situation, it is impossible to talk about HIV without making reference to sexual behaviour and in particular risky sexual behaviour. Yet sexual behaviours, risky or otherwise, are a personal matter that is considered private. At the time of this study, the Kenyan testing guidelines identified risk assessment during pre test counselling and behaviour change information during post test counselling as vital to the testing process (National AIDS and STD Control Programme, 2010). The requirements for pre test information at the time of data collection are illustrated in the figure below.



(National AIDS and STD Control Programme, 2008, p. 15)

Figure 5: Requirements of the pre test information session

A failure to directly talk about sex prevents the exploration of risky behaviour. A personalised risk reduction assessment which consists of an exploration of a person's sexual behaviour is a critical component of routine HIV testing and counselling. This information is critical to the establishment of a client centred behaviour change communication. The Kenyan PITC training manual for counsellors briefly makes reference to the discomfort inherent in talking about sexuality and asks counsellors to be comfortable with talking about sexual behaviour and using sexual words (National AIDS and STD Control Programme, 2007a). The scant attention given to the difficulty associated with addressing sexual matters during PITC training does not match the enormity of the difficulty revealed in the literature reviewed.

Breaking [bad] news of the HIV diagnosis is another difficult subject matter that is expected to take place during the PITC consultation. The difficulty of breaking bad news was reported in a study carried out in the US using ethnographic observations of consultations and interviews with palliative care team practitioners (Wittenberg-Lyles, Goldsmith, Sanchez-Reilly, & Ragan, 2008). This study, whose aim was to understand communication protocols in terminal prognosis disclosures, found that the process of breaking bad news is an uncertain one. Moreover, it is difficult for a provider to anticipate how a patient will react to bad news. Often the provider is unaware at the commencement of a consultation whether the consultation will end up with the delivery of bad news. The authors conclude that there is need to improve medical training on communication and provide a better link between the practice of communication and the environment communication is taking place in (Wittenberg-Lyles et al., 2008).

Gillotti, Thompson, and McNeilis (2002) in a study carried out in the US among medical students using video recorded interactions with simulated patients; found that communication of bad news requires different skills from those required in everyday communication in the health care setting. For instance, breaking bad news does not require copious amounts of information since patients may have a difficult time making sense of it in light of the difficult news delivered. However, this study was done using simulated patients and may not necessarily represent the real picture of patients receiving bad news. Even so it does suggest that health care providers need to be aware of the uniqueness of communicating bad news to patients.

In spite of this, the PITC training manual does not specifically address unique skills that the counsellor should have in order to facilitate breaking news about the HIV test results (National AIDS and STD Control Programme, 2007a). It only addresses the responses one would expect from a patient following disclosure of a HIV positive diagnosis but not necessarily the key strategies and skills a counsellor would use to break bad news. In addition the training manual and orientation package do not address the emotional support component of breaking bad news (National AIDS and STD Control Programme, 2007d, 2007i). Instead the focus is on communicating the test results and referral for follow up care. A summary of recommended information to be shared during the PITC counselling session is included in figure six below (National AIDS and STD Control Programme, 2007d, p. 23)

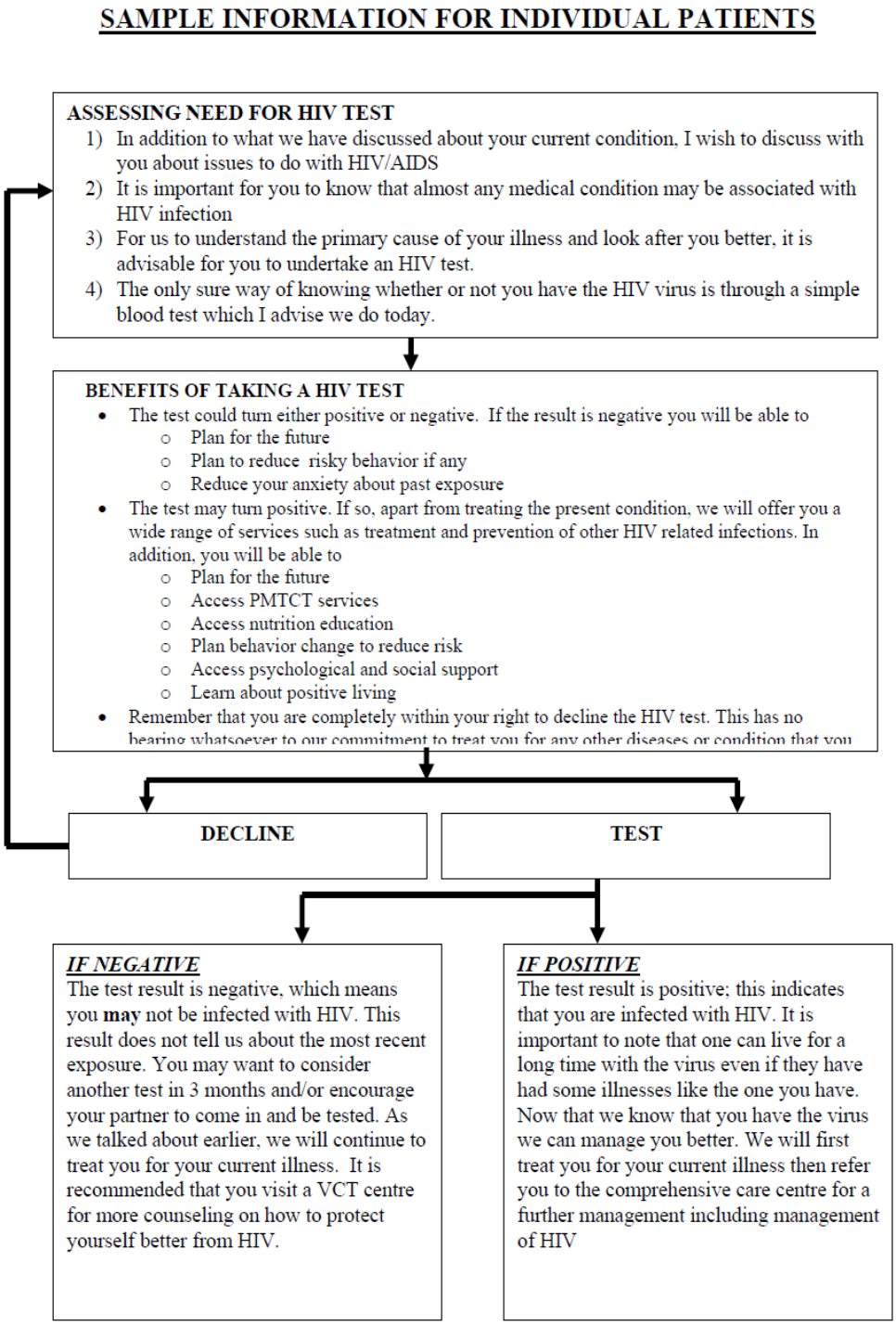


Figure 6: Sample information for individual patients

The above diagram suggests a training and practice gap in appropriate skills to facilitate communication of HIV positive results and the emotional support patients require following this disclosure. A systematic review of qualitative studies exploring nurse and midwife views and experiences of the provision and management of PITC found that all nurses in all contexts reported giving of HIV results as being stressful (Evans et al., 2016). The authors suggest additional training to empower nurses to deal with appropriate strategies to disclose HIV results to patients.

Breaking news is further challenged in this environment by the meanings attached to a HIV positive diagnosis. Disclosure of a HIV positive diagnosis is laden with a message of impending death that has characterized lay perceptions about HIV/AIDS (Nguyen, 2013). Death is itself a taboo subject matter particularly seeing that death is often linked with punishment for wrong doing in African settings. This occurs against a back drop of blame and culpability that accompanies a HIV positive diagnosis making breaking bad news a difficult task. Further on, a HIV positive diagnosis is associated with unacceptable immoral behavior. This was reported in a qualitative study carried out in Uganda using indepth interviews to examine experiences of pregnant women receiving routine HIV counselling and testing (Rujumba et al., 2013). In that study, participants associated a HIV positive diagnosis with betrayal and infidelity of their sexual partners whilst a HIV negative diagnosis was evidence of faithfulness of a sexual partner. At the same time participants in that study had concerns about their future survival and care and support for their children in the long term. In that case there is a likelihood that on receiving a HIV positive diagnosis, the patients may have concerns beyond

their physical wellbeing. This is suggestive of the complexity of patients' needs at the time of breaking news about the HIV diagnosis whether the diagnosis is positive or negative.

The PITC policy recommendations expect that the focus of the counselling session should be post test counselling after breaking of the [bad] news (WHO, 2012h, 2015; WHO/UNAIDS, 2007). The detailed post test counselling is only recommended for patients who receive a HIV positive diagnosis. Patients who receive a HIV negative diagnosis may not have adequate time to explore avenues for HIV prevention. In any case there are instances of patients doubting a HIV negative diagnosis (Rujumba et al., 2013). In such a situation patients may continue to expose themselves to risky situations since they are under the assumption that they are HIV positive (and not negative as suggested by the test results): putting themselves at risk of getting infected. Besides, they may not benefit from a detailed post test counselling on HIV prevention and behaviour change thus presenting missed opportunities for expansion of HIV prevention.

Following on the discussion about some patients' doubt about their HIV test negative results, there have been reports of patients doubting their HIV positive results (Rujumba et al., 2013). Doubt of a HIV positive diagnosis is linked to low risk perception: a key finding in light of the recent recommendations to remove risk assessment from the pre test information session during PITC (WHO, 2015). Failure to acknowledge a HIV positive diagnosis is likely to impact negatively on the uptake of services and result in poor linkages to care. Therefore, counselling during PITC has a key impact on HIV prevention and uptake of services. Hence it

is important to examine the practice of counselling in light of the changes that have been recommended with PITC approach to HIV testing and how this affects the practice of consent.

3.5 The question of choice

In the first chapters of this chapter, debates surrounding the issue of informed consent within PITC have been introduced. The concerns have been that with the implementation of an opt-out approach to HIV testing, patients' rights to informed consent may be violated as a result of coercive practices.

This section seeks to unmask the complexities and dynamics of consent drawing mainly from research carried out in antenatal settings where PITC has been carried for a longer time. In addition it illuminates the effect of the contextual translation of ethical principles in influencing how counsellors and patients obtain or fail to obtain consent during PITC. Further on, it demonstrates the tension that exists between PITC recommendations that are based on patient centered care and the health care providers' inherent professional obligation to ensure patients maximize the benefits of HIV testing. Prior to engaging in this discussion, the section first lays out the nature of consent in the Kenyan context, albeit to set the scene for consideration of some of the complexities posed by sociocultural norms in this environment. It then explores the complexity of choice using the classic work of Mol (2008) to illustrate the challenge of judging the quality of the patient provider interaction on the patients' ability to make an autonomous informed consent. The section then proceeds to examine informed consent within PITC in various settings

to highlight the complex terrain in which informed consent recommendations are implemented.

3.5.1 Logic of choice versus logic of care

Choice in HIV testing has been a thorny issue characterized by marked efforts to protect persons who are vulnerable to stigma and discrimination during and after the HIV test. Policy and guideline documents emphasize the need to maintain autonomy and volition during PITC to allow patients the freedom to opt-out of an HIV test offer. However, there are counterarguments that see the notion of an independent and empowering process of choice as unfeasible. This subsection presents theoretical discussions about consent. It begins by looking into the global concerns and then situate the reality of consent in the Kenyan context by exploring research on informed consent in research settings. Finally consent within PITC is addressed in light of the complexities of informed consent globally and in Kenya.

Choice has been framed within a consumerism approach that views individuals as targets to whom particular technologies and knowledge are sold (Mol, 2008). Central to the consumerism approach is individualistic consumer choice, empowerment and information provision. Choice and decision making are seen to be defining characteristics of self-determination and autonomy that are very highly valued within Western cultures. It is presumed that information empowers a person to consider options present in order to make a decision (Mol, 2008). However, this may have less relevance in the Kenyan context despite the fact that policy recommendations are modelled on these Western constructs of consent.

Consent in the Kenyan situation is discussed in details in section 3.5.2. Mol (2008) refers to this Western approach to decision making as logic of choice where information is perceived to be neutral and on receiving it patients are able to consider the information objectively and make a unidirectional rational choice. Further, the logic of choice model views information as growing in certainty and something that is distinct from individuals' emotions and values.

In contrast to this, Mol (2008) argues that in real life situations emotions, values and previous experiences are part and parcel of health care relationships which in one way or another affect the information shared and the subsequent decision made. Mol (2008) refers to this as logic of care. Logic of care attends to all aspects of life of a person living with a disease such as day to day life and people around the patient's life such as family and friends. These real life situations are unpredictable and may not always be reflective of scientific information that dwells on certainty. The goal of practice should therefore be to make sense of this murky 'world' rather than focus on bringing 'order' to a patient's life (Mol, 2008). For example, the choice of whether to test or not may be compounded by negative perceptions about HIV which may hinder patient's uptake of HTC. The appropriate process of consent may not necessarily be one that places this burden on the patient who will never be able to make an independent choice. Consequently, counsellors may feel obligated to 'push' patients to test and frame the HIV test as a requirement rather than a choice to increase uptake of HTC (Vernooij & Hardon, 2013). See section 3.5.4 for further discussion on health care providers driving their own agendas. This mirrors the informed consent situation in research settings in Kenya as

discussed below where the decision making process is not just confined to the information given but also includes a consideration of other factors such as maintaining social relationships with significant others (Kamuya et al., 2015; Kamuya et al., 2013).

Charles, Whelan, Gafni, Reyno, and Redko (1998) in an exploratory study illustrated how women with early stage breast cancer in Canada reconstructed the scientific information shared during the decision making process. Patients worked hard to make sense of the scientific information given by transforming it to their own terms based on their experiences and observations of other patients in the community who had either survived or died from cancer. In the end, patients made a value laden choice rather than a rational choice devoid of their own experiences and emotions (Charles et al., 1998). The researchers, argue that a rational actor decision making model (logic of choice) is not feasible. In this model, the doctor shares scientific information with patients, who are in turn expected to understand the information objectively and subsequently use this objective information to make a rational choice (Charles et al., 1998). The researchers instead developed an interpretive model to decision making (logic of care) which postulates that after the doctor provides information, patients transform the information received, giving it a personal meaning and interpretation. They conclude that this interpretive model is reflective of real clinical interactions since it recognizes the meanings which lay individuals attach to information about treatment benefits and risks and the way they make sense of these information and how this reconstructed information affects the choices they make (Charles et al., 1998).

Mol (2008) discusses the challenges of logic of choice to the individual. Firstly, choice implies responsibility for consequences that follow the decision a patient makes: leading to apprehension about whether the decision one makes is right or wrong and fear of one being blamed for the consequences of the choices they make. In contrast logic of care does not apportion responsibility (blame) for individual choices but rather acknowledges that patients may not want to take responsibility for their choices. Further on, they may not be in a position to make a decision particularly if they are sick or the choice they are required to make is too difficult (Mol, 2008).

Secondly, the nature of the patient provider interaction means that whilst clear recommendations of what should happen are given, in practice these recommendations may be difficult to implement. For example Charles et al. (1998) found that health care providers presented the decision at hand as treatment versus no treatment rather than two treatment options. In doing so the providers 'eased' the patients into choosing the treatment option. Subsequently, patients felt that deciding not take up the [only] treatment option offered to them was tantamount to not making a choice at all (Charles et al., 1998). Hence providers 'influenced' the patients to make a particular decision that they felt was in line with what health providers felt was appropriate for the patient. This is in fitting with the earlier discussions in section 3.4.1 that indicate that the patient provider interaction is often an asymmetrical one and the patients' are often not empowered.

Thirdly, Mol (2008) infers that patients often cannot make an independent choice because of the influence of external factors on the process of informed choice. She gives the example of a diabetic patient who, during a consultation, chooses to modify her diet as advised. However, this choice becomes difficult to uphold because the patient belongs to a family that frequently eats out: a situation that dilutes the patient's resolve to uphold her initial choice (Mol, 2008). This shows that informed choice is not solely an individual's choice as put forth by a medical model (logic of choice) but is rather a product of various factors within and outside the individual making a choice.

Similar findings are reported by Henwood, Harris, and Spoel (2011) in an analysis of how people make sense of decisions about healthy living. The authors found that choices about healthy living are not always individualized and rational but a rather complicated process that is uncertain, anxiety provoking and interdependent on other people's experiences (Henwood et al., 2011). The analysis concludes that in order for efforts to promote healthy living to be successful, policies must focus on logic of care that is cognizant of the fluidity of the process of choice.

Mol (2008) focuses on choice in a non-communicable disease whilst the study focus of this thesis is a transmissible disease. Informed consent in a non-communicable disease focuses on individual choices that do not necessarily affect the general population. However, informed consent in PITC introduces a different perspective: it deals with a transmissible disease whose prevention of spread is of public health importance. A decrease in HIV prevalence and prevention of new infections in the general

population is largely achievable through expansion of HIV testing by individuals. This presents a delicate balance between individual's rights to informed choice and the common good (collective responsibility) that comes with an individual choosing to take up a routine HIV test offer. Collective responsibility refers to the overall benefits to the general population (public health benefits) that are achieved by individual choices (Bayer & Fairchild, 2004).

The challenge of balancing individual rights versus collective responsibility in a communicable disease is echoed in an exploration of consent procedures of influenza vaccination in a nursing home in Netherlands (Verweij, 2001). The author who uses the phrase 'tacit consent' to infer an opt out approach to consent, argues that influenza vaccination of individuals provides collective advantages to residents in a nursing home by providing herd immunity to the most vulnerable. He concludes that whereas approaches to consent that drive the common good may be considered a violation of consent procedures as prescribed; there are strong arguments for the common good that renders this 'violation' acceptable in some situations.

Unlike influenza, HIV has been perceived as a sensitive disease in which stigma and discrimination and potential for infringement of human rights has been of concern. For this reason the PITC policy recommendations appear to emphasis the voluntary nature of the HIV test whilst at the same time reducing the bureaucratic processes that are associated with informed consent that have been seen as a barrier to expansion of HIV testing. Indeed WHO (2015, p. 10) emphasizes that consent must be

informed by pre test information during which patients must be made aware of the HIV testing process and of their right to decline testing. However, as the logic of care narrative suggests, this information is likely to be given and received through the lens of existing perceptions about HIV and the perceived negative consequences of receiving a HIV positive diagnosis. Mol (2008) infers that caring is not about separating scientific information from values but rather 'doctoring' the scientific information to make decision making as practical as possible within a real life patient provider interaction. My study seeks to explore how patients and providers co-construct consent within the murky world of HIV and the meanings attached to a HIV positive diagnosis within the Kenyan context. It is therefore important to understand the intricacies of the consent situation in Kenya and how difficult it is to draw on the Western narrative of independence, self-determination and empowering consent process.

3.5.2 Consent in the Kenyan situation

Lessons about the complexities and dynamics of informed choice in Kenya are drawn from an extensive body of research carried out at the Kenyan coastal region exploring consent in research situations (Kamuya et al., 2015; Kamuya et al., 2013; Marsh, Kamuya, Mlamba, Williams, & Molyneux, 2010; Molyneux, Wassenaar, Peshu, & Marsh, 2005; Okello et al., 2013). Whilst informed consent in these studies is examined in the realm of research situations, there are key lessons one can draw from them to illustrate the complex sociocultural context of the consent situation in Kenya. These studies are explored in this section.

Kamuya et al. (2015) used participant observations, focus groups and indepth interviews with various stakeholders to explore the idea of silent refusals in a situation where participants showed interest in the research project but kept postponing their participation for various reasons. The study reports that this occurred in instances where research participants did not want to overtly decline the offer to participate in the research study. The reasons for this were mainly: the need to maintain relationships with the field workers; avoidance of conflict within the family and the need to ensure one continued receiving benefits associated with the research study. Kamuya et al. (2015) infer that consent is a process that is imbued within the existing social relationships. Therefore, the process of consenting for research participants is not just about weighing risks and benefits of engaging in the research study, but also about maintaining relationships with family members, field workers and providers (Kamuya et al., 2015). The study reports that this challenge was dealt with by training the field workers to be cognizant of silent refusals, increasing the amount of time spent during the process of obtaining consent and ensuring supervision of field workers involved in the informed consent process. These strategies are indicative of the importance of training and supervision of persons involved in obtaining informed consent. Notably, this may require funding which may be a problem in public health facilities that are often resource constrained unlike the funded projects whose findings have been considered above.

Another study using quantitative and qualitative content analysis of documents, illustrated how informed consent is translated by the field workers (Marsh et al., 2010). The study showed that field workers did not

always use the provided guidelines / checklists since they perceived the information required as lengthy and unimportant. Consequently, the field workers used their own explanations in place of what was in the guidelines. On the other hand, the field workers perceived that the success of their work was based on a high number of participants accepting to take part in a research study. Hence, reluctance to engage in research or failure to understand information provided was met with frustration by the field workers (Marsh et al., 2010). The findings of this research suggest that guidelines about consent are translated by the providers to suit the local context. Of particular importance, is the finding showing that success of practice is pegged on the number of participants consenting to the research project rather than the quality of the informed consent process.

Power differences affect informed consent and the ability of an individual to feel free to dissent (Okello et al., 2013). Okello et al. (2013) used a qualitative study approach (focus groups and observation) to investigate the acceptability of a randomized control trial among parents, children and teachers in a school based project. The researchers found that parents often felt pressured to consent perhaps due to the fact that consent was obtained during group meetings and home visits. Use of individual one to one information giving sessions were seen a means of overcoming this barrier as this would lead to greater understanding and reduce potential influence from other parents (Okello et al., 2013).

Okello et al. (2013) found that the teachers in that study felt that they had little room to decline the request to participate in the research study. This was because their superiors, who were gate keepers, had already given

permission for the research study to be carried out. Likewise, the gatekeepers reported that once they have given permission for the study to take place in the schools, the teachers were not required to give individual consent. In line with this, the teachers felt that dissent to participate would be construed as insubordination to the superiors. For this reason, no teacher overtly declined to participate in the study. However, there were a few instances of silent refusal which acted as a mask for genuine dissent in light of the aforementioned issues among the teachers and their superiors (Okello et al., 2013). This study illustrates the hierarchical nature of relationships in this context and how much these relationships affect an individual's ability to freely make a choice in spite of the information offered.

Information giving is important in the course of obtaining informed consent to ensure that participants have an understanding about the processes involved. In HIV testing, it is expected that patients are given brief information about HIV testing prior to being offered a HIV test. The assumption therein being that the information offered is value free and objectively understood A qualitative research study aimed at investigating community understanding and perceptions of a malaria vaccine trial at the Kenyan Coast found that the relationships between the researchers and community members were key determinants of whether a participant accepted or declined participating in a research study (Gikonyo, Bejon, Marsh, & Molyneux, 2008). The study reported that offering information about a study on different occasions before seeking consent was deemed as important in the decision making process. Further on, there are context specific concerns that may be difficult to address within the remit of the

study period that may arise such as intra-community conflicts which may result in negative rumors about a research study. Such factors may not be accounted for in policy documents and recommendations about informed consent. The study concludes that whilst there is a move towards more stringent informed consent processes, these processes may not be responsive to the complexities of consent in the local communities (Gikonyo et al., 2008). They further suggest that guidelines need to be conscious of the unpredictable and fluid ethical dilemmas associated with research on the ground (Gikonyo et al., 2008).

The studies explored in this section highlight the effect of sociocultural norms on informed consent. In addition, they suggest that the process of obtaining consent from an individual is likely to be influenced by external factors such as social relationships. Consequently, individuals in this context may not take into consideration the information given when making a decision but rather focus on other factors which they deem more important. At the same time the studies suggest that people may not be in a position to overtly decline participation hence they are likely to use silent refusal strategies e.g. postponing participation in a research study or refusing to engage during the HIV testing process in order to maintain social relationships hierarchy and avoid conflict. The studies also suggest that in the process of implementing guidelines and protocols about informed consent, providers may translate and adapt them to what they perceive as being relevant to the context they are working in. As we will see below, a number of these issues are reflected in the process of informed consent within health care consultations particularly during HIV testing.

3.5.3 The issue of choice within PITC

Historically, informed choice has been central in ensuring that autonomy is maintained during HIV testing. Autonomy[11] to make decisions in HIV was considered particularly important in the 1980s and early 1990s when HIV was predominantly an infection of marginalised groups and when treatment was limited (Bayer & Edington, 2009). Initial debates about the ethics of HIV testing occurred within an environment of fear of stigma, exclusion and helplessness where knowing your HIV status did not lead to clinical benefits or improved wellbeing. Whilst this situation has somewhat changed recently, where biomedical, but not necessarily social, benefits of early diagnosis and prompt treatment abound, the previous concerns about patient autonomy in HIV testing still prevail.

The current effort to curb the ever raising HIV prevalence through routine HIV testing has led to substantial debates on how the PITC policy ensures that informed consent is maintained (Bennett, 2007; Csete & Elliott, 2006). The HIV testing practices are continuously geared towards routinizing the HIV test and as such reducing the stringent and lengthy testing process. Routinizing the HIV test is expected to normalize the HIV test just like other medical tests that are done using an opt-out approach (April, 2010; Bayer & Fairchild, 2006). It is argued that distinguishing the HIV testing process contributes to HIV exceptionalism and fuels stigma of the disease (Bayer & Fairchild, 2006).

[11] Autonomy in HIV was initially viewed in a context where those infected were largely marginalized groups such as homosexuals who were likely to be ostracized by virtue of belonging to certain groups. Consequently, these individuals' human rights were considered at risk even without the consideration of a HIV positive diagnosis in a situation where treatment was not available and the disease was highly stigmatized.

The WHO policy reiterates that PITC does not equate to denying patients a right to choose. In the place of the elaborate informed consent procedures of previous HIV testing models, the policy makes reference to 'minimum information for consent' (WHO/UNAIDS, 2007). The policy further elaborates that counsellors must inform the patient that s/he has a right to decline the test and that declining the test will not affect the patient's access to health services. The Kenyan routine testing policy echoes the WHO guideline by accentuating informed consent as a means of protecting patients from coercive HIV testing and 'guaranteeing' that the patient's right to choose is respected (Government of Kenya, 2006; National AIDS and STD Control Programme, 2010). The opt-out approach in PITC is seen as a strategy in reducing HIV exceptionalism by treating the HIV test just like any other clinical diagnostic test (De Cock et al., 2006; Obermeyer et al., 2012; Obermeyer & Osborn, 2007). I will now focus on a theoretical exploration of consent drawing on some of the issues that arise from the PITC policy recommendations.

Bayer and Edington (2009) have examined HIV testing vis-à-vis HIV testing policy and human rights issues and suggest that the 'opt-out' approach provides the patient with an 'informed right to refuse' as opposed to 'informed right to consent' (Bayer & Edington, 2009). A right to refuse approach, they argue, makes it difficult for the patient to say no as it is implemented with the objective of ensuring as many patients as possible go along with the HIV test once it is offered. Although their theoretical paper did not draw on any studies carried out on HIV testing consultations, it delineates the unique situation of informed consent within the PITC policy created by the opt-out approach. Nonetheless, this does

not differ from other medical tests that a clinician would offer patients. Even so, consent during PITC is complex since the decision to take up a HIV test or not is, unlike in other medical tests, confounded by other sociocultural issues (Obermeyer, Bott, et al., 2013). These include fear of stigma, a perception of being at low risk for HIV infection and the acceptance of male partner's permission to allow a woman to have a HIV test among others.

Research studies in various African settings expose the blurred boundaries between opting out and mandatory testing. In a mixed method study on consent concerns in Kenya during PITC in an antenatal setting, the researchers found that patients felt they could not decline HIV testing because they thought that if they did, further care would be withdrawn (Njeru et al., 2011). Furthermore, the patients interpreted the routine HIV test as mandatory and not optional. Another study conducted in an antenatal setting in Malawi found that routine testing was perceived as both compulsory and the only way to receive antenatal care (Angotti et al., 2011). Although both studies were carried out in an antenatal setting, the former study included a 50% male sample and hence had a mixed gender sample similar to the one in my research study. One can therefore postulate that offering the HIV test in the course of seeking treatment blurs the distinction between the HIV test and the treatment process that the patient is receiving in the health facility. Further exploration of studies demonstrating the coercive nature of the consent process is done in section 3.5.4 below.

Roberts (2002) in a theoretical examination of informed consent and the capacity for voluntarism, identifies illness-related considerations as a critical external pressure that influences informed consent and the capacity for voluntarism. She argues that physical illness alters the patient's priorities and impedes capacity to voice and reinforce his preferences. The presence of illness during the PITC process may therefore act as a constraining factor to obtaining informed consent. It may mar the patient's clarity on the situation presented before him impairing his ability to act autonomously by focusing on his illness rather than the PITC decision making process. However, if a patient is seeking treatment for ill health in a health facility, the provider may presume consent for undertaking all the relevant investigations to make a diagnosis.

There is likely to be diverse contextual interpretation of ethical principles associated with consent. A qualitative study carried out in Kenya to explore experiences of nurses with PITC found that nurses felt that it was their responsibility to ensure that patients tested (Evans & Ndirangu, 2011). Consequently, they interpreted a failure of a patient accepting a routine HIV test offer as a greater harm than accepting their ability to decline. Indeed nurses in that study reported applying strong pressure to 'force' patients to take up a HIV test. That study concluded that the process of interpreting PITC policy is complex and there was need for research exploring actual HIV testing practices and the patients' experiences with PITC in this context.

Similar findings were drawn from a systematic review which found that the majority of the studies reported the dilemmas faced by nurses in ensuring

that patients take up the routine HIV test offer (Evans et al., 2014, 2016). Consequently nurses used strategies to overcome low uptake such as repeated requests to test in subsequent hospital visits until the patient accepted to test (Evans et al., 2014, 2016). It would appear that the nurses felt obligated to ensure that as many patients as possible take up HIV testing so that they can maximize on clinical benefits of knowing their HIV status and receiving appropriate treatment. There is, therefore, a likelihood that this would impact on how the nurses framed the HIV test as explored in the section below.

3.5.4 Framing the HIV test 'choice': Organizational and contextual influences

Counsellors have to delicately balance public health and clinical benefits of testing with individual rights in the process of obtaining consent. Rennie & Behets, (2006) suggest that healthcare providers are trained to promote [public] health and hence they may unconsciously 'sell' public health benefits whilst down playing the rights of the individual to consent or negative aspects of testing HIV positive.

Cases of health providers driving their own agendas (maximizing clinical benefits) during counselling and attempting to influence the decision of the patient have been explored extensively by Silverman, (1987) in the context of a UK study of Downs syndrome. Silverman found that doctors used different types of discourse when communicating with parents of Down syndrome and normal children about heart disease. In the first case doctors tried to dissuade parents from choosing surgery while in the latter case they pushed the parents to have surgery. It was interesting to see

the way in which this was done. In parents with normal children the doctor medicalised heart disease and made it appear as though having surgery was the obvious choice leaving little room for the parents to decline. On the other hand, with parents of children with Down's syndrome the doctors de-medicalised heart disease and instead emphasised the social benefits of not having surgery and the negative effects of doing so. Therefore, through these different discourses the doctors were able to achieve high rates of heart surgery for normal children and very low rates for children with Down syndrome. In doing so, the doctors were able to maintain particular clinical policies. Similar situations have continued to be reported in research findings in the recent past. Pilnick (2008) found that discussions about Down's syndrome screening were designed in a way that required minimal acknowledgement from the patients rather than active patient decision making. This study concluded that presentation of information focusing on benefits of testing and being silent on or down playing the negative aspects of testing nudged patients into going along with the test.

This situation may also apply where health workers overtly employ strategies to maintain the policy of PITC in the clinical setting. In a US study by Sobo, Bowman, Halloran, Asch, Goetz, & Gifford, (2008), health workers were expected to offer a HIV test to patients who were at high risk of HIV infection based on their assessment. However, in order to overcome the challenges of being seen as judging and inevitably stigmatising the patient, health workers used unique ways of offering the HIV test. They offered the test to at risk patients by routinizing it and making it appear as something done routinely for all veterans or in some

cases presented as a requirement for all veterans. The providers made counselling and testing the norm rather than the exception hence increasing uptake. Even so this approach makes the patients who decline be seen as different and so reduces the freedom to say no.

Likewise, in antenatal settings, the possibility of not testing and opting out of the HIV test was downplayed in many instances focusing rather on the need to test for the good of the baby (Angotti et al., 2011; Musheke, Bond, et al., 2013; Rujumba et al., 2013; Vernooij & Hardon, 2013). Similarly, De Zulueta & Boulton (2007) found that the midwives framed the routine HIV test in antenatal settings as 'routine' and a formality that the patient had to go through without requiring choice. Although the latter study did not include an examination of the consultations, it identified that how the information is provided influences choice. This study concluded that presenting a test as one not requiring consent may result in the interpretation of the tests as mandatory. This situation is reflected in the PITC situation in African settings where health workers adopt the PITC policy to ensure uptake.

Angotti et al. (2011) carried out a study in rural Malawi to explore routine HIV testing among pregnant women in an antenatal clinic using qualitative methods. The study reported that not only did the participants view the HIV test as compulsory, they also thought that failure to accept the HIV test would result in denial of access of antenatal services. Further on, the women extended this compulsory testing to their husbands as well and asked them to accompany them to the antenatal clinic for a HIV test. Noteworthy, is the fact that some husbands who were not willing to be

tested did not decline explicitly. Rather they asked their wives to tell the health provider that they were working away in a different country and were therefore not available for the HIV test (Angotti et al., 2011). This can be explained by the cultural norms that exist in the African context in which one is expected to follow the health providers' directives and it is generally not acceptable for a patient to turn down a health provider and hence the deception. This is similar to the 'silent refusal' explored by Kamuya et al. (2015) in section 3.5.2 further above. The findings by Angotti et al. (2011) make a case for the need to have couple testing and counselling which facilitates the testing of men who either rarely accompany their wives during antenatal testing or who fail to adhere to requests to attend HTC once their women partners are tested. Couple counselling also plays a key role in disclosure between partners and facilitating adoption of HIV prevention behaviours between sexual partners (WHO, 2015).

An exploratory qualitative case study which examined everyday practices of HIV testing in an antenatal setting in Uganda revealed how health care providers interpreted the ethical principles recommended in the national guidelines (Vernooij & Hardon, 2013). The study found that the midwives felt that they were morally obligated to protect the unborn baby by ensuring that all mothers got tested. The providers felt that they were morally and professionally obligated to promote and adhere to public health goals of expansion of HTC and prevention of HIV transmission (Vernooij & Hardon, 2013). On the other hand, the mothers in the study looked up to the counsellors and did what they were asked to do without awareness that they could decline the HIV test. In that study there was no

particular instance when consent was obtained (Vernooij & Hardon, 2013). This situation denied the mother the option to opt out of the HIV test for her own reasons as consent was framed in the realm of positive outcomes for the unborn child.

A similar situation was reported in a qualitative study that set out to examine couple testing experiences with HIV testing in an antenatal setting in Zambia (Musheke, Bond, et al., 2013). Opt-out testing was not emphasized as the providers focused on the mother's and father's moral obligation to test for the good of the baby. Mothers reportedly felt that testing for the baby was a motivator for consenting for PITC. However, the fathers felt cornered and forced to test. Just like in the study reported above (Vernooij & Hardon, 2013), this study illustrated how the evolving moral and parental responsibility narrative in framing the routine HIV test offer deprived the couple of the opportunity to consider the decision of whether to test or not. Consequently, the recipients of care may be left feeling 'forced' to test and interpret the HIV test as mandatory and not a choice.

Obermeyer, Bott, et al. (2013) raises questions about the quality of consent which is affected by inadequate information about the right to decline and the fact that patients are not always given time to test. Arguably, and as illustrated in this section, the consent process is complex in environments where health providers have to balance the desire to provide patient centred care with ensuring patients have access to clinical benefits of HIV testing by 'enforcing' uptake of a HIV test offer. Indeed, framing biases within routine HIV testing may be influenced by the

counsellor's need to adhere to the PITC policy of increasing uptake of HIV tests. Moreover, the quality of their work may be judged on the basis of the number of patients who have been tested and not necessarily the quality of the counselling and the informed consent process (Buskens & Jaffe, 2008; Evans & Ndirangu, 2011; Rohleder & Schwartz, 2005). Hence, counsellors may feel under pressure to ensure that clients accept a HIV test. This tension is reflective of the push and pull between ensuring patients' rights to consent and the factors that influence that process.

In sum, the framing of consent within PITC presents a tension between health workers' interpretation of guidelines and their perceived moral and professional responsibility to ensure patients maximize the clinical benefits of taking up HTC. It seems that in the local context ethical principles of consent are translated within a complex web of what constitutes good care in various environments. It is thus suggestive that the information given during the health care interactions may be 'sieved' through this complex social terrain. This tension has been explicitly explored by Mol (2008) in her work on patients' choice in diabetes self-management as explored in the section 3.5.1.

3.6 Conclusion

The literature reviewed indicates that PITC is considered the main model in meeting missed opportunities for HIV testing in clinical settings. PITC presents an important and rare point of contact between the patient and the provider (counsellor) to address HIV prevention, care and support. This contact is significant because the counsellor is expected to explore the patient's risky behavior, as well as addressing their concerns and

emotional needs, provide health promotion information and refer to vital HIV services depending on the patient's HIV status and needs. The content that should be addressed during the PITC consultation is itself exceptional to HIV testing. There are also concerns about how informed consent and a difficult interaction that includes discussions on matters considered taboo is constructed and managed in PITC.

There is a general view that stigma in HIV still persists in spite of improvements in HIV treatment and widespread health promotion to counter act this. Evidence has highlighted the effect of stigma on hindering of uptake of HIV testing and services. There is, however, a lack of studies that have examined the impact of stigma on the PITC process itself, especially the implementation of consent and counselling. Furthermore, stigma is itself complex in how it is expressed and instigated, a process that has not been widely explored in diverse settings within the actual PITC process.

The tension between PITC recommendations about consent and counselling are widely explored. Reviewed literature suggests that in spite of recommendations in PITC guidelines, in the real practice world, providers adopt the recommendations to suit the complex context they work in. This valuable finding has largely been reported from PITC within antenatal settings with little or no studies focusing on real time consent and counselling in PITC other clinical settings. This is a significant gap especially with the normalization narrative that is geared towards integrating HIV testing and its services to existing health care services. A focus on social research on the actual process of HIV testing is

instrumental in informing key debates in the implementation of PITC in different contexts. Understanding how counsellors and patients navigate the PITC process within the existing tensions between PITC recommendations and the situation on the ground is the subject matter of this research study. The next chapter provides a discussion of the methodology used in this research study to address the gaps identified from the literature reviewed.

4 CHAPTER FOUR: METHODOLOGY

4.1 Introduction

The aim of this study was to examine how the core components of PITC (consent and counselling) are understood and enacted in everyday practice using normalization of HIV as a lens through which to understand and critique the HIV testing policy and practice. To achieve this aim, it was imperative to explore 'real time' patient provider interaction as well as patient and provider perceptions about HIV and their experiences with the PITC process. Due to the complex nature of HIV and the intricacies of enacting consent and counselling in diverse settings highlighted in the literature review, a qualitative research design using multiple data collection methods was adopted. These included pre test interviews with patients prior to the HIV test offer, observation and / or audio recording of the counselling session and post test interviews after the HIV test.

This chapter provides an overview of the methodological approach utilised in this research study. It begins with the aim and objectives of the research followed by a discussion of the philosophical underpinning for the study. A description of the study design including the sample, recruitment and data collection methods follows. Finally, the chapter ends with an outline of the data analysis techniques used and the ethical issues considered throughout this research study.

4.2 Research aim and objectives

This study aims to examine how the core components of PITC i.e. counselling and consent are understood, organized and implemented in

every day practice. It includes a particular focus on how the recommendations for high quality and ethical PITC are operationalized within the given social context. Towards this end the specific research objectives were:

1. To explore patients perspectives and understanding of HIV and HIV testing
2. To examine how patients' perceptions of HIV influence their communication and interaction with counsellors during the HIV testing consultation
3. To explore how the role of the counsellor is constructed by patients and health professionals, and how 'counselling' is performed during the PITC consultation
4. To explore how informed consent is understood by patients and counsellors, and how it is obtained during PITC

Using a social constructionist approach, this study began with an indepth examination of the patients perspectives about HIV and HIV testing using interviews prior to the PITC consultation. This was intended to appraise how existing sociocultural factors and perceptions about HIV shape PITC and, in particular, communication and interaction during the subsequent routine HIV testing consultation. The study then used observation and recording of the consultations to examine how patients and counsellors 'perform' counselling and co-construct informed consent. This also facilitated the exploration of how the patient and counsellor roles are constructed during the PITC consultation. Subsequently, indepth

interviews were carried out with the patients after the routine HIV test to elicit their perspective of the PITC consultation. Counsellors whose consultations had been examined were interviewed to provide their perspectives of the events of the PITC consultations. The link between the research objectives and methods is summarized in the figure below.

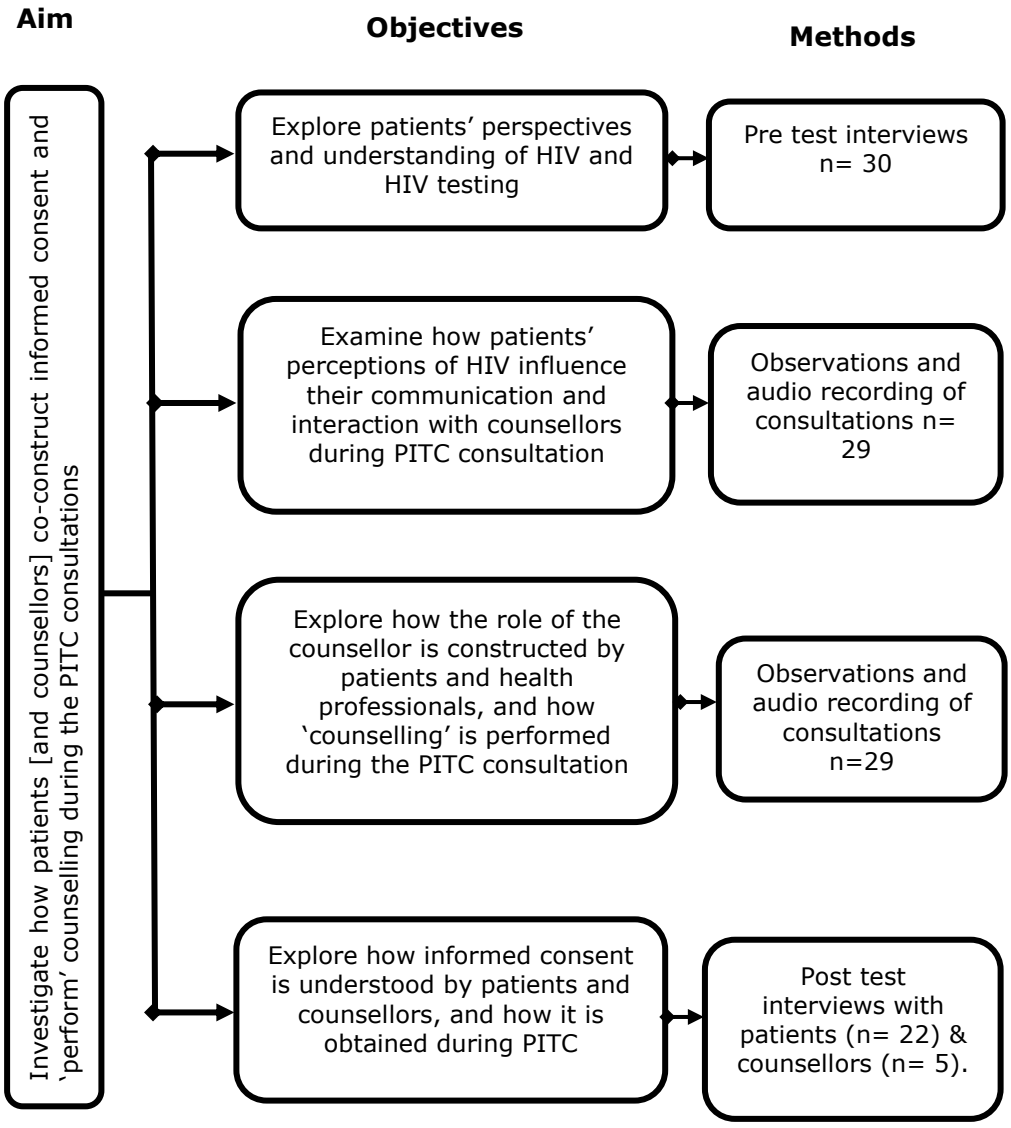


Figure 7: Summary of the aim, objectives and methods

The focus of the study was on how counselling and informed consent proceed in the Kenyan context in view of the sociocultural environment. For this reason, the methodology adopted for this study was one that would facilitate the uncovering of the deep sociocultural terrain in which PITC takes place in the Kenyan context. The philosophical underpinnings of this study are made in the choice of methodology for this research project, and are explored below.

4.3 Underpinning philosophy

The position adopted in understanding the social world depends on an individual's perspective of how the world can be experienced and understood. The methods used in a particular study are usually an expression of the underlying epistemological position which in turn shapes the research questions of a proposed study. This study stems from an epistemological and ontological principle that considers PITC as a socially constructed event and one in which those involved interpret the PITC recommendations within their social environment.

Epistemology is concerned with how knowledge is constructed and what counts as knowledge (Bryman, 2008). Over time, there have been different view-points on how knowledge can and should be generated which has predominantly included positivism on the one end and interpretivism on the other end (Benton & Craib, 2001; Hollis, 2008; Polit & Beck, 2014). Positivism, according to Bryman, (2008) has been defined in different ways although in a nutshell it can be taken as an epistemological position which advocates for the study of the social world using natural sciences methods. It is based on several principles such as

that knowledge is arrived at by the gathering of facts, the purpose of theory is to generate hypotheses that can be tested, science must be conducted objectively and that it is possible, through re-examining phenomena, to arrive at a single truth. According to positivists, these principles can be used in the study of phenomena, to produce a more refined access to reality and a set of knowledge of the social world. This position is strongly rejected by interpretivists.

Interpretivists argue that it is not possible to generate knowledge from the social world using positivist principles because knowledge is socially constructed and is thus dependent on other factors (e.g. cultural meanings of particular actions) that cannot be controlled in the same way as natural objects (Hollis, 2008). Hence there is a need to reflect on the distinctiveness of human beings as social actors. Unlike objects, human beings have a self-consciousness and are thus able to reflect on themselves and their situation (Benton & Craib, 2001). In the interpretivist view, therefore, knowledge as we know it is not a fixed entity but an understanding that is filtered through the lens of personal, social and cultural interpretations. Knowledge of the social world is viewed as being subjective and difficult to predict and shaped by the contextual dynamics which are variable. For example, this study postulates that the enactment of consent and counselling may differ in diverse contexts.

My epistemological position is an interpretive one: I believe that in order to understand a social encounter (in this case the routine HIV test); there is a need to be cognisant of the social and cultural dynamics affecting how it is experienced, understood and enacted. At the same time, knowledge

developed from studying this social world (PITC process) is to a lesser or greater extent filtered through personal and worldviews of the participants and the researcher. Accounts and understandings generated through an interpretive approach are co-constructed by the researcher and participant during the process of collecting data. For this reason engaging in a process of self-critical reflection (reflexivity) on how my role and my personal values may have affected the data collection and analysis was necessary (see sections 9.4 and 9.5).

Akin to the theory of knowledge and how knowledge should be studied, are ontological arguments about the nature and experience of being (Benton & Craib, 2001; Bryman, 2008). There are two ontological positions: objectivism and constructionism which are related to positivist and interpretivist epistemological stances respectively. Objectivism views social phenomena and their meaning as existing independent of social actors and thus having a reality of their own. In that case it is possible to have an objective reality since beliefs and values are dictated by a specific set of rules and regulations which are external to the individual (Bryman, 2008; Hollis, 2008).

On the other hand constructionism proposes that social phenomena are not only produced through social interaction but also go through a process of continuous revision by the individual (Bryman, 2008; Hollis, 2008). This means that a single phenomenon can have multiple realities which are fluid and likely to evolve depending on the situation at hand. A constructionist approach which reflects the interpretivist paradigm best suits my research objectives which begin on the premise that the PITC

process is by and large shaped by the social context. Additionally patient experiences with routine HIV testing may equally be unique and evolving depending on the context and their circumstances.

4.4 Study design

In view of my epistemological and ontological stand point and the research question of my study, a qualitative approach was most apt. Qualitative research focuses on understanding a phenomenon in its naturally occurring setting from the participants' view (Denzin & Lincoln, 2005; Polit & Beck, 2014). It aims to uncover the meaning individuals ascribe to a particular social and human problem (Creswell, 2009) and seeks to express events, actions, norms and values from the perspective of the people who are being studied (Bryman, 1988). It focuses on detail, tries to understand an idea within a given context and acknowledges and incorporates complexity (Bryman, 1988). Within qualitative research there are different approaches to how this meaning can be studied and understood. Hence there are different philosophical and theoretical underpinnings in qualitative research which are shaped by the phenomenon being examined and the researcher's own view of the phenomenon and the world (Creswell, 2009; Denzin & Lincoln, 2005; Hollis, 2008).

Due to the complexity of the issue under study and the need to draw on, and situate the issues within their existing contexts, the research adopted a qualitative approach combining interviews (before and after the HIV test) with observations and / or audio recording of the PITC consultation and interviews with counsellors whose sessions had been examined. I am

however, aware that different types of methods elicit different data and answer different questions (Murphy & Dingwall, 2003). Miller, (2002) suggests that it is possible to utilise different theoretical approaches to link analysed data from different methods while at the same time maintain the distinctive contribution and integrity of each perspective used. Further on, Seale C. (2000, p. 72) suggests that triangulation of methods can help deepen and enrich understanding of particular settings and events. Therefore, I chose to view my methodology as an association between different qualitative approaches each of which provided a different dimension of the phenomenon. A detailed discussion of the rationale for choice of data collection methods is in section 4.5 below

4.5 Data Collection

As mentioned above, this research study used several qualitative data collection methods. Data for each patient was drawn from pre and post test interviews, audio recorded and observed HIV testing consultations and reflection sessions and interviews with counsellors. The use of multiple methods, as Barry (2002) explains, allows the researcher to build a more realistic picture of the practice setting. In doing so, a researcher is able to present a more meaningful and realistic account of reality. The attendance to multiple realities in the study of medical consultations is depicted in a study of doctor – patient communication during GP consultations in the UK (Barry, 2002; Barry et al., 2000; Britten et al., 2000). The research methodology for this study (which has informed my study methodology), which is explained below, is extensively reported in Barry (2002). In that study, the researchers carried out interviews with patients, 0 to 4 days

before their consultation with the GP. This was then followed by audio recording of the consultation between the GP and the patient. Later on after the consultation, the researchers conducted interviews with the patients and GPs. In doing so the researchers in that study were able to attend to the multiple perspectives of the various players in the consultation. My study chose to adopt a similar methodological approach as illustrated below:

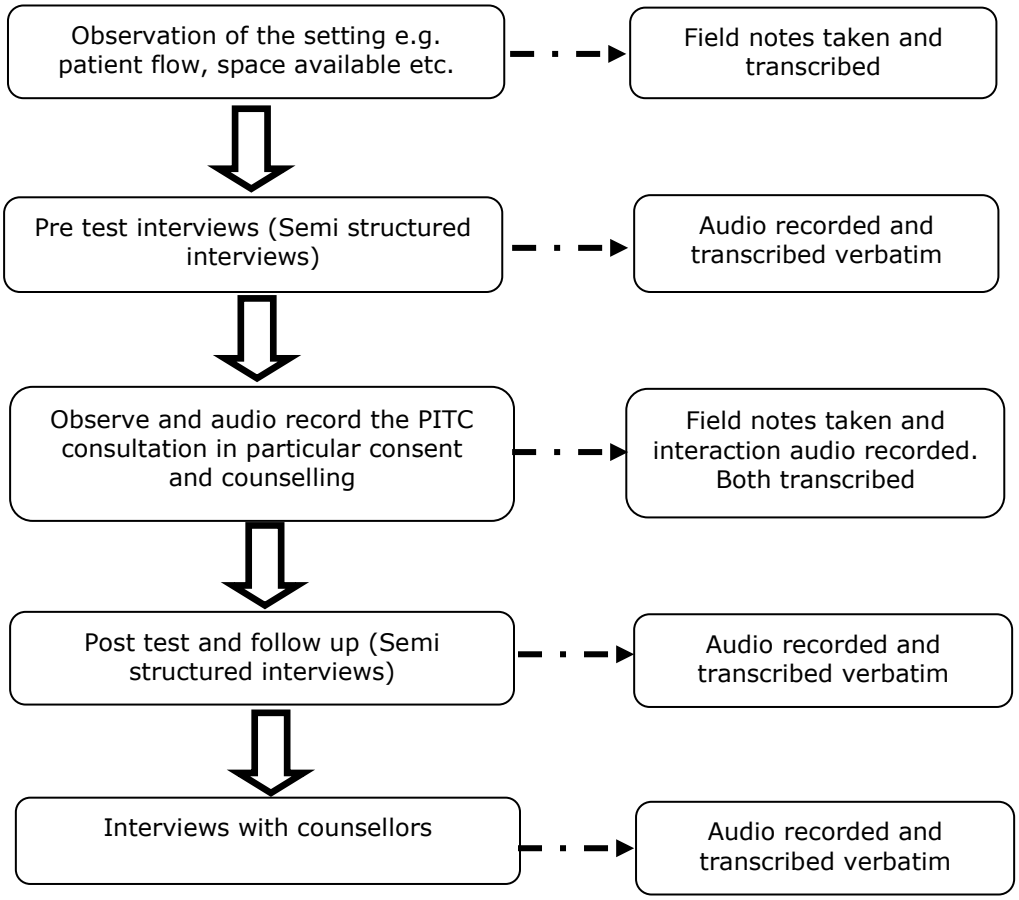


Figure 8: Procedure followed during data collection

In this section, I provide a discussion of the rationale for the choice of methods and include an exploration of the pros and cons of the selected methods.

4.5.1 Observations

Observations were used in this research study to examine the patient and counsellor interaction during the routine HIV testing consultation. The use of observations allowed the illumination of how patients and counsellors 'perform' counselling and co-construct informed consent within the context of normalization of HIV. This also facilitated the exploration of how the patient and counsellor roles are constructed during the PITC consultation. This was aimed at addressing the gap identified in the literature review that showed that there is a gap in social research examining how counsellors and patients adopt consent and counselling in the complex social environment.

Observational studies have their root in anthropology and ethnography where they were historically used as the ideal method to obtain information about different cultures and communities (Atkinson & Hammersley, 1994). This involved immersion in the social setting for an extended period of time with regular observation of people's behaviour. Observational methods not only provide information on people's behaviour but can also shed light on the normative rules or values of a particular culture through observation of the language and behaviour of its members (Bryman, 2008; Murphy & Dingwall, 2003). In my study observations provided a record of interactions between the counsellors and the patients

making it possible to identify and reconstruct patterns of action and the rules that organise the counselling and testing process (Miller, 2002).

Murphy & Dingwall (2003) note that an advantage of observations is inherent in the fact that data from observations result from a single transformation by the researcher in rendering the material suitable for analysis. In contrast, they argue that interviews result in multiple transformations whereby the researcher chooses what to ask and then the interviewee re-structures the response. Additionally observations provide valuable data on events, activities and behaviour which cannot be deduced through interviewing and analysing talk. However, observational methods are not without their limitations as explored below.

Observation studies have raised questions on validity and reliability related to the observer's role in the process. Firstly, even when the observer is a complete non-participant, s/he may influence the social setting by being present in it. Hence, I was cognisant of the fact that my presence during the counselling session may have influenced the consultation. Secondly, the observer has the potential to influence what to observe, what to record and how to analyse it. Arguably, one cannot study the social world without being part of it irrespective of the methodology used (Atkinson & Hammersley, 1994; Hammersley & Atkinson, 2005; Murphy & Dingwall, 2003; Silverman, 2006). All knowledge rests on a point of view which can be a mixture of the observer's prior knowledge, experience, values and motives (Murphy & Dingwall, 2003). The observer's account is always an interpreted construction of the unfolding events. The key is to maintain rigour through accurate documentation of the process, drawing links

between findings and existing research and critical reflection of how the research evolved and the researcher's role in gathering information and analysing results (Hammersley & Atkinson, 2005).

I dealt with the issues of validity and reliability of observations by going through a process of reflexivity regarding my role as a researcher in the process of collecting data. Additionally, I took detailed field notes that contain illustrations of what was happening to provide a reference point for analysis that was as accurate as possible (Silverman, 2006). Nevertheless, taking accurate and detailed field notes can be challenging in light of the many activities going on at the same time and the process of juggling between seeing, synthesising and writing down. It was difficult during the observation of the routine HIV testing consultation to pay attention to the nature of the unfolding talk and its content as well as the other activities going on at the same time. For this reason, audio recording of the patient-counsellor interaction was included in addition to the observations to capture the talk. Due consideration was given to carry out video recordings of the interactions. However, a preliminary field work prior to the data collection revealed a lot of reservations from counsellors from the study sites on use of videos. This was considered a major hindrance to the data collection process since the counsellors felt uncomfortable with video recording of the consultations. Therefore, video recordings were not included in the research.

Ethnomethodologists argue on the need to complement field notes with audio/video recordings to provide a concrete record of unfolding events and speech (Atkinson & Hammersley, 1994; Silverman, 2006).

Ethnomethodology "is a sociological perspective concerned with the way in which social order is accomplished through talk and interaction" (Bryman, 2008 p.693). In my study, audio recording of the interaction alongside doing observations and taking field notes, sufficiently tackled the problem of how to capture as much detail as possible during consultations. Observations allowed me to view the dynamics of the interaction, body language, emotions and other nonverbal cues. Audio recording also provided an avenue for further analysis of the discourses that were elicited during the interaction between the provider and the patient and a link between this and the wider sociocultural context. This was particularly important in trying to decipher how the counsellors and patients navigated the complexity of adopting the PITC recommendations about consent and counselling.

In this research project I drew on the strengths of the observations to examine the patient-counsellor interaction. At the same time, I dealt with the limitation of the observations' inability to elicit people's thoughts, views and explanations on events or behaviour by including post test interviews with the participants following the observed consultations. In doing so, I was able to address the gap identified in the literature where perspectives about the PITC process were mainly drawn from self-reports of counsellors and patients.

4.5.2 Interviews

Interviews were used to explore the patient's perspective both prior to and after the PITC HIV test as well as their experience over time i.e. the

outcome after one to three months of receiving a routine HIV test. Interviews were also used to explore the counsellors' perspectives of PITC.

Interviews are the most commonly used data collection method in qualitative research for a number of reasons. The ease of gathering a lot of information within a short duration of time, ability to gather a range of information, usefulness in eliciting people's experiences and ability to gather data which is not observable or where it is not possible to conduct observations (Bryman, 2008; Silverman, 2006). Qualitative interviews range from highly structured interviews where questions are asked in a particular order to unstructured interviews in which no specific set of questions is utilized (Silverman, 2006). This range represents a continuum in terms of the degree of control that the researcher wants to exact on the content and structure of the interview (Murphy & Dingwall, 2003). The decision on where to locate the interviews along this continuum should be determined by two factors: the research question and the existing knowledge on the topic (Murphy & Dingwall, 2003). Prior to my study, there was relatively little indepth exploration of patients' experiences with PITC in the Sub Saharan context. Therefore, semi structured interviews were adopted for this study.

Semi structured interviews are flexible allowing the interviewer the opportunity to pick up on things said by the participant as the interview unfolds, clarify issues during the interview and use prompts when need arises in the course of the interview (Bryman, 2008; Murphy & Dingwall, 2003; Silverman, 2006). In addition they leave room for the interviewee to raise additional issues which the researcher may not have thought of

prior to the data collection and not included in the interview guide. Allowing participants to talk about their own perceptions and accounts in my study promoted collection of rich data and uncovering of new dimensions, more so bearing in mind the probable divergent nature of experiences with HIV testing.

It is, however, worth noting that as a data collection method, interviews face a number of criticisms (Murphy & Dingwall, 2003; Silverman, 2006). First, there are questions about the informants' ability to recall events. Second, is the thorny issue of accuracy of interview data and the truthfulness of the respondents. A concern that is invalid from a constructionist perspective which views interviews as a process of eliciting facets of experience rather than 'accurate' descriptions of events. Third, respondents tend to alter their responses based on societal expectations and obligations including the need to portray a moral and socially acceptable image. However, from a constructionist position all interview accounts are representations and not descriptions of reality produced in a specific context and for specific purposes. Hence as Holstein & Gubrium (2002) suggest, I consciously attended to the interview data in ways that were sensitive to the social context especially in light of what else was going on during the routine HIV testing process. An account of how this was done in my study is included in the data analysis discussion in section 4.9.

The pros and cons of interviews and observations notwithstanding, utilization of both approaches to examine the patient-provider interaction enhanced a deeper understanding by allowing for exploration between

what the patients / counsellors did (or not) and what they said they did (or not). It was possible to relate the observations and the accounts of the patients and counsellors to achieve a deeper understanding of the consultation and the dynamics of the interaction between patients and counsellors. To demonstrate the rationale of using different approaches (observations and interviews) to examine communication and interaction, I will draw on two studies that aimed at examining the interaction between doctors and nurses (Allen, 1997; Svensson, 1996).

Svensson (1996) used interviews to examine nurses' role in the nurse-doctor interaction. From the interviews he found that nurses expressed how they exerted their position and constantly negotiated their roles with the doctors. Hence based on this, he concluded that nurses can influence interaction and norms in the hospital setting through negotiation. This was in contrast to previous findings which saw nurses as less assertive and hierarchically lower than the doctors. Conversely, Allen (1997) did a similar study but used interviews and observations. From the interviews Allen found that nurses reported their efforts to control their role. However, in contrast, on observation, she found that nurses rarely questioned what the doctor said or the roles delegated to them. Rather than discount the interview data as irrelevant or false, Allen sought to look at the deeper meaning in the milieu of the observation data. She viewed the nurses' interviews as a representation of an idealised moral order which the nurses were trying to depict.

Similarly, whilst interviews in my study provided patients' views and constructions of the events during the PITC consultation, incorporating

observations of the consultations provided further insight on the interaction. At the same time, the recorded interactions illuminated the discourses being drawn upon in routine HIV testing. This provided a second lens and allowed for a two prong view of the PITC consultation and, in particular, the co-construction of consent and counselling. Further on, it allowed for examination of how patients and counsellors constructed the consultation in light of existing norms of patient-provider interaction and the social meaning attached to HIV and its related issues.

4.6 Study setting

This study took place at HIV testing sites in two public health facilities (a District Hospital and a Health Centre) in my home town Nairobi, an urban town in Kenya. Kenya was selected for this study as it is the researcher's home country. Coincidentally, Kenya has been on the forefront in the implementation of HTC guidelines over time and was one of the initial countries to pilot PITC in clinical settings. The health facilities selected were within Nairobi for easy accessibility. The selection of government run public health facilities was driven by the fact that the majority of people receive health care services from these (Ministry of Health, 2011). Additionally, public health facilities often suffer from lack of resources and poor infrastructure which may influence the PITC process. Even so, approximately 80% of the Kenyan population lives in the rural areas and thus public run health facilities in urban centers may not represent the HIV testing services provided to the majority of the Kenyan population. This is particularly vital bearing in mind the urban – rural divide that exists in

Kenya (see section 2.3.1). Nonetheless, the selected study sites would provide useful insights into the PITC situation in the Kenyan context.

Mbagathi hospital is located next to Kibera, the largest slum in Africa. Therefore, its catchment population constitutes a large number of people who are underprivileged, with relatively low education levels and often either in short term unpredictable employment or unemployed. Historically Mbagathi was known as an infectious disease hospital (IDH) where persons with infectious diseases such as TB, measles, meningitis and leprosy were referred and treated. Later on, it was changed to a comprehensive health facility providing a myriad of in and outpatient health services. At the time of data collection, Mbagathi was a district hospital offering a range of services including curative outpatient and inpatient services, diagnostic services, maternal child health services, HIV testing and counselling and family planning among others. Mbagathi serves approximately 700 patients daily of which approximately 50% - 70% are receiving HIV care. The hospital relies on cost sharing except for maternity services (which were recently declared free) and HIV testing and ART services which are provided free.

HIV testing was done in several areas of the hospital: TB clinic, antenatal clinic, inpatient and outpatient departments. At the time of data collection Mbagathi had a total of six trained counsellors all of whom were nurse counsellors. At any given time there were two counsellors stationed at the outpatient area, one at the inpatient area and one at the TB clinic where they worked an 8-hour shift i.e. 8.00am – 4.00pm. On average each counsellor could test approximately 10 – 15 patients in a given day. When

there was shortage of nursing staff in the inpatient department, the counsellor on duty would be called in to assist with day to day clinical activities. Only five of the six counsellors' sessions were observed and audio recorded: two of these counsellors were later involved in the counsellor interviews[12]. The layout of the testing areas at the time of data collection is illustrated in the diagram below:

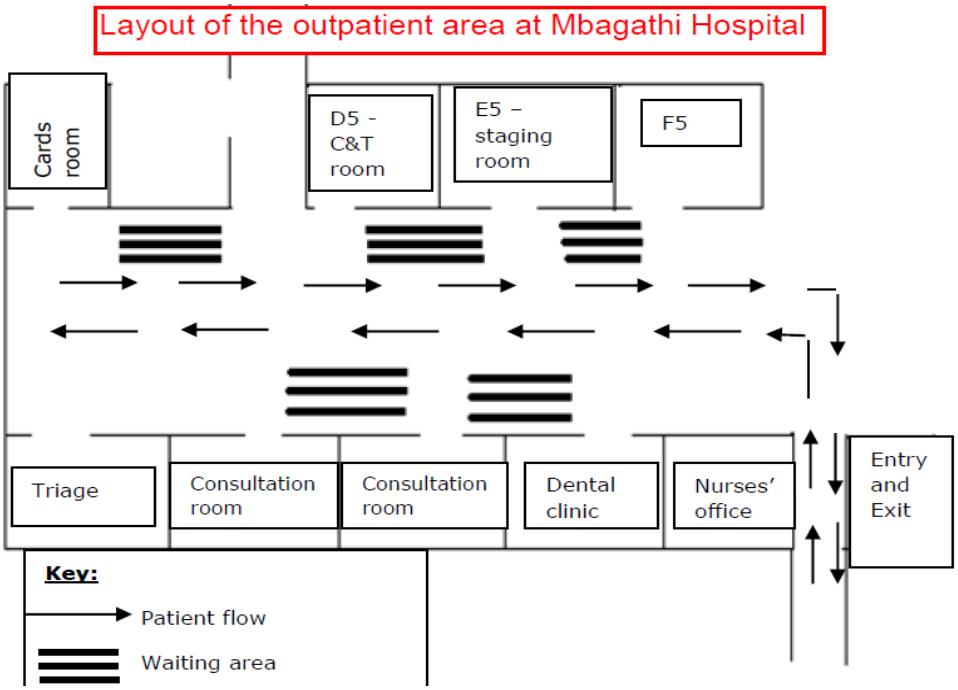


Figure 9: Layout of the outpatient area in Mbagathi Hospital

[12] Further details about the counsellors are provided section 4.7

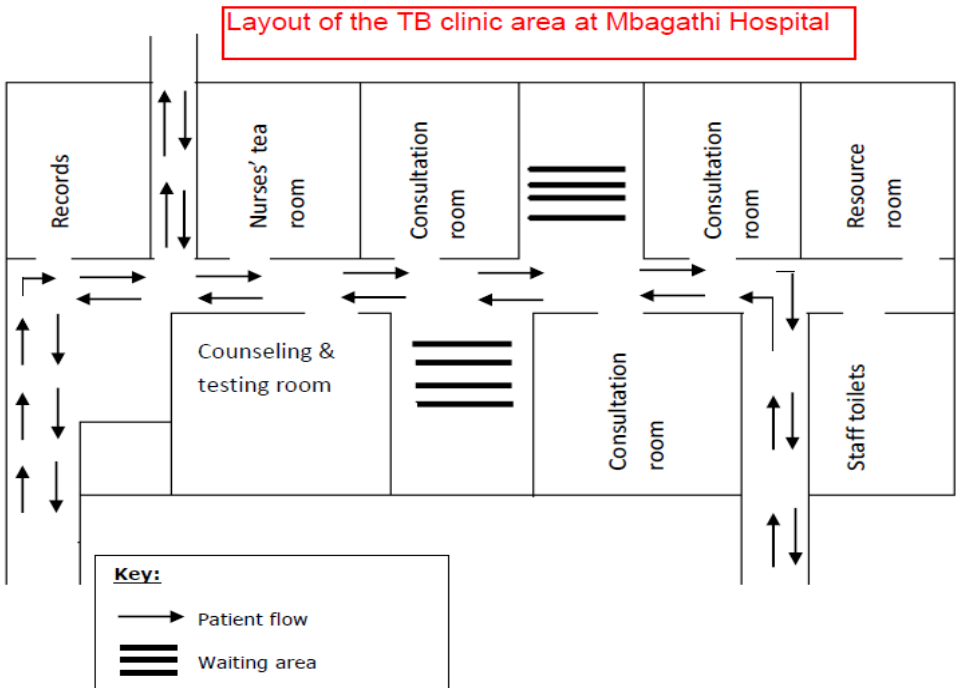


Figure 10: Layout of the TB clinic and testing area at Mbagathi Hospital

Riruta Health Centre is located near Kawangware slums in Dagoreti, Nairobi. Just like Mbagathi, the population served by Riruta constitutes of a population of needy people, with relatively low education levels and often either in short term unpredictable employment or unemployed. At the time of data collection, Riruta did not offer inpatient care. It provided outpatient services such as HIV testing and ART, curative outpatient services, family planning, immunization and TB diagnosis and management. HIV testing was largely done in a stand-alone structure which was made from a truck container that was divided into two rooms except for PITC for the antenatal patients which is done separately in a room within the main hospital building. There were four counsellors at the time of data collection. Two were trained counsellors whilst two were lay

counsellors. Only three of the four counsellors were involved in this study (one trained and two lay counsellors)[13]. The layout of the Riruta Health Centre stand-alone testing area at the time of data collection is illustrated below:

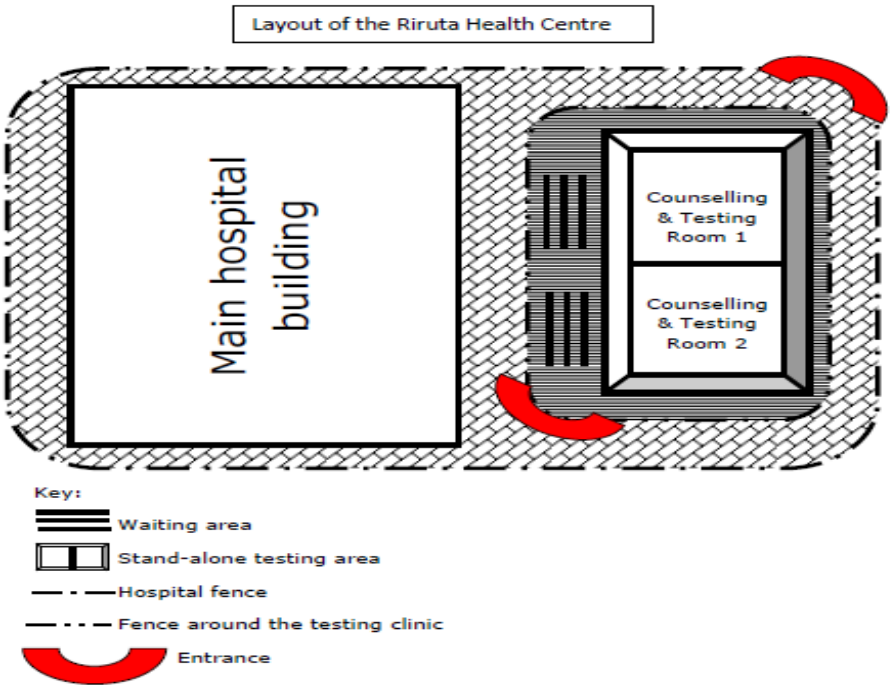


Figure 11: Layout of the Riruta Hospital and stand-alone testing area

HIV testing in the two aforementioned health facilities is done using rapid diagnostic tests which are able to provide results within 15 minutes of drawing the blood sample. The two health facilities have laboratories that are able to carry out a number of HIV relevant tests such as Elisa, CD4 counts and viral loading. HIV testing and drugs are provided for free but other diagnostic and laboratory services and drugs that are beyond the

[13] Further details of the counsellors is provided in section 4.7

care of HIV and TB care are given at a cost. The poor population which is largely served by the two health facilities is not usually able to afford these services. This is likely to impede uptake and retention of health care services.

4.7 Sample

The focus of this study was the PITC process in clinical settings outside antenatal settings. Antenatal settings have been a major focus of PITC and its implementation has been well research. However, PITC is also increasingly being operationalized in other clinical settings and there is a need to explore its implementation in these sites as well. The utilization of social research methods to examine PITC in clinical settings and elicit ingrained practice in African settings has been minimal. The literature reviewed (Chapter two – section 2.7.3 and Chapter three – section 3.5) also indicated that experiences with PITC in what has been observed in antenatal settings may be somewhat different from what takes place in none antenatal settings (Angotti et al., 2011; Musheke, Bond, et al., 2013; Rujumba et al., 2013; Vernooij & Hardon, 2013). PITC in antenatal settings entails protection of an unborn child from HIV infection through HIV testing and subsequent prevention strategies. This makes the consent situation unique from that of HIV testing in other clinical settings since it presents the notion of 'it's good for the baby'. Additionally, PITC in antenatal settings primarily targets women who are in turn encouraged to bring their partners for HIV testing: presenting a different dynamics to HIV testing.

A total of thirty patients who had sought care from two government health facilities (Mbagathi Hospital and Riruta Health Centre) and to whom a routine HIV test had been offered were recruited to the study. Each of the participants was followed through the PITC process i.e. before the HIV test, during the HIV test and after the HIV test whenever possible. A detailed explanation of the participant characteristics is provided in appendix nine and ten.

At the onset of the study, the aim was to examine the PITC process from the patient's perspective only. However, as the study evolved, it became necessary to explore the counsellor's voice and view of the PITC process. Therefore, five of the eight counsellors who had provided counselling and testing services to the 30 recruited patients were interviewed to elicit their experiences and views of the PITC process. Whilst the intention had been to include the eight counsellors, two of the counsellors had gone away on prolonged leave while one was on sick leave. Although those on leave had been replaced by other counsellors who had resumed work, it was not possible to include them in the study as the primary target was counsellors whose counselling sessions had been observed. Therefore, the selection of counsellors was not driven by the need to have a representative sample of all possible counsellors but rather the counsellors who provided counselling and testing for the sampled patient participants.

The sample size chosen was informed by the fact that a qualitative study needs to have what would be considered a small scope due to the emphasis on depth rather than breadth and the huge amount of data generated (Murphy & Dingwall, 2003). Qualitative research does not aim

for a representative sample or to generalize findings to other settings (Polit & Beck, 2014). Rather it aims to explore indepth a wide and diverse range of perspectives to open up and extend understandings of a phenomenon. Consequently, the target of 30 cases was selected as sufficient to provide a wide range of patient perspectives and experiences, while being manageable within the constraints and resources of the study.

Convenience and purposive sampling was used in selecting participants for the study. Convenience sampling facilitated the selection of the most readily available participants in the research setting. Patients were recruited from the different areas where routine HIV test was being offered in the research settings. Purposive sampling was used when selecting the sample of counsellors. Only counsellors whose sessions had been observed were interviewed.

4.7.1 Access to the sample

In Mbagathi hospital, most participants were accessed through the outpatient department where the majority of routine HIV tests are done. The rest were drawn from two other areas i.e. the TB clinic and inpatient departments where the routine HIV test is also carried out. Antenatal patients were excluded from the sample as they were not part of the sample population. Patients' flow vis-à-vis the access point(s) is shown in figure 12.

In Riruta Health Center, participants were all accessed from the stand-alone testing area. The patients were referred to the testing area from various departments e.g. TB clinic and consultation rooms. Since there was no inpatient department, there were no participants recruited from

the wards. Additionally, antenatal patients who were tested separately were not included as part of the target population. The flow of patients in Riruta Health Centre is illustrated in figure 13 further below.

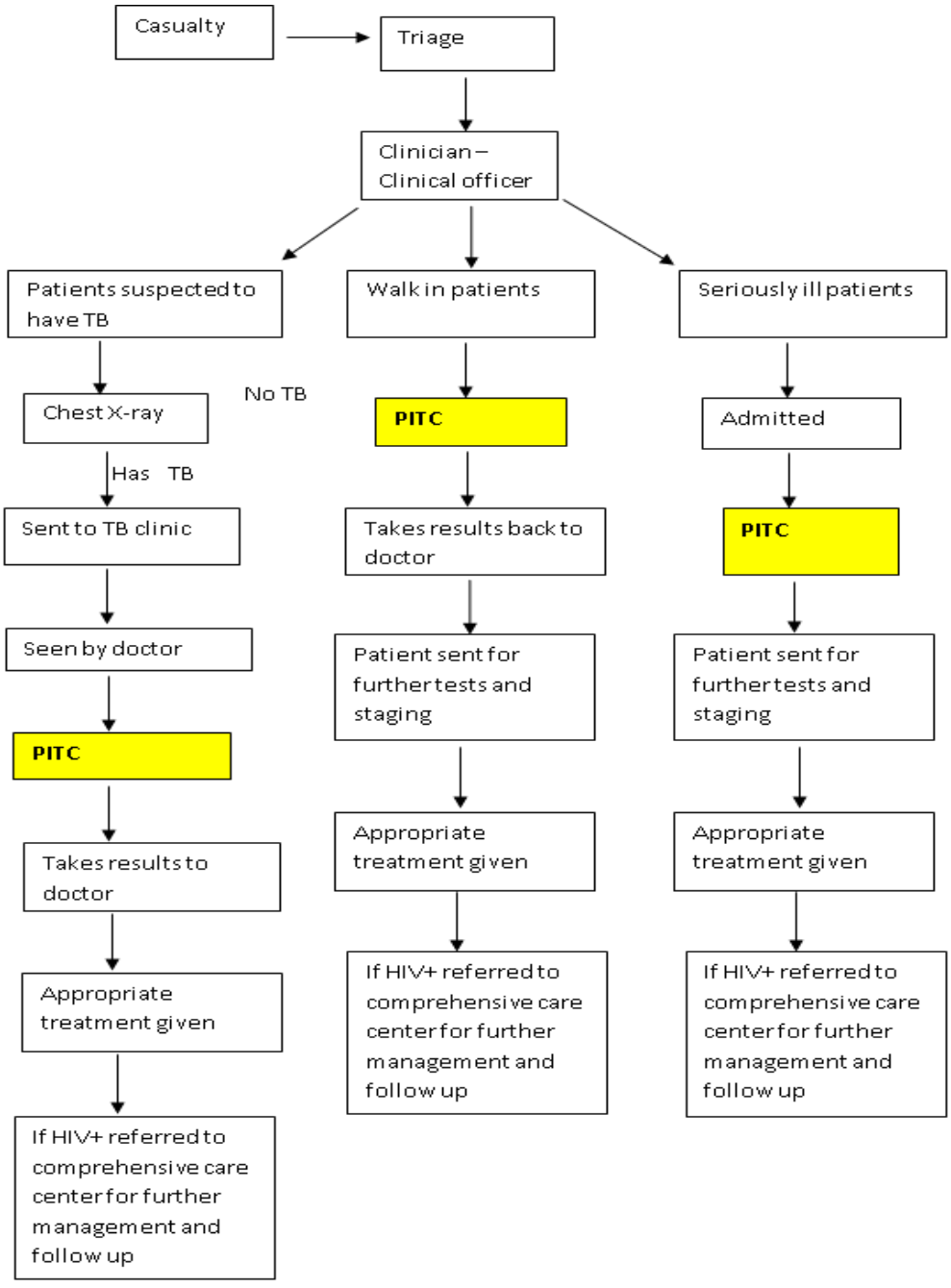


Figure 12: Patient flow pathway at Mbagathi hospital

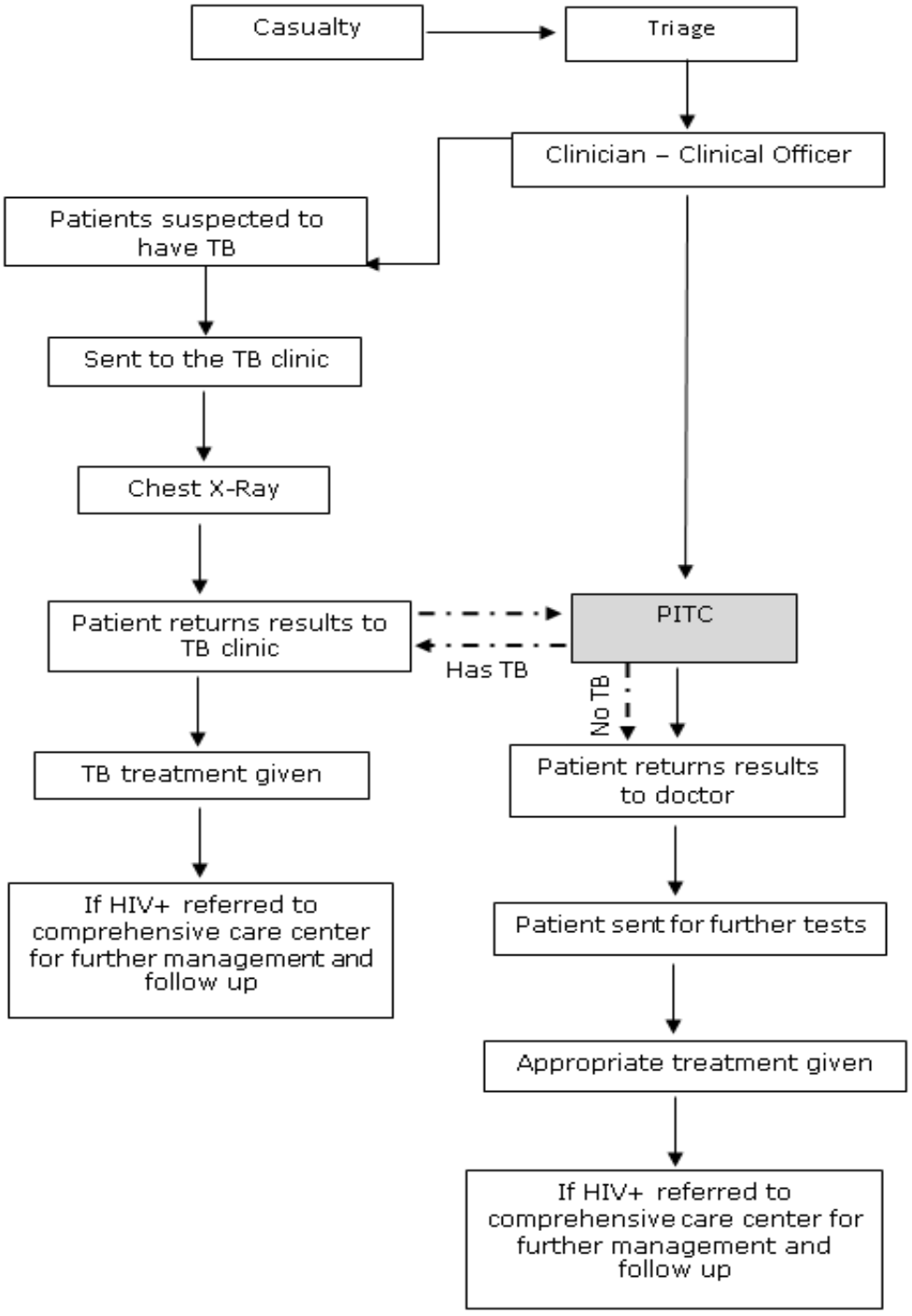


Figure 13: Patient flow pathway at Riruta

4.7.2 Recruitment procedure

In Mbagathi Hospital, patients were identified at the outpatient department, TB clinic and in patient department. In Riruta Health Centre, patients were identified at the stand-alone testing area. The initial target was those patients who had come to the hospital primarily for treatment, but were in the process of seeking that treatment, offered a HIV test by a health care provider. Later on, patients who had come for a repeat HIV test following PITC were included in the sample to explore some of the emerging issues from the initial data.

Participants were at the onset approached by a nurse working in the department and given a brief overview of the research study. Those interested in hearing more about the study were introduced to me. I then provided the potential participants with detailed information about the study and gave them an information sheet. The various steps of the research process were explained. Those willing to participate in the study were asked to sign an informed consent and the pre test interview was conducted. Following this, the routine consultation was audio recorded and / or observed after which post test interviews were conducted for those participants willing to continue with the study. After this, the participants who provided their telephone numbers were contacted one to three months later for a follow up interview. The recruitment process is summarized in figure 14 below:

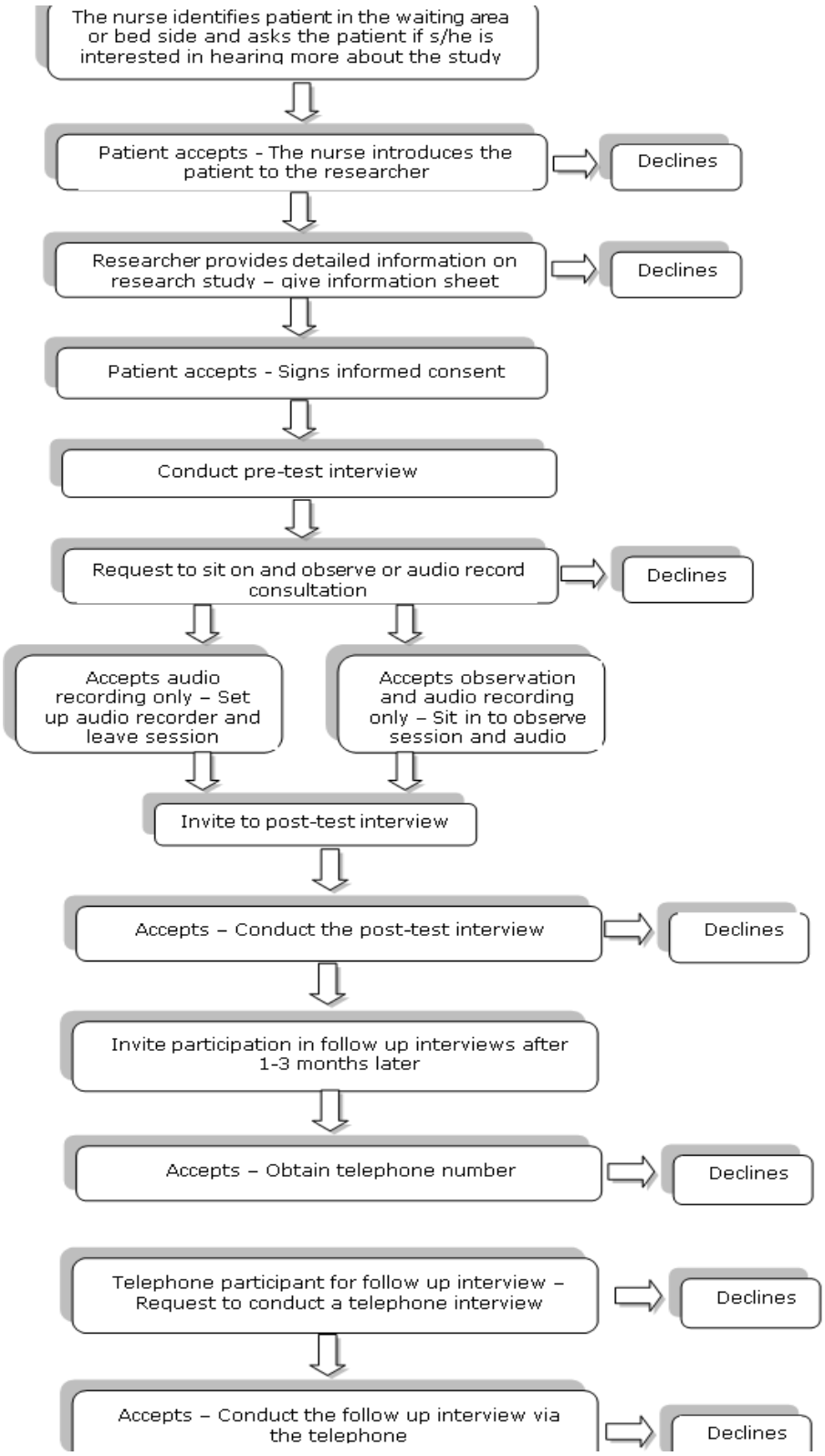


Figure 14: Recruitment process

4.8 Ethical considerations

As the researcher I was ultimately responsible for protecting participants by preventing and reducing harm which could be caused during the course of the study. Several ethical considerations were taken into consideration.

4.8.1 Vulnerable group

- The participants were patients who may have a chronic illness that is highly stigmatized. Hence I ensured that confidentiality of the participants' diagnosis and the information provided was maintained.
- Patients may have had need for information on HIV and HIV services. I ensured that patients were referred to the HIV/AIDS clinic in case they had any questions that I could not deal with adequately.
- Due to the nature of the psychological stress associated with a HIV diagnosis, provision was made for further counselling for participants who experience distress during the interview. However, none of the patients in the course of the data collection process required further counselling.

4.8.2 Informed Consent

The recruitment process outlined above was followed. English is not the first language of communication in Kenya although it is the official language. Hence, the patient information sheet was made simple and clear for the participants to understand. A Swahili translation of the same information was provided for patients who preferred this. In addition, prior to obtaining consent, I provided a verbal description of the study allowing

the participants an opportunity to ask questions and clarify areas which they did not understand. Patients were provided with adequate information both verbal and written in English and Swahili to ensure they understood what participating in the research study entailed. Patients were assured that participation was voluntary and they were free to withdraw from the study at any point without affecting the course of treatment or support. Only patients who consented were recruited into the study. Patients were required to sign an informed consent which was also available in Swahili prior to the commencement of the study.

I was also cognisant of the fact that the process of participant identification and recruitment raised particular ethical issues. As an outsider approaching patients who had just been sent for a routine HIV test by the clinician was a breach of their privacy. To deal with this potential problem, participants were approached by a nurse working in the department who was already involved in the patients' care and would in the process of providing that care be privy to the patients' information. However, using a nurse (health provider) to approach eligible patients may have made the patients feel obliged to accept participation in light of the existing norms of patient-provider dynamics. In view of this, once the patients accepted to meet me after an overview of the study was given by the nurse, I made it explicitly clear that their participation or lack of it thereof was not in any way connected to their course of treatment. The participants were further made aware that as the researcher, my study was not led by the health facility although a report of the results would be made available to the health facility. In addition, the nurse who made the initial contact with the participants was not involved in the HIV testing

consultation and hence could not influence the counselling and testing process for those who declined to take part in this study. Moreover, the counsellors providing counselling and testing were not in any way made aware of the patients who had declined participation in the study. This ensured that patients who refused to take part in the study received the care they would have received in spite of not being part of the study.

4.8.3 Confidentiality and anonymity

Participants' names and other personal details were kept confidential throughout and beyond the research study. Participants were given pseudonyms and codes from the onset which were used to identify them. The participants were informed that the findings of the study will be published, but their names or any other participant identifying information would not appear in the report. The nurse who approached the patients knew the identity of the participants in the course of making the initial contact. However, the nurse was not given any information that could link what had been said during the interview to a particular participant. Due to the stigma attached to a HIV positive diagnosis, I did not disclose the HIV status of the participants to anyone including their family, spouses or friends. Study data such as transcripts and field notes were anonymized and kept in a locked drawer and password protected personal laptop. Audio recordings of the interviews and consultations which were done using a digital recorder were transferred to a password protected personal laptop and deleted from the digital recorder. Following completion of the study, the data collected from this study will be securely kept for a period of 7 years.

4.8.4 Approval

Ethical approval was obtained from The National Council for Science and Technology, The Aga Khan University Ethics Committee and The Kenya Medical Research Institute. I also obtained permission from the Medical Officers of Health under which the two health facilities from which I collected data are governed. Permission was also sought from the unit manager(s) of the departments which were used to access the participants.

However, ethical matters are complex and cannot be guaranteed by following a prescribed checklist (Murphy & Dingwall, 2001). For example, signing of a consent form, though formally indicative of informed choice, does not necessarily take into account the contextual factors like the existing power differences between the researcher and the participants. Moreover, the emergent nature of qualitative design and the varying environment of social contexts, means that it is not possible for ethical guidelines to cover every situation that may occur (Murphy & Dingwall, 2001, 2003; Silverman, 2006). Consequently it was imperative for me to continuously reflect on ethical issues not just at the beginning of the study, but throughout the research process, making conscious efforts to deal with them the best way possible (Murphy & Dingwall, 2001, 2003; Silverman, 2006).

4.9 Data analysis

The aim of my data analysis was the content and context of the data collected. From a social constructionist perspective, focus was on the varied and multiple meanings towards HIV and HIV testing with the aim of understanding the complexities of the PITC process.

> "In social constructivism, individuals seek understanding of the world in which they live and work. They develop subjective meanings of their experiences – meanings directed toward certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow meanings into a few categories or ideas." (Creswell, 2013, p. 24)

Interview data was viewed as a representation and not a description of reality. Holstein & Gubrium (2002) suggest that including both the 'what' and 'how' of the interviews yields an appreciation of the content of the interview data and context in which the information is constructed. Looking at the context and the content of interview data can provide a deeper understanding of the phenomenon (Murphy & Dingwall, 2003). The interviews were analysed by considering the ways in which the participants represented HIV, themselves and their experiences with the routine HIV test.

To further deepen my understanding of the PITC consultation, brief reflection sessions with the counsellors after the consultations were carried. These reflections involved the counsellors sharing their feelings about the consultation I had just observed. They also discussed any inconsistencies that they may have noticed with the patients. In some instances counsellors expressed their concerns about a patients' risky sexual behaviour. Later on however, it became necessary to carry out indepth interviews with the counsellors to clarify some of the issues that had arisen after a detailed analysis of the data from the patients, field notes and post-interview reflections with the counsellors. This included an exploration of the counsellors' view on PITC and challenges they faced when implementing PITC among others.

Further on, the analysis of the different data sets and data from multiple sources (counsellors and patients) was imperative in order to get a deeper understanding of the routine HIV testing consultations. This called for a data analysis approach that would not only assist in managing the amount of data collected, but also allow incorporation of other data analysis approaches to facilitate analysis of specific data sets e.g. audio recorded interaction. For that reason I adopted the constant comparison method utilizing Charmaz's (2014) constructivist grounded theory approach to draw in the different sets and make inferences.

4.9.1 Applying constructivist grounded theory in my data analysis

Data analysis took place concurrently with the data collection. A process of continuous analysis and adaptation of data collection was done throughout the process. An initial preliminary analysis of the data set of the first five participants was done and subsequent interviews and observations based on issues emanating from this initial analysis. The process followed in data collection is summarized in figure 16 below.

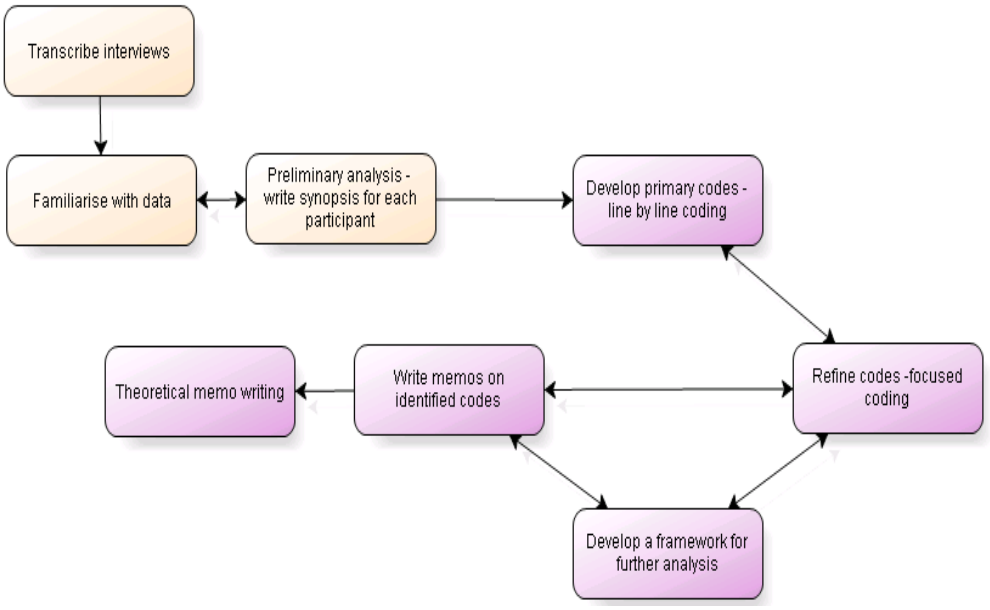


Figure 15 Steps followed in data analysis

The data collected including the pre and post test interviews, audio recorded interactions and the observation field notes were transcribed. Transcription of all recorded data was done solely by me. One advantage of this was that it facilitated the process of familiarization and immersion with the data. I was also able to develop thoughts on some of the codes that were emerging from the data in the process of transcription. Since I was the one who collected the data including observations of events, transcribing of the data allowed me to easily draw links between what I had heard and what I had observed such as pauses and none verbal cues (Oliver, Serovich, & Mason, 2005). However, being the sole transcriber may pose a risk of depiction bias. This was dealt with by going back and forth between the audio and transcribed data to ensure congruency between the two.

Transcripts were imported into Nvivo version 9 where they were analyzed using the constant comparison method. In order to familiarize myself with each data set, a synopsis of each participant was developed which consisted of field notes of my observations and my thoughts about the observed PITC consultation and the conducted interviews (See appendix 11 for a sample of the synopsis). This process facilitated an initial identification of key codes to look out for in subsequent interviews and questions that I could use to interrogate data as the initial analysis unfolded.

Following this, a comparison of data between the participants was carried out in sets of five participants. For instance transcripts from field notes, interviews and audio recorded interactions of participant one to five were analyzed together. The process involved writing down my thoughts about what the data means vis-à-vis the initial identified codes across the different participants (See appendix 13 for a sample of notes). The aim was to identify differences and similarities between participants and provide plausible explanations for what the data was revealing in order to refine the codes and develop categories.

As the codes developed, I engaged in a process of writing memos about each code illustrating my thoughts about why I chose the particular code or category and linking the code or category with the data (See appendix 14 and 15 for a sample memo). Developing memos assists the researcher to build and clarify a category by examining all the data it covers and the variations within and between categories (Charmaz, 2014). This process makes it possible to describe how a category emerges and develops whilst

identifying the beliefs and assumptions that support it. Most importantly, it incorporates the notion of making within case and across case comparisons at different points in time, within and between categories, between categories and sub categories and finally between categories and literature (Charmaz, 2014). This notion was particularly valuable in my research study. It facilitated the comparison of pre test interview, routine testing consultation, post test interview and follow up interview data across a participant and between participants.

The comparative analysis between the data set of the same participant illuminated the shifts that occurred in respondent's accounts along the PITC process. For instance, a participant reported not having engaged in risky sexual behaviour during the pre test interview. Similarly during the HIV testing consultation he denied having multiple sexual partners. However, later on during the post test interview following a HIV negative diagnosis he inferred being in a risky sexual relationship. This piece of data revealed the importance of maintaining a moral face particularly in view of blame for one's HIV positive diagnosis (see appendix 15: memo on maintaining 'moral' face). In this case if his HIV test result had been HIV positive it is likely that he would have maintained that he had not engaged in a risky sexual situation to avoid blame for his predicament.

4.9.2 The process of Analyzing audio recorded / observed interaction

The audio recorded talk of the consultations was transcribed and analysed using discourse analysis. The focus was on how the providers and patients positioned themselves in the context of the available interpretative

repertoires related to HIV and how they went about constructing the consultation within the immediate counselling setting and the wider sociocultural context. This provided useful information on the use of talk by patient and provider to drive particular agendas, social, cultural and power relationships between the provider and the patient and the effect of the existing structures and processes on routine HIV testing.

4.9.2.1 Discourse analysis

Audio recorded conversation can provide useful data to analyse how people involved in the counselling session go about constructing a social world together (Silverman, 2006). The counselling session is a form of naturally occurring talk. There are two key methods used in analysing naturally occurring talk namely conversation analysis (CA) and discourse analysis (DA). The two approaches have some fundamental differences related to contextual influences on talk, how to elicit meaning from talk and the role of prior theory when analysing talk (Silverman, 2006).

CA involves fine-grained analysis of talk as it occurs using highly detailed transcripts with a focus on minute details pegged on the talk sequence and a complete turn talking (Silverman, 2006). According to Bryman (2008) and Silverman (2006), CA has its roots in ethnomethodology which is interested in the circumstances associated with talk and reality construction in institutional settings where the talk is taking place (Miller, 2002). Therefore, its analysis is tied to the unfolding talk and no prior theory can be utilised unless it explicitly emerges from the talk. CA is based on three main assumptions: that talk is structured, action can be revealed in the talk and analysis must be based on the data and hence

shuns the use of prior theory during the analysis. Consequently, CA is confined to the immediate context where talk is constructed and answers the questions 'how' and 'what'. Excluding the wider social context leaves out the possibility of answering the question 'why' from the data obtained. Moreover, only the naturally occurring talk can be considered in the analysis which eliminates the consideration of other data which may have been collected on the research topic.

In contrast DA refers to an approach of analysing talk and other forms of discourses that emphasis the ways in which versions of reality are accomplished through language. It is more flexible and incorporates other sources of information like text, multimedia, policies and documents with less emphasis on naturally occurring talk (Bryman, 2008; Silverman, 2006). Subsequently, DA is concerned with both the relationship between the talk and the wider social process as well as its use within the context within which it is generated (Silverman, 2006). Therefore, it can answer the questions 'how', 'what' and 'why'.

DA allows for the consideration of factors which occur outside the setting where the talk takes place which can influence how the interaction unfolds. For example by using DA, it was possible to take into account existing lay perceptions and knowledge about HIV as well as social structures and processes and how these influence the interaction between the provider and the patient during a routine HIV test. This flexibility and the allowance to consider and use data outside the unfolding conversation made it possible for me to make use of data collected from the interviews and observations. This coupled with the consideration of information about the

sociocultural context expedited an informed exploration of questions relating to 'what' is happening and 'why' it is happening.

There are two main propensities in DA which are arguably not very distinguishable (Bryman, 2008). The first propensity is an interpretive repertoire which is concerned with uncovering the general resources that are used to construct discourse and enable particular actions among the participants. In this case general resources refer to shared social consensus about a phenomenon or in essence what everyone knows. For instance in a study on how doctors and nurses represent and make sense of their male patients, Seymour-Smith, Wetherell, & Phoenix (2002), used interpretative repertoires to identify how doctors and nurses draw on cultural resources for example by using phrases such as 'we know how men are like' to explain certain views about the male patient. In that study the authors did a detailed analysis of the conversation with an interest in the wider cultural, historical and power relations which affected the doctors and nurses construction of masculinity. The second propensity is concerned with identifying detailed procedures with which versions (i.e. of what is real) are constructed and made to look true by the participants. The decision on which one to choose among the two is wholly dependent on what the researcher aims to do with the data although at times it may be difficult to delineate one propensity from another.

In the context of my study, I explored phrases and terms used to denote shared understanding of HIV and sexuality and how both the professional and the patient handled and communicated issues (e.g. sexuality) which are considered taboo. I used interpretative repertoires as a means to

analyse how existing general resources (sociocultural constructions) about HIV were elucidated in the counselling session and how the providers and patients drew on this when communicating about HIV. Therefore, I paid attention to how the patients and providers positioned themselves in the milieu of the available interpretative repertoires of HIV and how they constructed reality within the wider social and cultural context.

There are some limitations of using DA. The flexibility of DA in terms of what is considered during the analysing of talk makes it hard to define exactly what DA entails (Silverman, 2006). Additionally, the fact that DA does not give much attention to how talk unfolds and to the turn by turn organisation of talk means that it does not use stringent rules about how data should be laid out. Therefore, contextual factors within the occurrence of talk such as who interrupts whom may be difficult to analyse in DA. Finally, the process of DA depends on the researcher's decision on what data to include and what prior knowledge to use in the analysis. Critiques of DA use the latter limitation to raise questions about how much the reader can rely on what the researcher thinks he knows about the wider social world and hence to what extent the findings are authentic and generalizable. However, these limitations of DA are similar to a great extent to those faced by other qualitative research approaches. Hence having an audit trail, discussing findings within the existing literature, comprehensive and critical evaluation of all the data including deviant cases can be used to maintain rigour within DA (Potter, 2002).

There are arguments whether or not DA should be used in conjunction with other methodologies. On the one hand Hammersley (2003), argues

that DA (and CA) should not be treated as self-sufficient paradigms but rather as useful methods which can answer particular research questions and or used in combination with other methods. On the other hand, Potter (2003) proposes that DA as an approach has a range of theoretical and methodological elements and thus needs to be used carefully when combining it with other methods that make different assumptions. He further explains that despite the fact that DA may not effectively answer certain research questions, it is self-sufficient to be used independently in answering relevant research questions. Both of these arguments notwithstanding, the ultimate goal of any methodology, whether used independently or in combination with other methods, is to enable the researcher to sufficiently answer the research question. Moreover, it is possible to utilise data from different methods while at the same time maintain a distinctive contribution of each perspective as alluded to at the beginning of this chapter. In my study DA was used to evaluate how existing sociocultural issues are reflected within the routine testing setting and how patients construct their social realities around HIV. Combining DA with the pre and post test interview and observation data was the best data analysis approach in answering the research questions of my study.

4.9.3 Maintaining rigour

Rigour was maintained through analysing the data systematically, getting a second view from my supervisors on the interpretations made, accounting for deviant findings and consistently comparing data within and between cases (Bryman, 2008; Green & Thorogood, 2004; Silverman, 2006). In addition, I engaged in a process of on-going reflection on my

role in the research process including how I may have influenced it (Hammersley & Atkinson, 2005).

Use of different data collection methods not only triangulated data to increase credibility (Bryman, 2008; Green & Thorogood, 2004) but also attempted to get a more comprehensive illustration of the phenomena under study. Using triangulation to enhance credibility in qualitative research can cause problems because different types of methods elicit different data and there is danger of isolating context from data when doing the comparison (Murphy & Dingwall, 2003). Additionally, the assumption that triangulation in social research aims to obtain an objective truth and one standard of a phenomenon is problematic (Miller, 2002). Rather, triangulation expands the scope and comprehensiveness of the analysis which aids in an indepth understanding of phenomenon under examination.

Although the aim of qualitative research is not to generalise findings, I delved to provide contextual details of the findings and relate the results to existing literature and theory (Bryman, 2008). In any case, although the study findings may not be generalizable in their entirety, key findings from the study may be applicable and transferable to other settings. Moreover, qualitative research can aim for analytic generality and creation of an evidence base through triangulation and analysis of findings from different research studies across different contexts. By maintaining rigour, it is expected that the results of my qualitative study will add to the existing body of knowledge and inform policy on routine HIV testing in the given context.

4.10 Conclusion

This study used a qualitative research approach using multiple data collection methods of interviews, observations and audio recording of patient-provider interactions. The focus was to uncover the meanings embedded in the interviews and observed interactions to illuminate the implementation of PITC policy recommendations in the Kenyan context.

5 CHAPTER FIVE: STUDY PARTICIPANTS

5.1 Introduction

This chapter is the first of three presenting data from the study. Later on a discussion chapter will coalesce the data presented in these three chapters in the context of existing literature, policy recommendations and theoretical arguments about informed consent and counselling. The aim of this initial chapter is to familiarize the reader to the characteristics of the participants and the study setting. Pseudonyms are used to represent the patient and counsellor participants in the presentation and discussion of the study findings.

5.2 Biographical characteristics of the participants

A total of 30 participants were recruited at the onset of this study. None of the participants approached to participate in this study declined to participate. Similarly, no participants to whom a HIV test was offered in the course of this study dissented to take up the HIV test. I am cognizant of the fact that the participants may have perceived the request to take part in the research as not optional or presumed that the study was part of the treatment process. This could have been the case because the initial contact with potential participants about taking part in this study was done by the nurse (see section 4.7.2). The reason for this was to maintain patient confidentiality.

Nonetheless, efforts were made by the researcher to emphasize that participation was voluntary and to delink the study from the health care services that they had come to receive. This situation is perhaps a pointer

to the complexity of the informed consent situation in the Kenya. Informed consent is often imbued within social relationships and existing power differences, making it difficult for patients to decline a request by the researcher or health care providers (Kamuya et al., 2015; Okello et al., 2013). Issues related to informed consent during PITC in this context are considered further in the discussion chapter.

Thirty participants were included in the pre test interviews prior to the HIV test offer. Provision of PITC was confined to weekdays 8.00am – 5.00pm in both facilities. Any patient coming after hours or on weekend did not receive PITC. Data collection was confined to these times.

Twenty nine counselling sessions were included. I could not trace one of the participants (Chepkwony) after the pre test interview at the TB clinic. Months later during the telephone follow up interviews, I learned from Chepkwony that he had been tested later in the day after waiting for several hours. The counsellor who was supposed to be carrying out PITC at the TB clinic at the time was occupied with providing HTC for clients who required it as part of their medical reports for employment, foreign travel etc. The medical report clients may have been viewed as a priority since these clients, who are one off, pay for the service unlike PITC which was essentially provided for free. The scenario reflected the fact that counsellors involved in PITC may be faced with multiple competing roles with PITC being one of many activities that they are expected to carry out. This may hinder PITC implementation especially in situations where there are few trained counsellors. In such situations patients may go away without testing if they become frustrated with the long waiting times.

Counsellors on the other hand may have to deal with extremely high workloads as illustrated in the note below. The issue of competing roles was only observed at Mbagathi:

> *Testing seems to be confined to nurse counsellors even though other nurses who have been trained are available particularly in the ward. Therefore, if the nurse counsellors are absent, or very few for that matter, patients miss out on testing even if other trained nurses are available. For example today (05-01-10), there is a matatu (public transport) strike so just like majority of the Kenyan working population, a number of health workers including nurse counsellors were not been able to report to work. The available nurse counsellor in the ward was not only expected to counsel and test patients in two wards but also provide clinical work. When I met her she was doing the drug and treatment round and hence she was not able to counsel and test any patients that day. (Field notes 05-01-10 Mbagathi)*

It is interesting to note that although the counsellors in all the testing areas in Mbagathi faced increased workload, other medical practitioners like the clinical officers who had also been trained to provide PITC were not doing it. The PITC role seems to have been abdicated to the nurse counsellors. These organizational issue seemed to impede the number of patients who were referred for and received PITC:

> *Although a number of doctors and clinical officers have been trained on counselling and testing they generally do not do PITC. Their responsibility is to refer patients for PITC. It was interesting to learn that the clinical officers tend to refer only the clients they think or suspect could be having HIV or are likely to have HIV based on their clinical complaints rather than all patients. Perhaps in a way this helps to reduce the number of clients queuing and requiring a HIV test and in a way reduce the nurse counsellors' workload. (Field notes 05-01-10 Mbagathi)*

The observation notes above illustrate how the health care providers in Mbagathi modified who they referred for PITC so as to deal with the huge

workload. Whilst this may have aided in dealing with the high workload, it impeded the intention of PITC by turning it into DTC. Not all patients seeking health care were offered PITC in all instances but rather those who were thought to most likely have HIV. These sentiments were also echoed by the counsellors who found differences in the number and nature of patients referred for PITC depending on the clinician on duty.

After the observation and examination of the 29 consultations, 22 participants were involved in the post test interviews. It became difficult to trace the seven patients in the various hospital departments and units where they were sent soon after receiving their HIV test results. All the seven participants had received a HIV negative result. During the follow up interviews a couple of months after the HIV test only 14 participants could be reached, out of which one declined to discuss his HIV testing experiences (see flow chart on dropout rates at each step of the study). The small number of participants who were followed up could not adequately facilitate the exploration of uptake of required services and in particular linkages to care following a HIV test. Indeed, I was only able to contact two participants who had received a HIV positive diagnosis during the follow up interviews. This was a key limitation for this research study in this regard.



Figure 16: Flow chart of dropout rates in the study



Figure 17: Flow chart of dropout rates at Mbagathi Hospital



Figure 18: Flow chart of dropout rates at Riruta Health Centre

Tracing patients is difficult in public health facilities because they generally lack a centralized electronic patient record system. Similarly, in everyday practice, follow up of patients who have been tested for HIV, especially those that require to start treatment and / or ART, becomes extremely difficult in this environment. The effect of a lack of an electronic centralized patient record system in the tracking of patients who receive HIV positive result has been a challenge in Sub-Saharan Africa (Topp et al., 2011). It is a key challenge in ensuring linkages to care and uptake of relevant HIV services.

In Mbagathi, patients were recruited from the three areas where PITC was carried out in clinical settings i.e. outpatient, inpatient and TB clinic. In Riruta, all participants were recruited from the stand-alone testing area. The focus of this study was PITC in clinical settings hence the exclusion of antenatal settings. Details about the two study settings and patient flow

have been explained in the methodology chapter in section 4.6 and section 4.7.1 respectively.

Testing area	Total tested	Male	Female
Outpatient	6	4	2
Inpatient	4	3	1
TB clinic	4	3	1
Total	**14**	**10**	**4**

Table 3: Participants tested at Mbagathi Hospital

Total number tested	Male	Female
16	9	8

Table 4: Participants tested at Riruta Health Centre

There were only four instances during this study that a spouse was present in the course of the PITC process. In two of the cases at Riruta, couple counselling and testing was done with both couples. The two couples received a HIV negative result. However, in Mbagathi, couple counselling was not done in the two instances where a spouse was present. For the first couple the spouse had already been tested for HIV and found to be HIV positive some years earlier. For the second couple, no couple counselling and testing was done. In fact, the spouse (husband) was offered a chance to test in passing which he dismissed. This was not the only time he had missed testing: he had also not been tested when his wife was expecting their one year old son.

> Hazina the counsellor finds out if Nasike's husband would like to have a HIV test as well. Although he says he is sorting out his wife's issues first, Hazina doesn't seem keen on including him in the session and neither does she follow up on this. Seeing that Hazina would not have needed to do any extra counselling and the time for the two tests would have been more or less the same why didn't she pick up on this and 'encourage' him to test as she had done with previous participants? Is it because he is not the patient? And then again why ask clients to come to health facilities with their spouses if the spouses will not be equally encouraged to test? I remembered that Nasike's husband had told me during the pre test interview that he had also missed an opportunity to test when Nasike was tested during PMTCT. (Field notes 11-01-10, Mbagathi)

In a situation where opportunities for couple counselling are encouraged, there appear to be few instances where couples were tested during PITC in the study settings. Couple testing and counselling is a key strategy in identifying additional people who may have HIV and require treatment (WHO, 2012f, 2015). It provides opportunities for discussion about HIV prevention strategies and facilitates mutual disclosure especially where one or both couples test HIV positive (WHO, 2015).

In the same vein, 20 of the participants were married, one was divorced while nine were single. Of the 20 who were married, only four had come accompanied by their spouses. In light of targeting sexual partners for testing, there is still a relatively huge number of participants in long standing relationships whose partners may go untested. In countries like Kenya which generally face a substantial number of discordant couples, testing of both partners becomes vital.

In spite of the low number of couples tested in this study, the number of men tested via PITC was relatively higher than that of women (see table 2 and 3). This finding is significant in Kenya where, although the number of

people testing for HIV has continued to increase, men continue to report lower rates of HIV testing in comparison to women (Kenya Demographic Health Survey (KDHS), 2015). This suggests that PITC in clinical settings provides a good avenue to increase access to HTC for men in this context, particularly in light of the challenges that PITC in antenatal settings has faced in involving men in HTC (Angotti et al., 2011).

The majority of the participants were from a low socioeconomic status and resided in the slum areas surrounding the two health facilities. Sixteen of the participants had primary education and below while only four had a college education. Three participants were unemployed, two were housewives, three were casual labourers while the rest were either self-employed or in low grade formal employment. The level of education and employment was typical of the majority of the general urban population that seeks care from public government health facilities where the cost of health care is highly subsidized. This suggests that PITC provides access to HTC for the disadvantaged populations as reported in other studies (Kimani & Ettarh, 2012; Obermeyer, Neuman, et al., 2013). However, it is important to note that this finding does not reflect the situation in rural areas, which unlike urban areas in Kenya, have sparse resources and the persons residing there are less likely to test for HIV (Kimani & Ettarh, 2012; Ministry of Health, 2014a).

Of the 29 participants whose counselling sessions were examined, only four (three males and one female) received a HIV positive diagnosis. These participants were Alphonso, Kimathi, Salim and Wayua (see participant profile in appendix nine). Alphonso and Kimathi reported that

they were unaware of their HIV status: they had not tested previously. Wayua reported having had a HIV test a year earlier, in what she described as a 'mandatory' HIV test before she could be transfused during a previous illness. She had received a HIV negative result at the time. Salim had tested five years earlier through VCT where he said that he had received HIV negative diagnosis.

On the whole, a total of seven participants in my study reported having not tested before. The findings suggest that PITC can play a role in providing HTC for people who have not tested previously and in increasing coverage of HTC. In doing so, it can contribute to the identification of HIV positive persons who would have otherwise gone undiagnosed even after coming into contact with health care workers in the course of seeking treatment in a clinical setting. Therefore, PITC contributed to reducing missed opportunities for HTC in clinical settings and providing an opportunity for persons who would ordinarily not self-refer for a HIV test to become aware of their status (Kennedy et al., 2013; Matovu & Makumbi, 2007; Topp et al., 2011; Waxman et al., 2013).

All the four participants who received a HIV positive diagnosis had been recruited from Mbagathi hospital. None of the participants recruited from Riruta received a HIV positive result.

HIV test results at Mbagathi			
Testing area	**No of patients tested**	**Negative**	**Positive**
Outpatient	6	4	2 (Males)
Inpatient	4	3	1 (Female)
TB clinic	4	3	1 (Male)
Total	**14**	**10**	**4 (3 males)**

Figure 19: HIV test results at Mbagathi

HIV test results at Riruta		
Number tested	Negative	Positive
16	16	0

Figure 20: HIV test results at Riruta Health Centre

The number of the participants who received a HIV positive diagnosis in my sample represented an HIV positive rate of approximately 13% of the total number tested (see figure below). The percentage is higher than the current HIV population prevalence rate which stands at 5.6% (National AIDS and STD Control Programme, 2013). The higher percentage of people receiving a HIV positive diagnosis than the prevalence rate may be due to the fact patients being offered PITC are ill and the illness might be triggered by an underlying HIV infection. The participants had come to the

health facility for treatment for complaints ranging from cough, head ache, stomach aches and general body weakness among others.

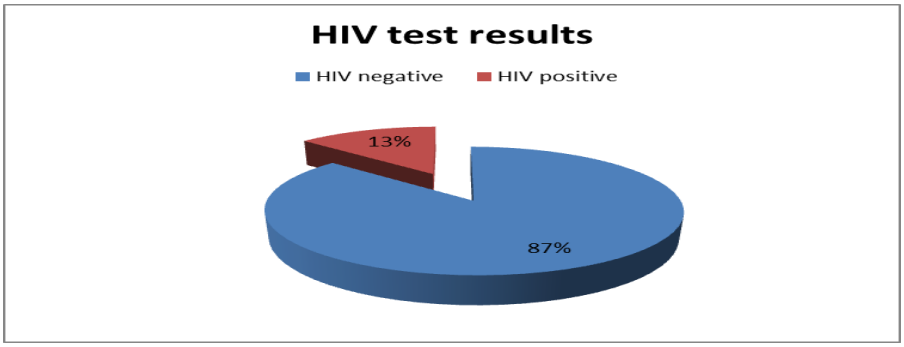


Figure 21 HIV test results of the participants

Counsellors whose sessions were observed were eight in total: five in Mbagathi and three in Riruta (see appendix two). In Mbagathi all the counsellors were trained professional counsellors with a nursing background whereas in Riruta two of the three counsellors involved in this study were trained lay counsellors. As explored later, there was little difference between professional and lay counsellors from the observed consultations. Use of lay counsellors has been proposed as an ideal solution to increase opportunities for PITC in view of the shortage of skilled health workers in the Sub-Saharan region (Davyduke et al., 2015).

The counsellors whose counselling sessions were examined were eight in total (See appendix two for their characteristics). Of these only five were available for interviews to explore their views on PITC and the observed consultations. The counsellors were not the primary target but rather the participants who had been sampled prior to the pre test interviews. Hence

the counsellors were not necessarily representative of the population of counsellors in the two institutions. For example all the counsellors interviewed from Mbagathi were professional counsellors whilst those from Riruta were lay counsellors. This was a key limitation to this study as described later in chapter 9.

5.3 Overview of key themes

Data collected from the patients and counsellors will be presented in the next two chapters. The findings are divided into four key themes as follows:

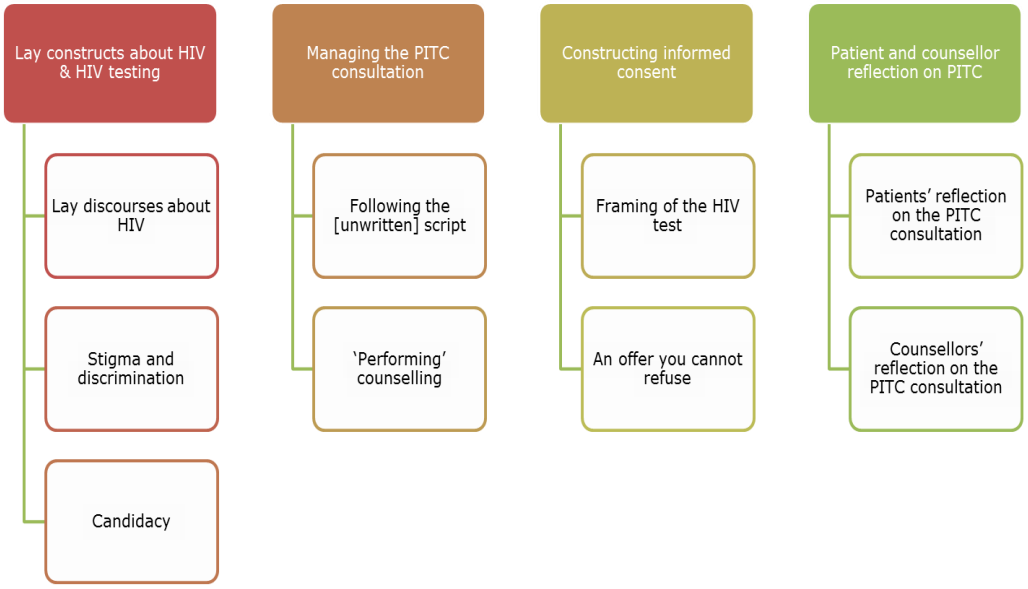


Figure 22 Key themes from research findings

6 CHAPTER SIX: LAY CONSTRUCTS ABOUT HIV AND HIV TESTING

6.1 Introduction

This chapter portrays the existing lay beliefs and perceptions about HIV which were held by the participants and how these were woven through a series of past experiences with HIV, their family, friends and those around them in the community. This theme is important because the participants come to the PITC process with pre-existing views and understandings about HIV through which they are likely to sieve what unfolds during the PITC process. Awareness of this background is essential in understanding the events that occur during the counselling and testing process and thereafter. The next chapter (chapter 7) demonstrates how these views and understandings influence the patients' actions and responses during the HIV test and their interaction with the counsellor.

Through listening to the participants' descriptions of their experiences with HIV and / or what they saw happening in the community, it was evident that there was a complex web of lay explanations about different aspects of HIV. These explanations were drawn from a mixture of what the patients observed in their day to day life as well as the health promotion messages that were widely available in the media and health facilities. This created a lay discourse of HIV which bore similarities to the prevailing professional understandings as well as some differences where lay observations differed from the health promotion messages. Some participants appeared to grapple with these inconsistencies when speaking

about HIV and HIV testing. This theme is explored further in the categories and sub categories summarised in the diagram below:

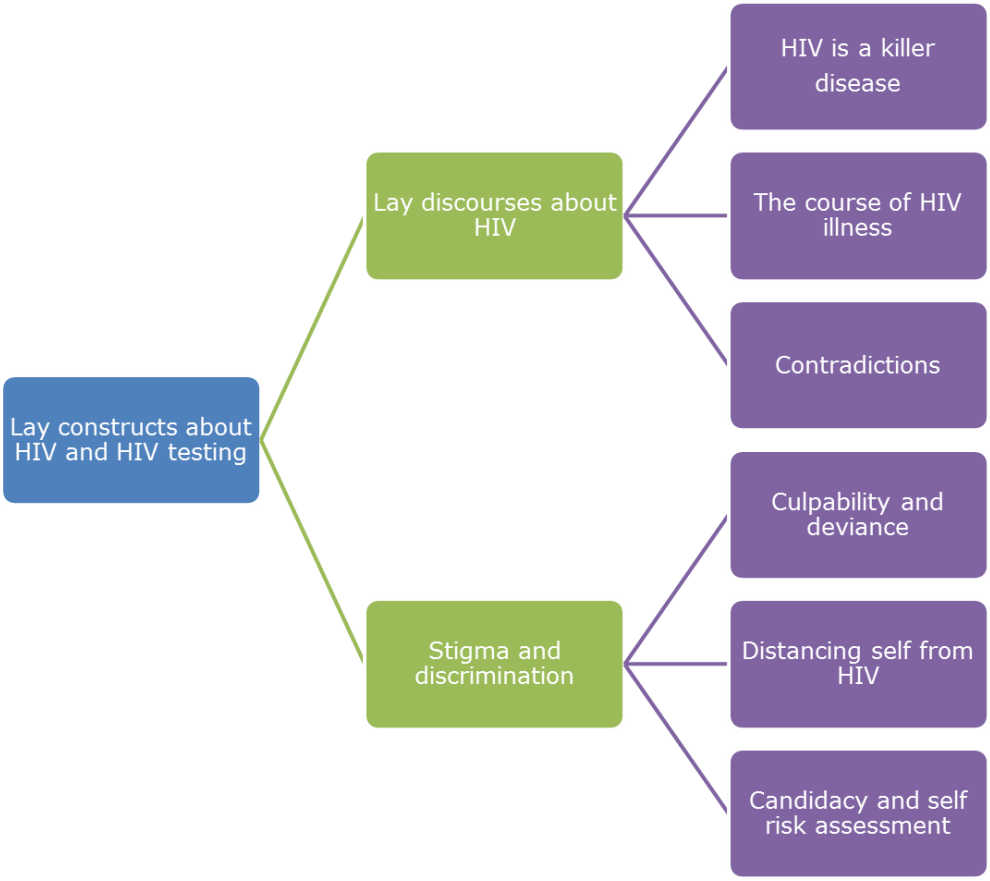


Figure 23: Lay constructs about HIV and HIV testing

6.2 Lay discourses about HIV

Discussions about HIV were shaped by its association with death and the fact that it is primarily a sexually transmitted infection. This is vital because it is on the basis of these two factors that participants used to explain HIV transmission, the course of the disease, its prognosis and the meaning of a HIV positive diagnosis.

6.2.1 HIV is a killer disease

All participants talked about HIV's association with death, with a number of them referring to HIV as a 'killer disease' during the pre test interviews and the counselling sessions:

Waithera (Counsellor): how do you view this HIV/AIDS?

Salim: In what way?

Waithera (Counsellor): what do you understand it is?

Salim: I understand that it is a killer disease.

(Salim 38 year old male – Counselling session - Mbagathi)

I have heard that HIV is a very dangerous disease, it kills people…

(Khamisi 24 year old male – Pre test interview - Riruta)

Salim and Khamisi had both taken a HIV test previously but still expressed HIV as an incurable disease. This is contrary to the common presumption that HTC played a role in improving knowledge and reducing negative perceptions about HIV through correcting common misconceptions. There were two likely explanations for this. First, it is possible that in spite of repeatedly receiving information about HIV from health care providers, participants still have to engage in every day social interactions where HIV is socially constructed as a killer disease. Consequently narratives about HIV may be characterized by an interplay of lay (experiential) perceptions and health promotion messages. Second, the two participants in the above excerpts may not have received any counselling during their past HTC. Indeed Salim indicated that his previous HIV test, though done via VCT,

focused more on the interpretation of test results and not on information or counselling:

> When explaining about his previous HIV test (through VCT), he talks about the lack of ample time to interact with the counsellor. As a result he felt that the information given to him at that time mainly included the interpretation of the test results rather than counselling or even general information giving about HIV. According to the VCT guideline and process of testing the time takes approximately 45 minutes. Now in this case the counsellors may have been 'forced' to modify the rather lengthy VCT process to fit into the contextual challenge of the limited time the clients seeking the service have. Does this mean that although counsellors are talking about following guidelines given to the letter, that in practice they actually find themselves having to be flexible? (Field Notes 13-01-10 Mbagathi)

VCT guidelines focused on a detailed counselling session that was based on the premise that patients who self-refer for HIV testing require extensive counselling. The expectation would therefore be that for patients like Salim who had undergone VCT, there would be reported experiences of comprehensive counselling and information sharing. The dearth of evidence on 'real time' VCT counselling and testing process may make it difficult to determine its implementation in diverse settings.

There was a commonly expressed view that a HIV positive diagnosis meant that one had no chance of living a healthy long life which created intense fear among the general population:

> *They are scared of HIV because it is killing and furthermore when you are a victim they know that there is no chance. (Kamau 53 year old Male Pre test interview Riruta)*

Although Kamau had expressed the above view, he was what the counsellors in the study referred to as 'repeaters'. Repeaters were participants who tested frequently sometimes even before the three month window period had elapsed. The counsellors were concerned about the increasing number of repeaters. In their view, repeaters were an indication of maladaptive behaviour change following HIV testing. After the patient became aware of the risk factors of HIV and their personal vulnerability in view of these, they failed to modify their behaviour and instead used the repeated testing as a means of reaffirming their negative status despite continuous exposure to risk:

> *Mm… I can also say that some of them just take it for granted because they think after they have tested they are negative, they go misbehave; they just don't take the information we have given them. Some of them they just go they expose themselves and they don't even come within that period of 72 hours and that is why you find most of them they are repeating, they are repeating without taking the information we give them about the risk behaviours. And that is why most of them coming, coming frequently. (Opiya Counsellor - Riruta)*

> *Oh yes. Oh yes. Yeah we have so many cases of people who come [for HIV testing]… who keep on coming, who keep on coming. Some of them [say], "I had a burst condom so I don't trust the result I don't trust where I have tested." Maybe somebody is in denial. You test positive and you don't believe that I am positive. How can this happen to me? So they keep on coming to confirm.*

And then maybe somebody is just careless, you keep on practicing unsafe sex and every time, every now and then you come to be tested to confirm (Waithera Counsellor - Mbagathi)

It is possible that the same individuals are getting tested often through PITC and account for the increasing number of people who have had HTC. It is difficult in this context to monitor who has tested and when they tested to avoid testing patients who keep on coming for the same. The other side of the coin on this is the misuse of the limited number of resources i.e. testing kits and health care workers in situations where persons who have never been tested may miss being tested due to lack of testing kits or unavailability of counsellors.

There was reluctance to seek a HIV test because it was akin to going to look for trouble, or death:

Interviewer: Is there something that makes people avoid testing for HIV?

Idowu: That thing [HIV], it's a dangerous thing.

Interviewer: Why is it a dangerous thing?

Idowu: Aii! You cannot joke with a policeman, because he can bring you immense trouble. We do fear. People fear.

Interviewer: Why do you think people fear?

Idowu: Because it's a deadly disease…

Interviewer: Why is it a deadly disease?

Idowu: Because you can die in fact…

(Idowu 33 year old male – Pre test interview Riruta)

Death from HIV was not just an inevitable end to the infection but was also expected to come as soon as one became aware of his HIV status:

> *I think when an individual is told he has HIV he sees as though he will die there and then. (Makori 72 year old male – Pre test interview Riruta)*

Knowing one's status was consequently seen as a way of finding out about an impending death. This notion has its roots in the past disease prognosis when people living with HIV suffered debilitating symptoms and died within a few years of falling sick because there was no treatment available to manage HIV.

Currently there is widespread use of antiretroviral (ARVs) drugs which have not only altered the disease progression but also ensured people live longer and healthier lives with HIV. However, the fact that there are people who are not diagnosed promptly and die soon after (late) diagnosis creates a situation that provides lay people with 'proof' that HIV is indeed a killer. A number of patients believed that although ARVs were now widely available, they were still not a cure for HIV but rather simply delayed the inevitability of death:

> *In the end won't he just die? But isn't that drug for protection only. A person will die. (Ekirapa 40 year old male Pre test interview - Riruta)*

The participants acknowledged the professional position that HIV was a manageable disease but from their experience they observed that people still died soon after HIV diagnosis. Indeed one of the participants, Alphonso, who had tested HIV positive died two weeks after his HIV test. During the follow up interview his wife said:

> *He just died. He was feeling dizzy and his body was weak. That is what continued until he died in the end. He had diarrhoea for two days and then he died. (Mrs. Alphonso – follow up interview - Mbagathi)*

Alphonso was a 42 year old man who had for the past five years refused to take a HIV test despite his wife (Mrs Alphonso) testing HIV positive during an antenatal HIV test. Alphonso finally tested through PITC after he came to the hospital with complaints of weakness, dizziness and weight loss. Coincidentally, during the pre test interview Alphonso had talked about instances where people died immediately after finding out they had HIV:

> *There are some people who when tested die the same day. (Alphonso 42 year old male, pre test interview - Mbagathi)*

In the case of Alphonso, the delay in getting a HIV test may have been responsible for his poor prognosis and rapid death. However, the respondents repeatedly observed similar scenarios in the community, a situation which caused fear and anxiety that being HIV positive meant the worst case scenario: impending death. At the same time an individual can be asymptomatic despite having HIV if one is on a successful course of

ARVs or prior to the onset of AIDS. The asymptomatic state, which can last for years, is not visible to others and therefore lay observations are not able to identify these cases of people living long and healthy lives despite suffering from HIV. The witnessed deaths following an HIV positive diagnosis facilitated the establishment of the link between HIV and death. It also provided lay people with evidence of the limitations of the treatment contrary to the health promotion information that HIV was now a manageable chronic disease. The observed incidences of death from HIV were more powerful than the awareness of improved prognosis due to the availability of treatment. This formed a rational basis for lay people to take certain actions (or not) like avoiding to take a HIV test. A HIV positive diagnosis was accompanied with a lot of stress because it meant that the patient had to constantly worry about death. In this situation uncertainty of one's HIV status was preferable to the knowledge that one is HIV positive.

6.2.2 The course of HIV infection

A person known to have HIV was expected to suffer difficult and often debilitating symptoms. The symptoms of HIV were widely thought to be difficult to hide from others and consisted of a steady decline from being healthy to dying as one moved from being HIV positive to the AIDS phase of the infection.

A key symptom in the course of HIV infection was progressive weight loss which visibly affected the body of the infected person and caused a degree of dread of HIV:

> *Eeh (yes) you see the way when a person gets HIV she gets sick. The, the body gets finished, as in when a person gets this disease she sees that now she is finished, her life is over. (Ameka 26 year old female – Pre test interview - Mbagathi)*

The insidious visible course of HIV was noted as distinct from other common diseases observed in the community:

> *Malaria I can say is malaria because malaria sometimes you can see the way it is taking you. You can be fat and you have malaria but if you see as though you have that disease [HIV] you are seen to continue getting finished slowly, slowly, slowly. (Bosco 26 year old male– Pre test interview - Mbagathi)*

The phrase 'getting finished'[14] was widely used to denote the fact that the weight loss was symbolically an indication of one's life draining away. The weight loss which was observable to others in the society made it difficult to hide a HIV diagnosis which made others privy to circumstances that a HIV positive person worked hard to keep a secret. This inevitably broke the confidentiality of a person's HIV status causing further anxiety about a HIV positive diagnosis.

Weight loss or deterioration of a person's health due to other causes was likely to be attributed to HIV even when that was not the case. As one participant describes below, the toll that the hardships that one faced when living in an urban area with little money to spare for food took on one's body were often construed as evidence of HIV infection:

[14] 'Getting finished' was used to denote progressive weight loss that culminated in a person with HIV dying.

> *When people see a person who was previously fat start losing weight, they say that person has HIV. They start saying that your life is headed for death. You must be having HIV. Just because of losing a little. You know here in this town life is very difficult. But if you go out there, the inability to afford all meals makes you lose weight but they will say it's because you have HIV. (Khamisi 24 year old male – Pre test interview - Riruta)*

The fact that it was difficult to hide HIV from others contributed to the distinctive nature of HIV. The noticeable course of the HIV infection not only reminded the sufferer that he was slowly dying but also made others privy to the presence of HIV and the health state of the person suspected to be HIV positive. No one in this study raised a concern about the bodily changes that take place following long term use of ART and how these changes often lead to unwarranted disclosure (Hardon & Posel, 2012; Kyakuwa & Hardon, 2012).

Whilst the inability to hide one's HIV status due to the visible symptoms was seen as a problem, one patient expressed the challenge that the altered course of the HIV infection triggered. The lack of weight loss and other observable symptoms made it difficult for others to identify a HIV positive person. This view was expressed by only one participant:

> *HIV – that disease is real, and right now it is there in plenty, especially now that these drugs are available, these ARVs, you find a person is fat, is smart, if you are told this person is positive you wouldn't believe. And these people have become smart; they are the ones spreading that disease. They are the ones spreading that*

disease. (Ameka 26 year old female – Pre test interview)

Two other participants, Kwamboka and Wamugunda also talked about situations where HIV positive people knowingly spreading HIV to others although they did not talk about this in relation to the use of ARVs.

The wide use of ARVs creates a paradox whereby on one hand it improves the quality of life of PLHIV whilst on the other hand there is concern that it may fuel the spread of HIV because of concealing the apparent symptoms of HIV/AIDS. In an environment where HIV was historically known to present with specific observable symptoms like weight loss, a system of 'diagnosing' others based on apparent symptoms has been rife. The success of ARV treatment results in only the untreated and late diagnosed cases being visible to others. These untreated cases continue to provide a basis for people's negative views about HIV and perpetuate the view that HIV infection inevitably debilitates and kills.

The belief that HIV was a debilitating and killer disease gave rise to concerns about one's future and that of their dependants particularly children:

> *You know a person usually just sees death? You see like me am a mother and am single, am the one who brings up my children alone. Now if you know you have it, you get worried when you look at your children. You start to ask yourself, "Who will I leave with these children?" So you get worried which affects you, you get stressed and that affects you. (Adhiambo 33 year old female – Pre test interview - Riruta)*

> *It is like for example if you have small children you might wonder who you will leave your children with. Or if you have other people depending on you within the family, you wonder where you will leave all these people. (Njeri 22 year old female – Pre test interview - Riruta)*

One of the counsellors echoed these sentiments and saw this as a deterrent to uptake of HIV testing:

> *Sometimes they have fear of the unknown, they have fear of maybe whether… and fear of life maybe I am a mother and then who will be left with my kid looking after him/her who will be left with my child? Who can take care of my child? I fear that now if am positive maybe I will lose my job or stigma at the place of work. I think those are some of the things why they are not tested. (Jelimo Counsellor - Mbagathi)*

The above excerpts illustrate the difficulties of dealing with HIV or even the possibility of a HIV positive result. A person not only has to deal with a very challenging illness but at the same time worry about what will happen to one's dependants once the individual gets too sick to take care of them or dies.

6.3 Stigma and discrimination

As discussed in the literature review chapter, stigma is often used to set apart people thought to possess defects or particular diseases that are presumed different or deviant. In the case of HIV, which is mainly a sexually transmitted infection (STI), it follows that the dread associated

with sexual transmission and the negative moral undertone of STIs shape how people with HIV are treated. As conveyed in the interviews discussed below, a HIV positive person is seen to be not only responsible for their illness but is also perceived to have contravened social and cultural norms. This theme is crucial because the meaning attached to a HIV positive diagnosis extends to a person's moral standing in society.

6.3.1 Culpability and deviance

Narratives from all the patients in my study revealed an association between HIV and a person's moral behavior. Words like 'prostitute', 'bad person', 'multiple sexual partners' and 'done wrong' were commonly used by the participants in this study when talking about HIV. These words were used with a moralistic undertone to infer transgression of what is considered acceptable moral sexual behavior. This finding has been echoed by other studies that have shown that HIV is often viewed as evidence of 'wrong doing' in a HIV positive individual (ActionAid International Kenya, 2009; Campbell, Foulis, Maimane, & Sibiya, 2005; Hamra, Ross, Orrs, & D'Agostino, 2006; Roura et al., 2008; Winskell, Hill, & Obyerodhyambo, 2013).

The fact that HIV is a sexually transmitted infection was a shared concern among all the participants. There was a common cultural understanding that HIV transmission was associated with promiscuity and having multiple sexual partners:

> *Eeh (Yes) you know people say those who have HIV move here and there. You find this girl whose status you do not know, you leave that one, you get another one again, you don't know her status,*

you go with her. Now things like those bring HIV. (Gakere 29 year old male – Pre test interview - Mbagathi)

A HIV positive diagnosis was seen as evidence of contravening socially acceptable norms of morality. Such a person was labelled immoral which resulted in shame particularly in a context where it was considered a taboo to contravene sexual rules:

Chacha: eehe (yes) they fear.

Interviewer: what do they fear?

Chacha: people knowing about them [having HIV].

Interviewer: so that other people do not know?

Chacha: eeh (yes).

Interviewer: because when people know?

Chacha: they will be ashamed.

Interviewer: why do people get ashamed?

Chacha: because of their behaviour.

(Chacha 29 year old male – Pre test interview - Mbagathi)

In this environment, having multiple sexual partners was considered wrong although there were gender differences in the application of this rule. Women were labelled as prostitutes for having more than one sexual partner or for having sex outside marriage. Yet, it was deemed acceptable for men to have more than one sexual partner to the extent that culturally polygamy was recognized. In addition, having more than one sexual partner or having sex outside marriage among men was secretly condoned and no one openly condemned it. However, with HIV in the picture, even men in some cases did find themselves labelled for having illicit sexual

partners. Since sexual behaviour was viewed as a personal choice by the individual, being HIV positive brought with it an element of culpability for one's illness.

Consequently, patients perceived or known to be HIV positive were faced with gossip about their perceived infringement of social norms in the communities where they lived. Several participants explained the situation vividly:

> *They assume that maybe, maybe she was a prostitute. [They say] She was a prostitute who did this and that, so she is suspected of many things. (Kwamboka 22 year old female – Pre test interview - Mbagathi)*

> *They view them [PLHIV] badly, it is as if they are no longer human beings. People gossip about them out there saying that they have the illness [HIV], and that their life is over. They don't even want to share things with them. Even eating together with them they do not want to or even stay with them… (Kanoni 30 year old female – Pre test interview - Riruta)*

Blame was one of the key characteristics of stigma where the affected individual was held responsible for their predicament. A distinction was drawn between those who were held responsible for their HIV status and those who were deemed innocent. While sharing their experiences in relation to stigma, a few participants explained the need to avoid stigmatising HIV positive people because it was not in all cases that people were responsible for their HIV positive status:

> *They are just human beings and you cannot know how she got that disease [HIV]. It is not a must that she got it through sex. Maybe she got it through an accident or she was injected with a needle that had the virus. Now you cannot say you are isolating her because she has AIDS. Or the husband has brought it to her. She is innocent. You cannot know. (Ameka 26 year old female – Pre test interview - Mbagathi)*

The fact that someone else may have brought the infection to the person in question created a sense of compassion. In this case, the individual in question was not considered culpable for their status and thus did not deserve to be stigmatised.

In the background of these negative HIV perceptions and labelling of PLHIV, people may shy away from taking a HIV test or focus on keeping their HIV status a secret at the expense of seeking treatment and support for fear of others becoming aware of their HIV status. Indeed, the following quote by one of the participants summarises how being seen in a HIV testing centre can lead to questions being raised about one's moral standing and conclusions made that one is HIV positive:

> *Others think that maybe if you come here [HIV testing centre] you will meet with people who know you, they will think you are a prostitute that is why you want to be tested. A person does not want to be seen by another one when she goes for testing. Now you think that. Won't they think I am a prostitute? And they know am in a relationship with so and so or maybe for example I am*

> *Christian, a person who is a Christian fears. If I am found by someone here who is not a Christian, she will say so and so had come to be tested does she really pretend that she is a Christian. Now many people refuse to come because of embarrassment. They don't want to be known they go to VCT. (Adhiambo 33 year old female – Pre test interview - Riruta)*

Similar sentiments were expressed by the counsellors during their interviews. All the counsellors attributed the patients' intense fear of testing for HIV to the widespread stigma associated with a HIV test, the fear of the unknown following a HIV test and the lack of information and awareness about the importance of knowing one's status:

> *The first reason I think is the stigma. The people fear to be stigmatized because for example when people go for door to door testing where they find that people will say that those who go there [for HIV testing] they know themselves. So you are stigmatized in the community. Another thing is people are not enlightened, they do not have information. (Waithera Counsellor Interview - Mbagathi)*

> *Most people do not know the advantages of knowing their status so they just ignore. If they don't know they don't come for testing. (Abdul Counsellor Interview - Riruta)*

In contrast to the many reports about isolation and discrimination of HIV positive persons, two participants felt that there was currently less stigma and discrimination than what was witnessed years ago:

> *A human being is a human being there is no seclusion. They will*

eat together because today this person has it, tomorrow it will be you. Now there used to be fear a long time ago but right now, I don't see it. (Alphonso 42 year old male Pre test interview - Mbagathi)

I don't think people with HIV are isolated much; they live together with other people. In the past people were scared of staying with a HIV positive person and you could not eat together with such a person, greet him, but now people live together with such people even if they suspect them [of having HIV]. There is no fear. (Makori 72 year old male – Pre test interview - Riruta).

These two participants had similar circumstances since they were living with spouses who had tested HIV positive. Alphonso's wife had repeatedly tested HIV positive although Alphonso had persistently refused to test and insisted that he was HIV negative. His current HIV test revealed that he was HIV positive. It was quite interesting that in spite of his view about stigma, he had not sought a HIV test although his wife had been HIV positive for the last 5 years. Even so, at a different point of the same interview, he reported that people often work hard to keep their diagnosis a secret so as to avoid discrimination.

Makori had inherited his late brother's wife only to learn later that she was HIV positive. His HIV test after months of learning about his wife's HIV status had turned out to be negative. After several repeat tests he continued to receive a HIV negative: he was therefore in a discordant[15]

[15] Discordancy in HIV refers to a situation where one sexual partner is HIV negative whilst the other is HIV positive.

relationship. Makori's situation indicates the importance of both partners testing for HIV. It is important to point out at this point that Makori's inherited wife had not disclosed her status to him. Rather he had found out her status by chance.

Another participant who had a HIV positive sister was of the opinion that the treatment PLHIV received in the community was determined by how their close family members treated them:

> *You find that there is that issue of family, the close family, your wife, your husband also contribute to how society out there treats you. You see. If they neglect you and leave you alone then definitely even the community out there will do very little to help you. You see…. I have seen it. In my home, my elder sister is positive. She gave birth just the other day during post-election violence. I realised she comes home and she knows that there are some people who know but she waits to see how you people will react. But it's not everybody who knows, it's only me and my mum who know. You see. But then it's like she is my sister so what do I do? I have to support her in a way that she will fit in the society. Up to now nobody has suspected anything because me myself I don't talk about it. I was told by my mum but I did not ask her, but she knows that I know and my mum does not talk about it. Even when we go buy medication it's done in secret. I go I buy and bring [them] to her in secret. So there is no issue of exposing to each and every person that it's like this or that. And she feels good. She feels accepted. But unlike in cases where we turn our backs to her,*

and then she is left to fend for herself which is not fair. (Nangila 29 year old male – Pre test interview - Riruta)

From the above excerpt we see that keeping a HIV positive diagnosis a secret was a big part of avoiding stigma from the community. Ensuring normalcy in how family members treated their HIV positive relatives and not disclosing to others obscures the underlying HIV status. It also removes any undertones that might create the impression that there is a HIV positive person living in the homestead. It is also noteworthy that although Nangila found out about his sister's HIV status from his mother, he and his sister have never discussed her HIV status. This is despite the fact that Nangila is the one who brings his sister's HIV medication:

> Nangila talks a lot about his HIV positive sister during the pre test interview. His sister's HIV positive status is only known to him and his mother and they are the ones who take care of and obtain medication for her. His mother had told him about his sister's status. Interestingly, he and his sister have never talked about it. She, however, knows that Nangila knows her status (he is the one who goes to the chemist to purchase her ART). Nangila is aware that his sister knows that their mother had talked to him about it. I was surprised to find out that Nangila usually purchases the medication (ART) for his sister rather than obtain it free from Riruta Health centre. In course of the interview I asked him to find out more from Abdul the counsellor how and where he can get the ART for free. He did not seem too keen. Later on I had a conversation on the same with the counsellor (Abdul) during the reflection session after Nangila's HIV consultation. Abdul explained that there are some people who choose to buy the drugs rather than get the free ones so that they are not seen at HIV centres waiting for medication or waiting to be seen. (Field notes 20-07-10 Riruta)

Keeping discussions about his sister's HIV status away from everyday discussions in the family assisted in maintaining a sense of normalcy and facilitated what Moyer (2012) refers to as 'respectful concealment'. Non-

disclosure in this case played a role in maintaining the moral standing of the HIV positive person and ensured that respectful social relationships were sustained.

The availability of ARVs assists patients in managing stigma because the medication ensures that the obvious discernible symptoms of HIV remain hidden. Arguably, on the other hand, ARVs help perpetuate stigma by enabling many people to pass as not having HIV and consequently highlighting the cases of late diagnosis or treatment that have a very poor prognosis. Nonetheless, Nangila's extract seems to exemplify awareness of stigma through the great efforts taken to conceal his sister's status.

6.3.2 Distancing self from HIV

As examined in chapter 3 (section 3.3.2), Goffman postulates that stigmatising people by creating a feeling of 'otherness' and 'difference' gives people a feeling of comfort and personal invulnerability towards a particular risk or disease. From my findings people often talked about HIV as something that afflicted other people and one which they had no association with. For example, in a number of cases patients gave accounts of not having any idea about HIV or even knowing anyone who was infected with HIV. In a country where the HIV prevalence rate is quite high it was unlikely for one not to have heard of or know of an individual living with HIV:

> *I have not heard any story [about a HIV positive person]. Because when I leave my home to go to work, I go to work. When I leave work to go home, I go home. I do not involve myself with other things. (Kimathi 35 year old – Pre test interview - Mbagathi)*

Kimathi talked about having heard about HIV in the media but when it came to talking about people he may know with HIV he was noncommittal. By presenting the notion that they did not know anything related to HIV, the patients were adopting a position that they could not in any way be linked with an illness that was highly stigmatised and associated with issues that were frowned upon in the community. Not talking about a disease or subject matter that is considered a taboo ('verbal avoidance') provides a social distance from it and a sense of comfort (Wood & Lambert, 2008).

Distancing oneself from HIV had a direct impact on disclosure of HIV to others including sexual partners. HIV was handled with a lot of secrecy and pretence to the extent that people chose to talk about it in general terms rather than personalise it in case others got wind of their HIV positive status:

> *People talk [about HIV] in general. [They say] ah we are all dying from HIV but they cannot say I am dying from HIV or I am on treatment, they can't. That is a secret they keep in their heart. (Mrs. Alphonso - Pre test interview -Mbagathi)*

In this case, verbal distancing of self from HIV through general and vague talk was a means of attempting to conceal one's status from others and thus protect oneself from the risk of being stigmatised and rejected. Concealing one's status at the expense of support from family and friends is preferred to the risk of disclosing one's status only to be rejected by those close to you. Some participants gave examples of how people were

isolated and discriminated against when their HIV status became known in their communities:

> *You know back home I have seen several people being detested at some point. Even if you are a lady you are detested in your homestead and rejected. It gets to a point that you are even insulted and accused of bringing the infection and therefore you should take care of yourself when you are sick. That time you have no strength and the illness has overcome you. You need help from others but at that moment they reject you. (Shiku 32 year old female – Pre test interview - Riruta)*

In such instances, secrecy equals death becomes obsolete as PLHIV may suffer severe emotional and physical isolation and abuse. It is maintaining that delicate balance between the advantages versus disadvantages of disclosure that is of great concern to persons who have received a HIV positive diagnosis. It would appear that biomedical advantages of disclosure related to improved access and adherence to treatment pale in the face of social detriments of disclosure. Living with HIV therefore becomes a social process of managing secrecy of one's diagnosis in everyday social interactions.

Kenyan communities are characterised by strong social relationships among families which provide an important network for physical, emotional and social support to individuals. The stigma linked with HIV challenges these support networks and often results in individuals being isolated and without help as illustrated in the two excerpts above. A breakdown of these relationships particularly when one is in a situation

where they need both physical and emotional support to deal with HIV is a double blow to the patient's ability to cope.

The severing of family ties has an even greater impact since HIV has transformed into a chronic illness whose care and support has been shifted from the hospital to the community. PLHIV are no longer hospitalised throughout their illness and a lot of care and support is now dependent on family and friends. Patients who were well aware of this state of affairs faced a catch 22 situation: failure to disclose their status meant they did not get any care and support while disclosing posed the risk of rejection from the people they were expected to depend on. Consequently patients faced with a HIV positive diagnosis are likely to have untold pressure as they fathomed how they would face the difficult days which they knew would eventually come with the onset of AIDS.

6.3.3 Candidacy and self-risk assessment

The notion of candidacy has been discussed in chapter 3, section 3.3.1. According to this notion people in everyday life provide accounts of who is likely to suffer from a particular illness on the basis of identified risks drawn from lay experiences and observations and health promotion information. In a similar way participants in my study used their experiences and observations of HIV to make judgements about their own risk and that of others. In the case of HIV, the assessment of one's candidacy is compounded by the stigma and discrimination associated with HIV. Consequently, individual's acceptance of being at risk for HIV, may be viewed as synonymous to an acceptance of engaging in unacceptable [sexual] risky behaviour. This often resulted in poor self-risk assessment

even in instances where the patient was obviously engaged in risky sexual behaviour. Followed often by failure to seek a HIV test unless the HIV test was offered to the participant by a health care provider.

Across the pre test interviews there was a recurrent reference to the risks associated with HIV infection. Having HIV was associated with sexual promiscuity and as such people known to have multiple sexual partners were presumed to be HIV positive:

> *You know it is said that those who have HIV are the ones who move around. You get this lady whose status you don't know, you leave her, you get another one again whose status you don't know and go with her. Now things like that are the ones that bring HIV. (Gakere 29 year old male Pre test interview - Mbagathi)*

Interestingly, in assessing his own risk and need for HTC, Gakere 'painted' himself as a married man who did not engage in multiple sexual relationships and hence not at risk of HIV infection. For this reason he had never tested in spite of his wife attending PMTCT within the last three years of this study:

> *You know I cannot. I could not think of going for a HIV test because I knew that because I was married and it was not like I was having extra marital affairs. (Gakere 29 year old male Pre test interview - Mbagathi)*

Marriage was seen as a safety net that exempted individuals from being at risk of HIV infection. A number of patients saw their marital status as an obvious indicator that they could not possibly have or contract HIV:

> *You know when you have a wife and children; you do not think that things like that (getting HIV) can happen. (Ekirapa 40 year old male – Pre test interview - Riruta)*

This assumption was in keeping with the social expectation that required a married person to be faithful to their sexual partner. It indicates the patient's effort to strategically construct their presentation of self as a moral, upright person. As we will see in the next chapter, it affects how people behaved in the testing sessions. Nonetheless, this finding is significant in an environment where people in long term relationships account for approximately 45% of HIV reported incidences in Kenya. Especially, in the background of the findings reported in chapter five, which showed the low number of couple testing and counselling taking place in the study settings.

There was a feeling that those who are unmarried were likely to engage in sexual promiscuity and were automatically alleged to be at risk of having HIV. Therefore, if such an individual had an illness that was serious and mimicked the well-known signs of HIV such as severe illness accompanied with weight loss, it was presumed that they had the HIV infection:

> *Now there was a time I got sick and I was taken to the hospital even my own pastor was sent to come and see if I have AIDS. Now I have not been sleeping around, I know I have not had sex with any man. But I was very sick it was as if I was going to die the next minute. So I went to the church myself and took the paper to them to confirm that I did not have AIDS. It was malaria because I had travelled to [name of town] which is very hot and the other*

> *town which is a bit cool which contributed to getting malaria. And I got healed. But because I do not have a husband they said maybe because she does not have a husband she is sleeping around. You see that is wrong. I did not sleep around. And I don't have AIDS. I have malaria. (Lulu 41 year old female – Pre test interview - Riruta)*

Lulu was a very religious widow who had been single for a while following the death of her first husband. She had come to the hospital for a review after she was discharged from the hospital following a miscarriage after recently marrying her second husband. Lulu talked passionately about how she had maintained her morality during the time she was single despite being suspected of being promiscuous by those around her. It did emerge from the interviews that she had tested frequently for HIV although she did not give the exact number. The frequent HIV testing during her widowhood was perhaps done in a bid to prove to her church members that she was HIV negative. A HIV negative result meant that the person did not fit the profile of a HIV positive person and therefore did not possess the characteristics (promiscuity) of a HIV candidate.

One participant felt that his unmarried status placed him in a situation that warranted him to have multiple sexual partners and that was why he chose to test often for HIV:

> *The thing I want, I like being tested because I have not married. I am still having fun. I want to test so that I can stop having fun. I stop those things of moving here and there. That is why I have come to test. (Khamisi 24 year old male Pre test interview - Riruta)*

Khamisi had come to the hospital for a repeat HIV test following a previous HIV test one month ago. Despite indicating that after the current HIV test he would alter his risky behaviour, he had tested several times before and not taken any steps to stop having multiple partners. On the one hand it is possible that after several HIV negative results despite his risky behaviour Khamisi had become complacent about the risk of contracting HIV. In that case he may not have seen the need to modify his behaviour since the HIV negative result gave him an assurance that he was still safe. The fact that he came back for a repeat test after only one month[16] instead of the stipulated three months could be an indication that this time round he was quite anxious that he may have contracted HIV. On the other hand, faced with the current HIV test, the reality of getting infected with HIV may have brought the realisation that he needs to change his risky behaviour.

Whatever the case might be, the conflict that Khamisi was facing illuminated the fact that adoption of health promoting behaviour was not a simple matter. Knowing his risk and being aware of the expected behaviour change in order to maintain his HIV negative result had not led to a modification of his lifestyle at the time of his current HIV test. One can postulate that knowing one's candidacy did not automatically result in an alteration of risky behaviour to avoid or reduce the risk of getting HIV.

Irrespective of one's marital status, there appeared to be a general low rate of appropriate self-risk assessment and subsequent action to seek a

[16] Khamisi on this occasion had deliberately come for a repeat test which is ideally done after three months following a HIV test that had been done previously.

HIV test. A perception that one was not a candidate and hence may not be at risk of HIV infection often resulted in a decision not to initiate a HIV test:

> *Interviewer: What has made you not take yourself for a HIV test?*
>
> *Chacha: Because I do not have the [HIV] infection. (Chacha 29 year old Pre test interview - Mbagathi)*

Another participant Makau indicated that he and his girlfriend have never sought a HIV test before since they did not think they could be infected. However, in spite of this Makau explained humorously his attempts to self-refer for a HIV test which often resulted in him paying several visits to a VCT centre and leaving without getting tested. The PITC test done at the time of data collection was his first HIV test. He received a HIV negative result:

> *Interviewer: Before today, have you ever considered going for a HIV test?*
>
> *Makau: I have thought about it. But when I get to the door [of the VCT centre], I go back home*
>
> *Interviewer: So you have considered testing before*
>
> *Makau: Of course. But when I get to the door, I go back. I am scared*
>
> *Interviewer: What are you scared of?*
>
> *Makau: They may give me results that I am not expecting?*
>
> *Interviewer: In what way?*
>
> *Makau: The results I receive may shock me*
>
> *(Makau 21 year old male Pre test interview - Mbagathi)*

The counsellors were supportive of the PITC approach to HIV testing. They felt was appropriate in an environment where lay people ordinarily feared taking a HIV test and rarely took the initiative to seek a HIV test. The counsellors were of the opinion that the routine HIV test accorded people who would not ordinarily test a chance to know their status:

> *According to me I feel PITC is a good approach because it helps us attend to clients who most of whom have never even tested. You know some people just stay at home unless they are sick they will never go to a hospital, they will never even visit a VCT site. So PITC is an approach that is actually working. (Ihuoma Counsellor Interview - Riruta)*

> *When you see a patient coming to [name of hospital] that patient is sick and maybe he has tried several places. So am helping this client to come out of that and to get the right treatment. Because for example if there is not PITC we would just treat malaria and that person will keep on… and maybe we will not help this patient to at least cut the life expectancy. (Jelimo Counsellor Interview – Mbagathi)*

Poor self-risk assessment and the general distancing of one self from HIV to avoid stigmatization were key deterrents to seeking HTC. These findings provide a good rationale for the implementation of PITC in clinical settings. It assists in ensuring that patients who are scared of HIV testing or who do not necessarily perceive themselves as being at risk, receive a HIV test

when they come into contact with a health care provider in the course of seeking treatment.

The ingrained lay perceptions about HIV remained unchanged even after the participants had gone through the counselling sessions. The HIV test results, whether positive or negative, were not just viewed in the context of physical wellbeing. Patients viewed the meaning of the HIV test result in the context of its moral implication. For example, patients who were diagnosed HIV negative felt their result demonstrated that they were not promiscuous:

> *Interviewer: what does being informed you don't have HIV mean to you?*
>
> *Ekirapa: It means that I don't move around.*
>
> *(Ekirapa 40 year old male Post test interview - Riruta)*

The HIV test result was also seen to denote the sexual partner's fidelity. A HIV positive result meant the spouse is unfaithful while a HIV negative result meant that the sexual partner is faithful:

> *Interviewer: the result you have just been given, what does it mean to you?*
>
> *Ameka: it means am faithful to my husband and my husband is faithful to me.*
>
> *(Ameka 26 year old female Post test interview - Mbagathi)*

Though a simplistic way of judging immorality and breaking of social norms, the social meaning and implication of the HIV test result is important to the patients as it fits into their already existing beliefs about HIV. This explains why after a HIV negative result a few patients suddenly became a little more open about their risky behaviour during the post test interview. In contrast, the patients who were HIV positive continued to distance themselves from 'questionable' behaviour linked to a HIV positive diagnosis. Indeed, two of the four patients who received a HIV positive result focused on clarifying during the post test interview that they did not engage in any bad behaviour and they were not sure how they would have received such a diagnosis.

This potential moral meaning of the HIV test could partly explain the degree of anxiety the patients talked about having prior to and during the HIV test and the great sense of relief they felt after receiving their HIV diagnosis.

6.4 Conclusion

This theme demonstrates that participants use lay and experiential knowledge to form perceptions about HIV. The health promotion information available e.g. messages on seeking HIV testing is therefore not utilised in its entirety but rather pulled out and used selectively and in conjunction with prior lay knowledge. Often it was the observed matters that took precedence over the available health information. For the majority of the participants, HIV was viewed with a great deal of apprehension because it was seen as a killer disease with debilitating symptoms. This coupled with the stigma associated with the fact that HIV

was primarily an STI shaped the meaning of a HIV positive diagnosis. A HIV positive status meant suffering, evidence of immorality and isolation from family and friends.

There are instances where individuals remained supportive of their relatives who were known to be HIV positive albeit trying to keep this concealed from others. In the face of the meaning of a HIV positive diagnosis, participants carefully constructed their own risk in order to position themselves in a certain way so as to maintain a good moral stance. The meanings attached to a HIV positive diagnosis negatively impacted on decisions to self-refer for HTC. Consequently, PITC provided an avenue for participants who would ordinarily fail to seek a HIV test to receive a HIV test offer and get tested: increasing coverage of HIV testing in this context.

This theme is important because it illuminates the competing explanations about HIV. The participants' accounts reflected the apparent shifting perspectives about HIV and HIV testing depending on the situation at hand. It also highlights the impact of perceptions about HIV on prevention, treatment and care. Further on, as we will see in the next chapter, awareness of the lay constructions of HIV provided insight when analysing the patients' actions and views during the HIV test and the role they play during the PITC consultation.

7 CHAPTER SEVEN: MANAGING THE PITC CONSULTATION

7.1 Introduction

In the previous chapter the respondents' perceptions about HIV and HIV testing were discussed. It emerged that patients came from a social background where HIV was viewed as a killer disease often associated with immorality and sex. Both were culturally sanctioned taboos from which people went to great lengths to distance themselves. In the present chapter, the PITC consultation will be explored through the following categories and sub categories:

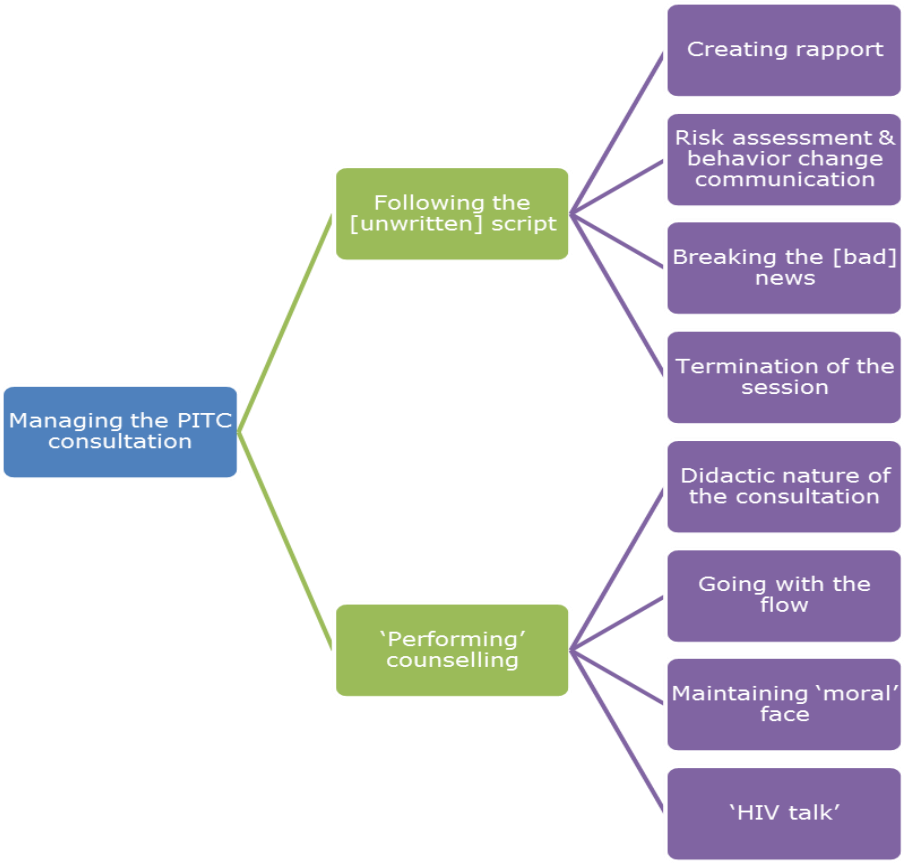


Figure 24 Constructing the PITC consultation

Twenty nine HIV testing consultations involving eight counsellors were examined. The HIV testing consultation generally included pre test counselling where information on how HIV is transmitted was covered and followed by an explanation of how the HIV test would be carried out and the results interpreted. The counsellors then carried out the HIV test and while waiting for the results engaged in a monologue that mainly included information on behaviour change in the event of a HIV negative result and what to do in the event of a HIV positive diagnosis. Once the required time for the HIV results to be ready had passed, the counsellors broke the news of the test results or asked the patients to read the results for themselves. This was quickly followed by a termination of the consultation either immediately or after recapping information relevant to the HIV test result. In exploring the PITC consultation, I will make comparisons between the PITC guideline recommendations and what the counsellors actually did during the consultations. There were small variations between counsellors but all the consultations examined followed a more or less similar sequence which was divergent to the recommended guidelines (see Figure 25 below).

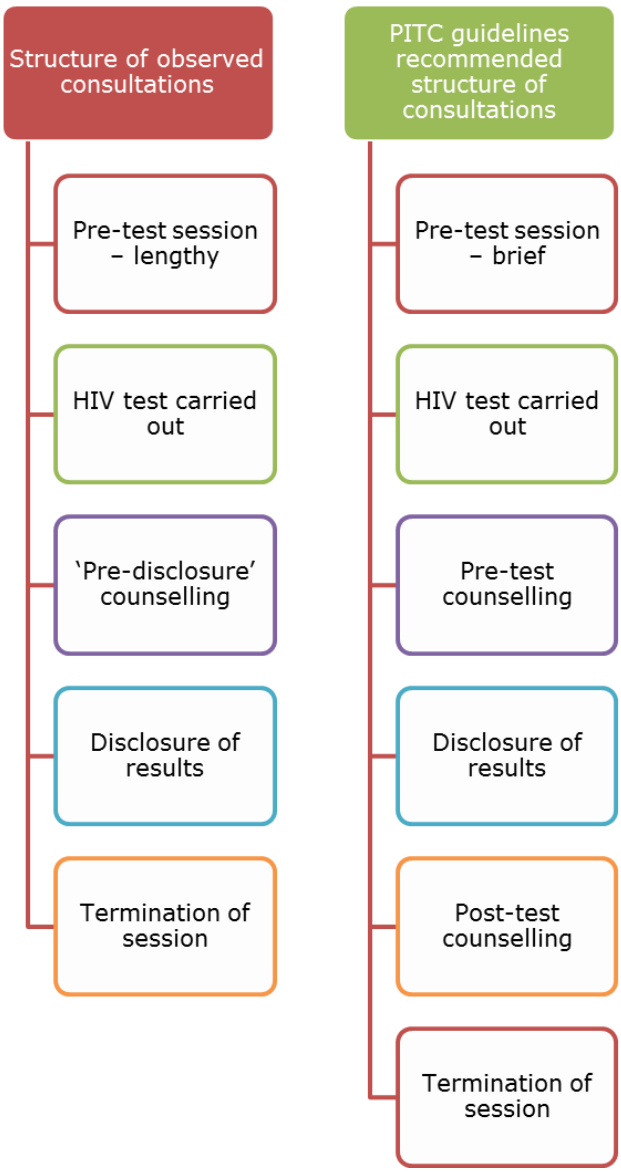


Figure 25 Structure of the consultation

7.2 Following the [unwritten] script

The majority of the counsellors adopted a similar structure in the consultation which differed from what was recommended by the PITC guidelines. For instance, the guidelines recommend a brief pre test counselling i.e. 'brief information giving session' and a detailed post test

counselling after the HIV test result is disclosed. However, the counsellors gave a detailed pre test counselling and slotted in 'pre-disclosure' counselling when waiting for the HIV test result to be ready which they considered as post test counselling. In this case although the information was framed as post test counselling in reality it was pre-disclosure counselling due to the fact that the patients HIV results were not yet known. This adjustment was necessitated by the fact that the counsellors were often left with time in between collecting the blood sample and the results being ready (approximately 15 minutes). They filled this time by giving the patient a substantial amount of information in a didactic fashion and hence were left with little or no information to discuss with the patients after the results were disclosed.

Even without using a written checklist during the consultation, the counsellors appeared to use a mental checklist that required them to follow a specific order when covering various topics. In cases where the next topic was forgotten the counsellor retracted what s/he was about to discuss and focused on what s/he had left out first before proceeding to the next topic. For example, during the consultation with Bosco, Hazina had forgotten to explain how the test results will be interpreted prior to carrying out the HIV test but remembered just as she was about to draw the blood sample for the HIV test. Instead of carrying on with drawing the sample and then explaining the result interpretation while waiting for the results, she stopped the process of collecting the sample and explained what she had missed out before proceeding:

Hazina[17]: Mm. Sit over there we test [pointing at the table where the test is to be carried out].

Bosco: I will sit.

Hazina: mm?

Bosco: I will sit.

Hazina: It is alright.

Bosco: If there is no death.

Hazina: mm?

Bosco: If there is not dying then I will sit [counsellor and Bosco walk to the table where the test is to be carried out].

Hazina: You will not die [counsellor starts to put on gloves].

Bosco: And you find that someone has it?

Hazina: Oh sorry [counsellor remembers she had not explained and shown the client the chart on how to interpret the HIV test result from the rapid test kit. Ungloves]. Now there is thing I will show you that we will test with. You have told me that you have been tested before?

Bosco: I have not been tested.

Hazina: You have not been tested? Now we test with these gadgets of testing. If you see two lines emerging, it means you have the virus, when one line emerges it means you don't have the virus. Have you understood?

(Counselling session - Mbagathi)

[17] In this interaction, Hazina was the counsellor and Bosco the patient.

The practice of sticking to a strict structure and sequence was also observed when patients asked questions which would have required the counsellor to take a detour from the planned structure to first handle the patients' concerns. In such situations, the counsellors put off answering the patients' questions until later when they planned to discuss issues related to the patients' query. From this example it is evident that despite not having a checklist to follow during the time of the consultation, the counsellors are rather formulaic and inflexible with the structure of the consultation, leaving little or no room for alteration of the content or the order they prefer to follow. These findings suggest that by following a specific rigid structure the counsellors are able to feel in control of an otherwise volatile consultation laden with heavy emotional tension and involving discussions of sensitive and often taboo topics. A rigid structure also routinizes the consultation and makes it largely non-patient centred which consequently allows the counsellors to get through a rather uncomfortable interaction. What is interesting is that although the structure used by the counsellors differed from the PITC guideline, it was generally similar among all the counsellors. This raises the question about how the counsellors chose the structure they were using and why, despite not using a checklist at the point of delivery, the majority of the counsellors followed the same structure and sequence to the letter.

In order to further illuminate the didactic nature of the HIV testing consultation, the subsequent section presents how key sections of the counselling and testing process were tackled. This will be explored using four key steps of the HIV testing consultation namely:

1. Creating rapport
2. Risk assessment and behaviour change communication
3. Breaking the [bad] news
4. Termination of the consultation

7.2.1 Creating rapport

The organisational structure in which PITC was implemented influenced creation of rapport between the counsellor and the patient. The organisational structure at the outpatient department meant that the counsellors and patients had only one brief opportunity to meet and go through the HIV testing consultation. Patients came for treatment on the same day and were referred for PITC and expected to carry on with the next step of treatment after the HIV test. It was during this first encounter that the counsellors were expected to create rapport, offer and carry out the HIV test and engage in a discussion that included sensitive and personal information e.g. sexual behaviour. In contrast, counsellors at the inpatient department had an opportunity to meet patients prior to the testing consultation since the patients were admitted to the ward and were there for a period of time.

Observations of the two counsellors based at the outpatient department revealed that they both made an informal walk about meeting the patients who required PITC. During this initial meeting the counsellors introduced themselves, inquired about the patients' general wellbeing and health, explained why they were there and obtained a few details from the patient such as information about any previous HIV tests. They then explained

that they would return shortly to carry out the HIV test. Consequently, when it came to the actual HIV testing consultation, the counsellors in the inpatient department were not meeting the patients for the first time and the basis of the interaction was slightly different from the sessions conducted at the outpatient department.

The counsellors in the study consultations initiated their sessions in different ways with only one observed session beginning with greetings.

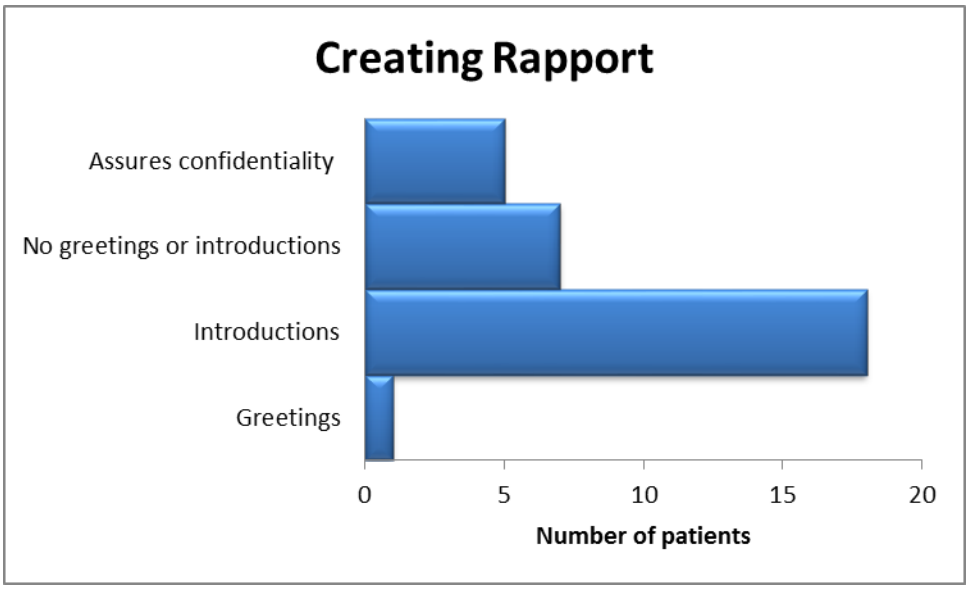


Figure 26 Creating rapport

Whilst it would be expected that all the counselling consultations would begin with introductions and greetings, only four of the eight counsellors (Maria, Opiyo, Jelimo and Bhoke) started all their sessions by introducing themselves and informing the patients about their role:

> *My name is Jelimo and I work here as a counsellor. (Jelimo - female counsellor - Mbagathi)*

My name is Maria and I am a counsellor. What is your name? (Maria, female counsellor - Mbagathi)

The other four counsellors skipped the greetings and introductions and went straight to asking the patients to explain why they had been referred by the doctor or what they had come to see the counsellor for:

Waithera[18]: Has the doctor told you why he has sent you here?

Salim: I have just been sent here.

Waithera: You have just been sent? He did not tell you what you are coming to do in this room?

Salim: I was not told he just wrote this [this paper] for me.

Waithera: What did he tell you?

Salim: He told me to come for counselling here and if possible I should know their status.

Waithera: What do you think of this HIV/AIDS?

Salim: In what way?

(Counselling session - Mbagathi)

Consultations that begun like the one illustrated above did not set the scene for an interaction that would involve talking about personal and sensitive issues. In this situation the counsellors appeared eager to get down to the business at hand rather than spend time creating rapport and

[18] In this interaction, Waithera was the counsellor and Salim the patient.

attempting to set the scene in preparation for the consultation. Arguably, by failing to create rapport at the beginning of the consultation, the counsellors were deliberately distancing themselves from the patients and setting the tone for a professionally dominated and didactically delivered counselling and testing session.

The PITC guideline strongly recommends that confidentiality is one of the key components of the PITC process and that patients should be assured that confidentiality will be maintained during the testing process. However, only two counsellors assured patients of confidentiality at the start of the session while a third counsellor included information on confidentiality after collecting the blood sample for the HIV test:

> *When we carry out the [HIV] test here, everything we do remains confidential that it's a secret. It does not go beyond this door. Everything that happens here remains here. (Opiyo, male counsellor - Riruta)*

> *I cannot go and tell your sister that I have tested you and you have this disease and there is no doctor who has the right to let that secret known to anyone. You are the only one who can tell (disclose) to the person you want to. (Bhoke, female counsellor - Mbagathi)*

Assuring patients about the confidentiality of the information divulged during the session including the HIV test results would arguably contribute to making the patient feel at ease and more comfortable in being open during the consultation.

7.2.2 Risk assessment and behaviour change communication

The objective of the HIV testing consultation according to the PITC guideline is to assess patient's risk for HIV and provide relevant information to facilitate modification of risky behaviour and adoption of behaviour that will protect the individual from risk of getting HIV. In order to carry out an effective risk assessment, the counsellors are expected to obtain information about the patient's social circumstances including the number of sexual partners, use of condoms and previous HIV test and results. On the basis of the information obtained from the risk assessment, the counsellors are expected to tailor the post test counselling (behaviour change communication) to suit the patient's social situation. However, the HIV testing consultations examined presented a different picture where risk assessment was not done at all in 10 consultations.

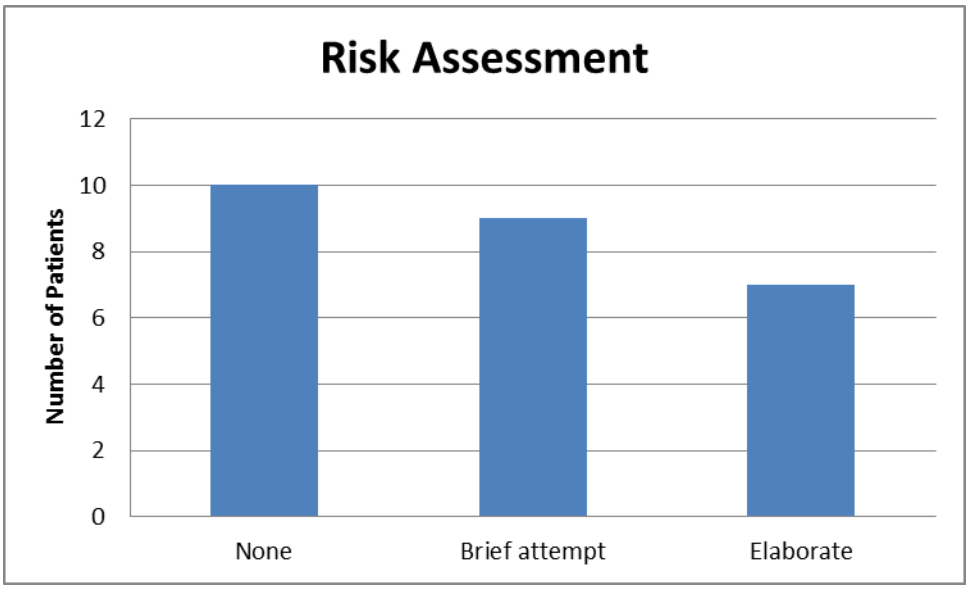


Figure 27 Risk assessment

An evaluation of the counselling sessions revealed that only one counsellor did a risk assessment for all her patients while another counsellor, Maria, did not do a risk assessment at all for the two patients she tested. The other counsellors presented a mixed picture. On the one hand they undertook a risk assessment with some of their patients while on the other hand they indirectly carried out a risk assessment by vaguely asking about engagement in extra marital relationships with other patients. One such example is Hazina in the three sessions I was able to observe and audio record. In the first session, Hazina did a risk assessment by finding out the patient's HIV testing history and if he had engaged in any extra marital affairs. In the second session, Hazina indirectly attempted to do a risk assessment by making suggestive remarks:

> *Hazina: … but you know everyone knows his lifestyle, the way you have been living your life, something like that.*
>
> *Kimathi: Eeh.*
>
> *Hazina: If you had a friend.*
>
> *Kimathi: If I turn out to be HIV positive you will give me information on how to live.*
>
> *(Counselling session - Mbagathi)*

In the above excerpt the counsellor's language implied that she was talking about the patient's sexual behaviour but without directly asking him about it. The patient on the other hand appeared to have understood the intended purpose of the counsellor's statements but he preferred not

to give a response. In the third session the counsellor did not carry out any risk assessment at all.

Counsellors appeared to have a feeling that they were intruding into the patient's personal life when assessing for risk:

Waithera: Do you have a friend? Do you have a wife?

Chacha: No.

Waithera: Now the reason I am asking it not because I want to intrude into your personal life at all.

(Counselling session - Mbagathi)

Indeed the risk assessment involves probing into an individual's lifestyle and evaluating their sexual behaviour since the majority of HIV infections are sexually transmitted. Yet as discussed in the previous chapter, there is a general cultural view that discussion of sex is taboo and people often find it difficult to openly talk about it. The difficulties of assessing risky behaviour were also illuminated in situations where counsellors abandoned the endeavour after the patient's responses to the questions were either evasive or reflected a reluctance to engage in such a discussion:

Jelimo[19]: Are you married?

Nyamai: Me?

Jelimo: Yes.

[19] In this interaction, Jelimo was the counsellor and Nyamai the patient.

Nyamai: Now can someone like me fail to have a wife really?

Jelimo: It is good to ask. I did not mean to offend you.

(Counselling session - Mbagathi)

In the above scenario we find that Jelimo started her risk assessment by inquiring about the patient's marital status. This strategy was used to start the risk assessment by a number of counsellors. The extent to which the counsellors either carried on with the risk assessment or abandoned the effort and moved on to discuss other issues was often based on the patient's response. Let us look at another example of risk assessment by Jelimo in a counselling session with a different patient:

Jelimo: Are you married?

Makau: Not yet.

Jelimo: Do you have friends?

Makau: Yes.

Jelimo: Do you use protection?

Makau: No.

Jelimo: Before you knew each other [had sex] did you test?

Makau: No.

Jelimo: And didn't you think about testing?

Makau: We thought we were alright.

(Counselling session - Mbagathi)

The patient's responsiveness and openness in the above excerpt facilitated a more thorough probing of the patient's risky situation. Nonetheless the phrases used are highly coded but mutually understood by both the patient and the counsellor. For instance *'friends'* meant *'sexual partners'* and *'know each other'* inferred *'have sex'*. However, there were a number of situations where the counsellors did not do a risk assessment at all and therefore it is difficult to attribute the lack of risk assessment entirely to the patient's responses.

Following a risk assessment, the PITC process requires that the counsellor carries out behaviour change communication to enable patients to identify risky behaviour and adopt health promoting behaviour. Only nine patients received elaborate behaviour change information with the rest receiving brief or no information associated with behaviour change geared towards aiding the patients in maintaining a HIV negative result.

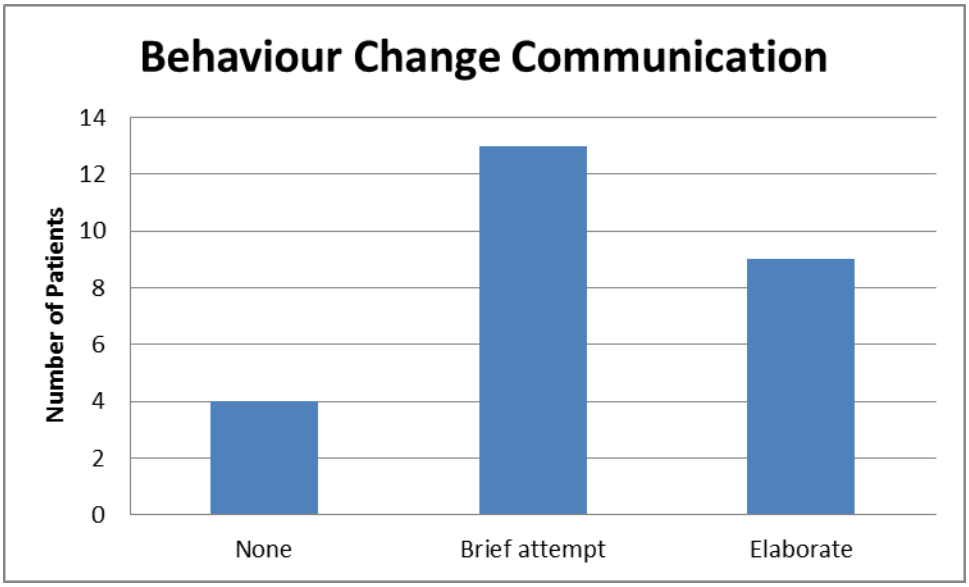


Figure 28 Behaviour change communication

In instances where behaviour change information was given, the nature of the information shared was generic and not client specific. This is because behaviour change communication was in most cases not preceded by a risk assessment. Consequently, the counsellors were not privy to the patient's social circumstances, including their risky behaviour, which were a prerequisite to the provision of individualised information. At the same time, the information was given prior to the disclosure of the results making it difficult for the counsellors to tailor it to the patient's circumstances and needs.

The examination of the consultation further revealed that there was more focus on information relating to a HIV positive as opposed to a HIV negative result. However, from my sample only four out of the 29 patients whose HIV testing consultations I observed turned out to be HIV positive. It therefore means the 25 patients who received a HIV negative result were not able to benefit from vital information on HIV prevention and behaviour change tailored to their circumstances. The information given prior to the test results despite being framed as 'post test counselling' in this situation did not address the needs of the patients' results. Consequently, the HIV prevention objective of the PITC guideline is not visibly dealt with in these consultations.

7.2.3 Breaking the news

Interpreting the rapid HIV test results involves identifying the number of red lines that appear in the testing strip. A single red line denotes a HIV negative result while two red lines denote a HIV positive result as illustrated in the diagram below.



Figure 29: A HIV positive result reading

The counsellors commenced the process of explaining what the HIV test involved and how the results will be interpreted during the pre test counselling session. This included an explanation of how the test would be done and how the test results would be interpreted:

> *This is the kit we will use to test and we will follow these instructions… This is how the kit looks when it has not been used and if you look there is this line which we call the control and there is a space. Now in this space, a line can surface. This is where we put blood, two drops of blood and the reagent will be put in this area. When the reaction occurs the reagent will mix with the blood and rise just like fuel rises in a tank. Now if one line appears here, the result is obsolete because the kit has expired and therefore we would have to repeat the test. Two lines, one above the control and the other one below means you have HIV… (Abdul, male counsellor - Riruta)*

The general process of breaking the news involved the counsellor asking the patient how many lines s/he can see on the testing strip and what they mean:

Maria[20]: So Kwamboka, here are your results…… how are your results?

Kwamboka: They are ok.

Maria: So how many red lines can you see? You told me you are able to read. You can see?

Kwamboka: That one, yes.

Maria: How many?

Kwamboka: One

Maria: And the second test kit?

Kwamboka: Only one.

Maria: What does one red line mean?

Kwamboka: You are negative.

(Counselling session - Mbagathi)

In some instances the patients were able to make a correct interpretation of their results as in the example above. In others, however, the counsellor ended up breaking the news rather than inviting the patient to do it:

Jelimo: Now if you check here based on what we talked about earlier, what did we say one line meant?

Nyamai: They are three [lines].

Jelimo: I am saying when there is one line; a person does not have the virus. If there are two you have the virus the person has the

[20] In this interaction, Maria was the counsellor and Kwamboka the patient.

virus. How many [lines] are there? How many lines does yours have? It is one line which means you do not have the virus. Ok?

Nyamai: Hmmm.

Jelimo: I am grateful for your time.

Nyamai: Thank you. (Session comes to an end)

(Counselling session - Mbagathi)

In the five consultations where the patients failed to correctly interpret the results for themselves they appeared to have expressed some uncertainty and even suspicion that they might be HIV positive. The patient's refusal or reluctance to interpret the results is an indication of the apprehension that they experienced as they anxiously waited to know their HIV status. By making patients deduce the results for themselves, the counsellors were distancing themselves from the stress of having to break bad news, deflecting the responsibility towards the patient. Interestingly, the process of breaking the news even when it was a HIV positive result appeared emotionless in all observed consultations except one. In the interaction between Bhoke (counsellor) and Wayua I could feel the counsellor's struggle as she led her patient Wayua to interpret her own results:

Bhoke[21]: Now I would like us to read out results. Let us start with this one. How many lines can you see?

Wayua: Two.

[21] In this interaction, Bhoke was the counsellor and Wayua the patient.

Bhoke: Two. Ok. And in this one?

Wayua: Two.

Bhoke: Both are showing two [lines]. What does that mean?

Wayua: I have the virus.

Bhoke: That is what it means. You have the virus in your body.

Wayua: (Gives a loud sigh).

(Counselling session - Mbagathi)

Subsequent interviews with the counsellors painted a different picture of their demeanour and strategy in the consultation. The counsellors cited the process of disclosing the test result, especially if this was bad news, as a difficult and emotional activity that weighed them down emotionally.

Maybe somebody has come, he doesn't know or she doesn't know her status. You just do the session joyful but at the end if you test that person and it comes positive, now that's where the problem is. Somebody came in thinking that am negative (laughs) and then if it turns to be positive now, there are others who may react in a different way maybe they are shocked so you have to deal with that situation till that person accepts the results although there are others who will completely refuse. They say no am ok, I have never been sick so am not positive. Those are also the challenges we face (laughs). (Abdul, counsellor interviews - Riruta)

> *Positive results are not good even for you. There are many times when you get overwhelmed. You put the results there and maybe this is someone who is the same age with your children and you know you are a human: am human even if am a counsellor. You think that this person has a long life ahead of him and then the results turn positive. Or maybe it's an old woman, you see your mother in that woman. So eeh in general positive results are not encouraging to give but since you have done your pre testing properly, the pre test shows how the results will be, how do you see? They interpret their results… I think it is good for them to interpret their own results. As you can see we have the charts, you talk about these charts and when you give them the results you tell them: 'according to this picture can you tell me how is your result?' So it becomes easier that way (Waithera, Counsellor interviews - Mbagathi)*

Allowing the patients to interpret their own results therefore seems to give the counsellors some sense of relief from the difficult task of giving bad news. It is evident that the counsellors felt they were quite emotionally involved in the consultation despite the observed/recorded consultations appearing to be very routinized and detached. They were perhaps adopting the process to 'protect' their emotional wellbeing. Nonetheless this may well be an example of public and private accounts. The counsellors presented themselves as engaging and caring (public account) whilst the observed consultations displayed the way they actually behaved: routinized, non-engaged and distant (private account).

In spite of the challenge of engaging in PITC and in particular having to deal with a very difficult interaction, the counsellors largely felt that they lacked support in terms of training and counsellor supervision. Lack of opportunities for further training was seen as a hindrance to equipping the counsellors with additional skills as well keeping up to date with new information and updates.

One counsellor felt that these vital training opportunities were often grabbed by senior nurses who were not directly involved in the provision of HIV testing within the health facility. There were however, organisational differences in this situation whereby the counsellors in Mbagathi were hardly given any opportunities to get access to training and updates while in Riruta there was a clear working system for this:

> *We are not involved. You see somebody, you see this update is supposed to be for counsellors but you will find us here working. Although there is always a shortage we need those feedback, we need those information because we are the people dealing with the people on the ground (Waithera, counsellor interviews - Mbagathi)*

> *In our organization if there is something new, all the counsellors are called in for a meeting, we are given the information. If it is something that's, that's urgent like ok, you have the information but there is something new but it is not so major, we are just sent an email and you print it out and you read it and you go on. And sometimes also the supervisors also go round checking what you are doing and if there is anything new they tell you. (Ihuoma. Counsellor interviews - Riruta)*

Failing to include counsellors who are involved in the direct implementation of the PITC policy creates a gap in the transmission of policies from the formulators to the implementers. It also means that counsellors are not able to adequately give feedback on the key issues that need to be considered in the formulation of guidelines to improve their ability to implement the PITC policy in the real world settings in which they work. It is noteworthy however that the training and updates were viewed by the counsellors from the perspective of getting information about HIV and treatment and not viewed as an opportunity to acquire training in the necessary 'soft skills' required during counselling like communication and obtaining informed consent.

7.2.4 Termination of the session

In the majority of the sessions, giving the results signalled the end of the counselling session with only 8 out of the 29 counselling sessions observed ending with an elaborate exploration of information relevant to the HIV test results and / or the patients' feelings after finding out their HIV status:

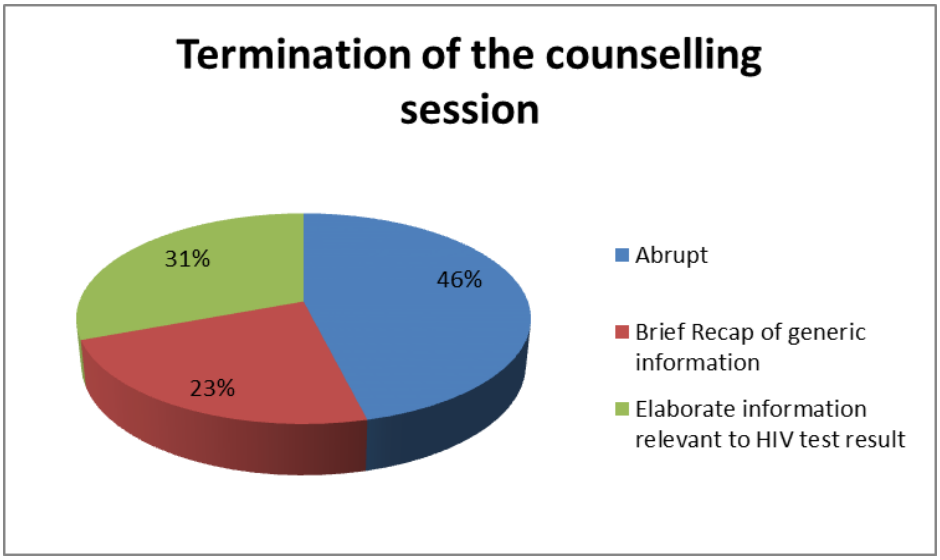


Figure 30: Termination of the counselling session

The sessions came to an abrupt end after the HIV test result was known without further information pertaining to the results or an exploration of the patient's feelings about the results:

> *Abdul: yes it is one line, you are ok. Now go back to the doctor and give him this [paper] he will give you the medicine he had prescribed. But after three months [test again], and if your children are grown up, tell them the importance of knowing their status.*
>
> *Ekirapa: Ok. Thank you (Session ends)*
>
> *(Counselling session - Riruta)*

This also occurred when the HIV test result was positive:

> *Hazina: Now that means you have the virus. We earlier on agreed on how the results will appear.*
>
> *Kimathi: Hmm.*

Hazina: Now there is a clinic where after you leave this room the doctor will direct you to. Let us go back there (Kimathi walks back to the counselling desk). Now you said earlier that you stopped taking alcohol, do not start taking it again. Also do not smoke.

Kimathi: Ok.

Hazina: What you will need to do is to take your medication properly and eat well. Now you will take this [paper] back to the doctor

Kimathi: Ok (session ends)

(Counselling session - Mbagathi)

From the above excerpt, although the counsellor gave a little information following the HIV positive diagnosis there was absolutely no exploration of the patient's emotional wellbeing or his feelings about the HIV test result. The talk about not taking alcohol and stopping smoking cigarettes appears rather misplaced in the context of the enormity of a HIV positive diagnosis. Arguably, the counsellor in this scenario is avoiding engaging in an exchange that would prove uncomfortable for the patient and herself. This situation presents the HIV testing consultation as a rather medicalised encounter in which giving the HIV test result appears to be the objective of the HIV testing process rather than the provision of situation specific information and support. This is in contrast to the stipulation of the PITC guideline. As mentioned earlier, the PITC guideline places emphasis on post test counselling which it indicates should occur after the HIV test is

revealed and should be tailored to the patient's HIV test result as well as his social circumstances.

In contrast to this scenario, there were eight situations where the counsellors explored the patient's feelings at length following the disclosure of the results. They also reiterated vital information that was specific to the HIV result therefore placing the health promotion information in the context of the disclosed test. Nonetheless they too had filled the time while waiting for the results with a general monologue. For example Bhoke took time to assist the patient (Wayua) with the HIV result she had just received. She did so by exploring if she had expected the HIV positive result and the things in the patient's life that may have contributed to the HIV positive result. However, only one consultation of Bhoke was examined and hence it is not possible to indicate whether she took time to do this in some or all of her HIV testing consultations. Following this explanation the observable tension began to ease as the patient openly talked about having been in a relationship with a person who she had suspected of being unfaithful. Later on the counsellor assisted the patient in exploring who she would disclose her results to and what she would be required to do next.

Another counsellor, Ihuoma, focused on exploring with a patient (Khamisi), how he intended to maintain his negative status. It was only during this exploration after the results, that the patient admitted having engaged in risky behaviour and the counsellor was able to reinforce the need for couple testing prior to engaging in unprotected sex. She was also able to make him aware that the onus of adopting health promoting behaviour

such as not having multiple sexual partners lay with him. From these two examples it appears that continuing with the counselling session after the HIV test results are revealed provides patients with information that is directly relevant to their HIV status as opposed to leaving the counselling session with a generic set of information which the patients may not necessarily link to their HIV status.

In conclusion, the HIV testing consultation in the majority of the cases followed an inflexible structure that was not-patient centred. The counsellors did not often make attempts to create rapport or to obtain patients' personal information. This resulted in a generic and formulaic consultation that was not tailored to the patients' needs. This routinized consultation failed to meet the objective of aiding patients with modifying their risky behaviour as well as assisting patients to deal with the emotional difficulty resulting from a HIV positive result and adequate information on the support available to them. The same detached approach carried on to the end of the consultation with the majority of the sessions ending abruptly without dealing with the patients' emotional needs or feelings about their HIV status. On the whole, the overall structure and sequence of the HIV testing consultation differed from the one outlined in the PITC guidelines making it difficult to meet the objectives of behaviour change, referral to relevant support and emotional support to deal with a difficult HIV diagnosis.

These findings suggest that by following a specific rigid structure the counsellors are able to feel in control of an otherwise volatile consultation laden with heavy emotional tension and involving discussions of sensitive

and often taboo topics. A rigid structure also routinizes the consultation and makes it largely non-patient centred which consequently allows the counsellors to get through a rather uncomfortable interaction. What is interesting is that although the structure used by the counsellors differed from the PITC guideline, it was generally similar among all the counsellors. This raises the question about how the counsellors chose the structure they were using and why, despite not using a checklist at the point of delivery, the majority of the counsellors followed the same structure and sequence to the letter.

7.3 'Performing' counselling

As the consultations unfolded, the counsellors emerged as the dominant participants in the interaction while the patients were often passive. In this section I examine how the patients and counsellors adapted their roles to drive certain [hidden or implicit] agendas and show how the consultation was a product of sociocultural norms in the Kenyan environment.

7.3.1 Didactic nature of the counsellor – patient interaction

Looking at the overall picture of the counselling sessions, there were two extreme cases of how counsellors interacted with the patients. On the one hand there was Ihuoma whose sessions were very interactive and who spent her time involving the patient by getting their views on issues and also information on their personal social situation. By doing so, her scripts were not marked by lengthy one sided monologues consisting of countless items of information for the client. Because she involved her patients a lot, it followed that the information she gave tended to be client specific and only added to what the client had said or provided information where the

patient did not have any. In contrast, Abdul's sessions were very instructional and characterised by extended monologues, often running for a page or more, and consisting of a myriad of information about HIV. He also tended to be very inflexible and even attempts by the patients to ask questions were often put aside and looked into later on in the session where he felt it was more suitable to do so:

> *Abdul: … Nangila do you have a question?*
>
> *Nangila: I wanted to ask, if a person has HIV, why is she not allowed to breastfeed?*
>
> *Abdul: I will capture that question later. Coming back to the kits that am going to use…*
>
> *(Counselling session - Riruta)*

In the above example, even when Abdul gave the patient a chance to ask questions he deflected these and went ahead to do what he wanted to do next i.e. to give an explanation of how the test kit worked. Perhaps the counsellor had not expected the patient to ask any questions as this was not common or he may have not have been ready to deviate from his plan. In the end, his sessions appeared to follow a strict structure to the point that one session with one patient was more or less similar to that of another patient even when the circumstances of the patients were evidently different. Also, putting aside the patient's questions to a later time during the counselling session took away patients' active involvement in the session rendering them merely passive participants.

The rest of the counselling sessions combined elements of the two extreme examples given above. Although Waithera's sessions were usually rather didactic there were instances when she was able to pick up and attend to cues from the patients and diverge from the set plan to focus on the issue at hand. For example, she noticed that Ameka's husband was rather nervous when she was collecting the sample for the HIV test. However while acknowledging his obvious nervousness she did not explore with him what he was feeling or why he was nervous. Instead, she made a general comment about having had an earlier discussion about how a person who is diagnosed with HIV is expected to live with the illness. This is then followed by generic information about what one is expected to do following either a HIV positive or negative result. Interestingly, the patient does not express his concerns or reason for nervousness but rather expresses the importance of having a HIV test done. In this case both the counsellor and the patient 'ignored' the individual emotional needs and instead carried on with a medicalised exchange.

> *Waithera: Why are you anxious my brother [referring to Ameka's husband]? It seems even your heart is pounding! Haven't we talked about how a person is supposed to live? To be asked to test doesn't mean you have the virus, alright?*
>
> *Ameka's husband: Yes.*
>
> *Waithera: Sometimes you go to the hospital and you are told to test for malaria. And other times malaria is present other times it is not present. Now the way you have been tested how do you feel?*

Ameka's husband: It is ok.

Waithera: What does that mean?

Ameka's husband: Ok because it is good to know based on the many days I have stayed [since testing], I feel it is just alright.

Waithera: Also you need to know that there are two sides of HIV. There is HIV positive or HIV negative. You know if you are negative today, it doesn't mean that you are living your negative life it depends on your lifestyle. Behavior change. Alright? The way you handle yourselves. The way you handle yourselves personally. How will you live? Today we have been tested you have been found without the virus. How will we live our lives? Alright?

(Counselling session - Mbagathi)

In this case although the counsellor had picked a cue from the patient she did not engage with him or tailor her response to his situation. Rather, she continued to give some unrelated information before proceeding with the consultation. At the same time the patient did not overtly express his concerns or redirect the counsellor to his concerns when she failed to address them.

The lengthy monologues delivered during the 15 minute wait for the test result consisted in most cases of a myriad of information that was not given in any order or aimed at addressing specific issues. They were delivered without any specific information on the patient's circumstances or knowledge of the patient's HIV status. For example, in the excerpt

below the counsellor (Maria) talks about nutrition, support groups, ARVs and the next steps in the event of a HIV positive result:

Maria: ..... Which foods constitute good food Mrs. Alphonso?

Mrs Alphonso: like cabbage, meat, eggs, milk and others.

Maria: and others. That is true. Good food means eating the three groups of food. There are proteins, proteins are found in beans, meat, fish what is affordable because the money we have most of the time is not sufficient. But if there is some [money] available which can buy fish today there is some available to buy beans tomorrow because that is what someone can afford. Then there is starch. Where do we find starch? (Does not wait for response) *In maize meal, in rice, in bread and such foods. Then eat some vitamins some vegetables as you have said which are available. Eating appropriately is eating the three types of foods in a meal. It is not eating a lot of meat in the morning and then you eat something else, no. It is eating a little meat with some potatoes some cabbage. Enough! In addition when someone finds he has the virus he should join a support group for those who have it. Here at [name of area] we have two support groups for those who have it. The first support group is for those who are on drugs to control the virus and the second one is for those who are not on drugs to control the virus. When a person is found to have the virus one is required to test the level of immunity CD4 count. This will tell whether the immunity is high or low. When the immunity is high there no need to use drugs to control the virus because the body*

has enough immunity but when the person gets sick even a little he needs treatment to keep the immunity high. Ok? But when the immunity is low it will require the use of drugs. So there are those two support groups and when we get the results we tell someone which group to join. The importance of the support groups is to meet other people. One knows that although so and so is there and you mean even this person is also there then someone knows that this thing is for humans and a person can live with it and you get encouraged to continue living. There are also drugs which if say, for example, we find that Alphonso has the virus you will be given drugs for what brought you to the hospital then you will be given a drug we call septrin to restore your body's immunity and then you will have your immunity level checked. If you are found to have HIV when you return the results of the CD4 count you will be referred to the clinic which will start you on the drugs to control the virus (ARVs). Before someone has used the ARVs he is counselled so that he can know how many times to swallow the tablets, how will the drugs help, what are the side effects…. you are informed on all that this are drugs to reduce/control the virus because there are no drugs to cure. There are drugs to?

Mrs Alphonso: reduce it.

Maria: Yes. And usually someone is able to go back to his normal activities. Do you have any questions up to this point? Have we understood?

Mrs Alphonso: yes (Counselling session - Mbagathi)

It is worth noting that all this information was given while patients were waiting for the HIV test result and was therefore at that point not specific to the patient's circumstances. Nonetheless, providing this information at this point of the counselling session allowed the counsellors to fill in the time while waiting for the 15 minutes that the HIV test result required to be ready. It appears improbable that the patients who were already in an anxiety provoking situation would effectively internalise all this information. Arguably, even without the HIV test in mind, this information seems too much for an individual to grasp within the short time the counsellors have available.

In the few instances where the counsellors made an effort to involve the patient throughout the consultation, they still left little room for the patient to respond by phrasing questions in a manner that did not necessarily call for a response:

> *Hazina: You know that there are people who have the virus and live a good life?*
>
> *Bosco: Mmh.*
>
> *Hazina: As long as you follow what the doctor tells you, isn't it?*
>
> *Bosco: (Nods).*
>
> *(Counselling session - Mbagathi)*

In the above exchange Hazina, the counsellor, did not give Bosco a chance to say whether he actually knew anyone with HIV who is living a good life but rather quickly carried on with the conversation. From the response

given by Bosco (Mmh) it was not at all clear whether he was acknowledging that he knew people who were living well despite a HIV positive diagnosis or whether he was merely moving the conversation along. The second statement by Hazina was very instructional i.e. "as long as you follow what you are told by the doctor". From this example we see that the counsellor becomes paternalistic taking up the role of an individual who is telling the patient what he has to do with little room for engaging with him on the issues being discussed. This type of interaction was characteristic of what took place in the majority of the counselling sessions observed and recorded.

In contrast to the observed consultations, counsellors during the interviews felt that the provider dominated interactions were due to the patients' inability to open up. Indeed they did not view themselves as contributing to the situation due to their paternalistic approach to the session:

> *Some of them don't open up, those are the challenges. Eeh for example 'you are told you are sick my dear let us find out what is happening with you'. Then, they will, they will fail to open up, they are in denial, there is those ones in denial: you test positive or you test negative and you deny these are my results. (Waithera, counsellor interview - Riruta)*

The observed consultations showed that the provider dominance and passive patient interaction was interactionally achieved by those involved adopting certain roles.

In contrast to the observations, counsellors implied that often patients had other problems that they had to deal with in the course of providing PITC. Counsellors presented themselves as facing a dilemma as they tried to assist patients in dealing with their personal problems and the same time carry out the HIV test. These accounts conveyed the impression that the interaction does not always follow a rigid predetermined structure contrary to what was observed.

> *You know mostly in these sessions we deal with testing and counselling, counselling about the test result and the test outcome. So sometimes issues like family, poverty and all would come in. But how I address that I would, I just make the client know that right here, right now we are talking about testing for HIV so maybe the client would choose from all those things that they want what is the priority. If they want us to talk about family issues we will talk just about that. There are clients who just come here and you think this one wants to be tested and they come in and they say, I know my status but this and this is disturbing me. So you deal with what the client has brought up. If the client says I want to be tested and then during the session they say I have a problem at home, now you have to focus on the client. You will do the testing and then the counselling maybe we will do another time, when you are ready you just come we do counselling (Ihuoma, counsellor interview - Riruta)*

This contrast illustrates that counsellors were aware of what they should ideally do. Therefore, the interviews were a representation of an idealised

moral order which the counsellors were trying to depict but which they could not achieve due to the realities of the practice setting. The observations of the setting showed the counsellors often have lengthy queues of patients waiting to be tested. Pressure of time is an impendent to how much the counsellor can do during the PITC consultation. Moreover, the PITC guidelines work on the assumption that the patient's informational and emotional needs are limited to the HIV test itself which is clearly not the case.

7.3.2 Going with the flow

Although the counsellors took control of the sessions and dominated them the patients did not seem to voice any concerns or attempt to interject during the proceedings. In fact, the majority of the patients did not take up offers to ask any questions, respond to questions or raise any concerns when given a chance to do so.

> *Ihuoma: …..When you make love without a condom you can re-infect each other and bring down the body's immunity. He can also infect you with a drug resistant virus. There are drug resistant viruses which do not respond to medication. And if he is not adhering to his treatment, and you have unprotected sex with him, he can infect you with it. It is therefore important to use a condom. Do you have a question?*
>
> *Muna: (silent)*
>
> *Ihuoma: It is also important to take a balanced diet? What is a balanced diet?*
>
> *Muna: fruits*

Ihuoma: A balanced diet is food that has all the nutrients. All nutrients. You eat food that has carbohydrates, proteins and vitamins. What are the examples of carbohydrates?

Muna: (silent)

Ihuoma: Like maize meal, rice …..

(Counselling session - Riruta)

A few patients, however, managed to raise questions during the sessions even when an opportunity to do so had not been presented. In line with this, there were instances where the patients appeared to have had specific agendas prior to coming to the session which they intended to pursue even when an opportunity was not given to them to do so.

For example Nangila seemed so keen to find out how he could get free ARVs for his sister that even when the counsellor (Abdul) glossed over this question and moved on to interpret the results, the patient brought up the issue again soon after. The counsellor then had to address it and provide him with the information he needed about where his sister can get the drugs for free. Another example is Kamau who at the end of the session stood up to leave but stopped and asked Abdul the counsellor for some condoms. In these instances the patients enunciated their issues despite the counsellor's inflexible session which left little room for their concerns to be dealt with. These two scenarios are perhaps different because these patients had come for follow up repeat HIV tests following PITC and appeared to have an agenda they wanted met during the HIV test. However, the majority of the other patients had not anticipated or expected to be offered a HIV test and therefore were likely not be

prepared for what would happen next. In any case, the fact that they had been offered a HIV test when they did not expect one and they had gone along with it by going to the counselling room, indicates that they were already in a sense just following what they had been asked to do by the doctor.

In the instances where the counsellors made an effort to engage the patient or to draw a response, the patients gave very short non-committal retorts or the classic 'I do not know' reply:

Maria: Which one [HIV prevention method] do you think you can choose?

Alphonso: I don't know

(Counselling session - Mbagathi)

Hazina: Now tell me, what do you expect the [HIV] results to be?

Bosco: Ah! Whatever they [results] decide.

(Counselling session - Mbagathi)

This left little room for the counsellor to fully engage the patients which could explain the counsellor dominated sessions. One possible reason for this state of affairs could be the fact that each participant is operating within the defined cultural norms of the patient – provider interaction which defines the patient as a passive actor who remains accepting to the health care provider's instructions. Therefore, patients co-construct the provider dominated nature of the consultation.

7.3.3 Maintaining a 'moral face'

In the previous chapter, I alluded to the perceived profound link between HIV and immorality and transgression of acceptable norms associated with sex. It was therefore not surprising that patients went to great lengths to dissociate themselves from the risky behaviour linked to HIV transmission and present themselves as ideal patients who followed the expected advice during the consultation. At the same time some patients presented themselves as uninformed and unaware of HIV, its transmission or anything related to the infection:

Hazina: Do you know about HIV?

Kimathi: I do not know.

Hazina: You do not know how someone get it?

Kimathi: I do not know.

Hazina: Eeh.

Kimathi: because when I leave my house in the morning, I come back in the evening, I don't have this, behaviour.

(Counselling session - Mbagathi)

In the above interaction, Kimathi links a question on awareness to his personal behaviour and thus responds by dissociating himself from anything deemed to be unacceptable. An admission of knowing how HIV is spread was in this case translated to mean an admission to engaging in risky sexual behaviour. In an environment where HIV is talked about in both print and audio media, it is difficult for a person not to have heard

anything about HIV. Moreover, with a high HIV prevalence, the majority of the Kenyan population is likely to know someone or at least have heard of someone who has or is suspected of having HIV.

The same situation was observed when the counsellors sought to find out from the patients why they had been referred by the doctor to the counsellor. Only three patients told the counsellors they had been referred for a HIV test whilst the rest said they had no idea why they were in the counselling room. This is despite the same patients talking to me during the pre test interviews about their impending HIV test just prior to the HIV testing consultation. In a cultural context where patients are expected to be unaware and uninformed, then the patients are in these scenarios attempting to adopt the expected role in a health provider – patient interaction. At the same time by presenting themselves as uninformed about commonly known basic information about HIV the patients can avoid blame being apportioned to them in case of a HIV positive diagnosis. If an individual does not know how HIV is transmitted or how to prevent its spread then they cannot be held responsible for their HIV positive status.

7.3.4 HIV talk: Euphemisms and coded language

'HIV talk' refers to the play of words that the participants and the counsellors engaged in during the PITC process. The interactions between the counsellors and the patients were characterised by a particular 'language' that portrayed the sensitive nature of the social context of HIV in this environment. By exploring the interplay of words, the underlying

and often unstated suppositions about HIV became clear as patients and counsellors extensively used euphemisms and coded language.

The use of language that was coded and highly metaphoric allowed the participants of the consultation to avoid the tension and difficulty that came with making a direct reference to the sensitive issues. It also allowed those involved to talk about sensitive issues without feeling that they were breaking any communication norms particularly when making direct references to sex. For example:

> *..... so that when you are walking around without shoes you will know where you are headed (Bosco 26 year old male counselling session - Mbagathi)*

In this situation, 'walking around' referred to having multiple sexual partners while 'without shoes' inferred without a condom. Hence Bosco talked about an individual having multiple sexual partners without using a condom whilst using words that made it possible to express his message without the uneasiness that would otherwise accompany it. In spite of this metaphoric language, both the counsellor and the patient understood each other partly due to the fact that a large proportion of the language was borrowed from everyday lay interactions. Such ambiguous interactions allowed the involved parties to talk about sensitive issues while maintaining a wide berth from explicit reference to taboo topics that is socially defined as acceptable. Equally, individuals seemed to find it hard to refer to HIV by name and in its place used terms such as: 'it', 'that thing', 'that disease' and 'that HIV'. Choosing not to name HIV directly

perhaps created a sense of distance from the infection and gave the patients a feeling of comfort.

Patients in some cases adopted words and phrases that were used in health promotion messages in the media and incorporated them into their talk. For instance 'VCT' was used on a number of occasions to infer a HIV test rather than its actual meaning i.e. a model of HIV testing. Other phrases used by the participants such as 'know your status' (jua hali yako) and '[out]side arrangement' (mpango wa kando) were reflective of the most recent media campaigns which focused on encouraging people to get tested and discouraging multiple sexual partners. At the same time lay discourses regarding HIV were depicted in the HIV talk. For example words like 'fear', 'death', 'shock' and phrases like 'not a disease like any other' were used by all the participants. By looking at these terms it is possible to grasp the patient's perceptions and views related to HIV.

Although much of the HIV talk was highly coded and encrypted, there were instances where explicit and direct language was used. In all of these cases, the counsellors and patients tended to use English words rather than Swahili words and phrases when referring to sensitive issues. Even in a session that had been solely conducted in Swahili, the counsellors and patients substituted the Swahili 'taboo' term with an English term as illustrated in the excerpt below:

> *…tunaona asilimia themanini ni through unprotected sex. Whichever the sex. Unajua kuna watu pia, hujidanganya ukifanya homosexual sex hio hautapata. Unajua kuna watu wakona beliefs*

kama hizo? Lakini tunajua hio ugonjwa iko very fast. Whichever the sex, provided it's not protected…. (Opiyo male counsellor - Riruta)

…we see that 80% of infections are through unprotected sex. Whichever type of sex. You know there are people who lie that engaging in homosexual sex you would not get [HIV]. You know there are people with such beliefs? But we know that the infection is transmitted very fast. Whichever the sex, provided it's not protected (Opiyo male counsellor - Riruta)

Abdul (counsellor): Mtu anapataje virusi?

Mariamu: unprotected sex.

Abdul (counsellor): amesema unprotected sex. Kwa unprotected sex, ni kumaanisha hakuna mpira….

Abdul (counsellor): How does someone get the virus?

Mariamu: unprotected sex

Abdul (counsellor): you have said unprotected sex. In unprotected sex, it means there is no condom …

(Counselling session - Riruta)

Perhaps it was easier and more palatable to be explicit when using English that when using Swahili. Only two counsellors were observed using the Swahili word for sex *(ngono)* in their sessions while none of the participants used this word.

The need to use more palatable language could explain why counsellors

were reluctant to engage in risk assessment and why patients were largely reluctant to open up about their own risky behaviour as presented above. Talking about risky behaviour and doing an indepth risk assessment would have automatically necessitated talking about sensitive issues and the use of explicit language as opposed to the vague inexplicit language with which the participants were more comfortable.

7.4 Constructing informed consent

Consent in PITC was unique in that it started when the doctor asked the patient to go for a HIV test as part of the treatment process. The patient was given a piece of paper with the HIV test request. The patients were directed to take this request form to the counsellor who after carrying out the HIV test was expected to record the HIV test results. It is this piece of paper that the patient was required to return to the doctor before the course of treatment could continue and drugs issued. The fact that the HIV test was part of the treatment process hampered volition on the part of the patients because it appeared as though if they wanted to get treated they had to take the HIV test.

This section briefly explores how informed consent was obtained (or not) during the routine HIV testing consultation. In the background of the didactic nature of the interaction that has been explored in sections 7.2 and 7.3, it is imperative to examine how informed consent was managed. Through examination of consultations it was evident that the counsellors framed the HIV test as part and parcel of the process of seeking treatment. The HIV test result was required if the patients were to receive appropriate treatment for the illness that had primarily brought them to the health

facility. At the same time the patients had not only primarily come for treatment, but they had also not expected to be offered a HIV test or to make decisions about any aspects of their care. This theme is explored further in the following categories: framing of the HIV test, an offer you cannot refuse and patients' response to the informed consent process.

7.4.1 Framing of the HIV test

Undergoing the HIV test appeared to be a condition of receiving treatment. All the counsellors framed the HIV test as part of the treatment process and as a requirement for the patients to get an appropriate diagnosis and care:

> *You were feeling unwell and you went to the doctor and told him that maybe you have a chest pain or whatever and he has written a prescription for you but he wanted to know your HIV status. That is why you are here. I will test you and there is a place I will indicate your status. You explained to the doctor that you are coughing and you have chest pains does not mean that you have the virus. We test to confirm so that even when you buy the medication and you return to the doctor he will know how you give you the treatment. (Counsellor Abdul talking to Ekirapa - Riruta)*

> *And also in the hospital there are some drugs which before a person is given we must know if he has the virus or not. It also lets us know which treatment to give you. (Counsellor Jelimo talking to Gakere - Mbagathi)*

> *All diseases can get a person with HIV and they can get a person without HIV. That is why the doctor would like to differentiate whether you have or don't have [HIV], so that he can get to know the appropriate treatment. (Maria – counsellor interviews Mbagathi)*

This left the patients with little or no room to consider the HIV test offer as a choice they could make. Additionally, given the fact that the HIV test offer was given to patients at a time when their priority was to get treatment then it would follow that it was difficult for them to distinguish the routine HIV test from the health care services they had come to seek. It might well be argued that by accepting to turn up at the counselling room, the patients were implying consent to PITC. However, there were instances where patients indicated that they were not aware about why they had been referred to the counselling room.

It is noteworthy that a number of counsellors placed the decision to offer the patient a HIV test on the doctor and not on themselves. This created an impression that as counsellors they were merely following instructions to offer the HIV test. It also created the impression that they had not initiated the test and were thus not necessarily in a position to accept a decline of the HIV test offer.

Besides framing the HIV test as imperative to the health care the patients were to receive for their illness, the majority of the counsellors did not explicitly obtain consent for the HIV test. The counsellors carried out the HIV test after giving instructions to the patients to imply that they were proceeding with the actual HIV test:

Sit there we carry out the test [pointing at the table where the test is to be carried out]. (Hazina Counsellor)

Abdul: Up to this point do you have questions? Are you ready to carry out the test?

Njeri: I do not have a question. (Abdul carries out the test)

(Counselling session - Riruta)

The test was carried out even when the patients had not necessarily said yes. Indeed, the interactions by the counsellors were not necessarily intended at eliciting a yes or no response to the HIV test offer. Subsequently the patients understood the routine HIV test as mandatory in order for them to get treatment:

So you cannot be treated the chest, you must first pass through VCT? (Bosco Counselling session - Mbagathi)

The HIV test offer was given in a context where patients had not come expecting to make any decisions about their own health care. In this setting, patients in health facilities adopt a passive role focusing on following instructions in order to get treatment:

For me there is nothing that made me do this. It is just what the doctor told me, now what do I do? (Kimathi Post test interview - Mbagathi)

The circumstances of the patients i.e. being sick and primarily coming for treatment seemed to have made them feel they had no choice but to go along with the HIV test:

If I wasn't sick I would not have gotten tested (Alphonso post test interview - Mbagathi)

It can be argued that by complying with the request, the patient was then accepting the procedure that was about to be carried out even in cases where it was evident that the participant was actually feeling the opposite or did not understand why the HIV test was necessary:

Now I do not know why he thought of sending me for the test, he did not tell me anything. He just told me to go and get tested and then I take back the results. (Njeri, Pre test interview - Riruta)

Counsellors were cognizant of the fact that offering the HIV test when one is sick skewed the patients' ability to make a choice about the HIV test offer:

You know when a doctor, a medical practitioner, tells you I think, you know when you are ill and you are told, so and so I think [name of person] I want to test you because of one two three and you are sick, you have taken several drugs. Even you, you accept you start thinking, I think it is good. Because if the doctor has seen like that, because maybe you have been sick severally, you have maybe lost weight, or there is something and when the doctor initiates for the whatever… Actually rarely do they, when they get to that room, because I have also worked in casualty, they rarely refuse. (Jelimo counsellor interviews - Mbagathi)

7.4.2 An offer you cannot refuse

None of the patients in all the consultations directly declined the HIV test offer. Yet although they went along with the HIV test, it appeared that a few patients were reluctant to test but could not directly verbalize this. Instead, they gave indirect cues which revealed that they would rather opt out of the HIV test offer. For example, in one interaction between Ihuoma the counsellor and Idowu the patient, it seemed that Idowu was not ready to test but he did not overtly say so. Instead he spend some time 'delaying' the collection of the sample by asking questions on information he had just been given. From the interaction it was also evident that he was very nervous about the impending test and seemed uncertain about going through with it:

Ihuoma: I will just take your blood, and as the test is running we shall talk. Ok?

Idowu: Will you tell me my status immediately or I will go.

Ihuoma: Your results will be ready before you leave.

Idowu: Ok ok ok

Ihuoma: You will have to see your results yourself. It is not me who will tell you. It is you reading it for yourself.

Ihuoma: So I will just take your blood, run the test…

Idowu: Ok thank you.

Ihuoma: So I will just take your blood, run the test…

Idowu: From where?

Ihuoma: Here (pointing at his finger)

Idowu: From the head or where?

Ihuoma: From your finger

Idowu: Ok ok ok ok… is it painful

(Counselling session - Riruta)

In another interaction between Jelimo (counsellor) and Makau (patient), Jelimo after explaining the pathophysiology of HIV asked Makau: "Can we test right now?"

Jelimo: Now I would like to know, are you ready to test?

Makau: Right now?

Jelimo: Eeh (yes).

Makau: Eeh (yes).

(Counselling session - Mbagathi)

When asking "right now", Makau had expressed his reluctance. This was later illuminated when he told the counsellor that he had only tested because he was unwell. Evidently, patients were not necessarily in a position to explicitly decline the routine HIV offer as was expected in the opt-out approach utilised in the PITC model of HIV testing. Indeed Makau and Idowu were 'silently refusing' the HIV test without doing so overtly.

Counsellors were aware of the silent refusals but chose to ignore them. They viewed going ahead with the HIV test in the absence of an overt decline as an advantage in an environment where people were generally reluctant to take an HIV test due to lay constructs about HIV. They perceived the nature of the PITC process, as provider initiated to be important since it guaranteed increased uptake of the HIV test. The counsellors chose to see the patient's inability to say no to the HIV test offer as an advantage to increase uptake rather than an infringement of the patients' rights:

> *So PITC is an approach that is actually working. Cos you know when the doctor is like superior, if it's a doctor-patient situation, the doctor is superior and when the doctor says, 'utaenda kwa VCT' (you will go to the VCT) they will not argue with that. So even if it is this client who had said, ah mimi sitawai (I will never test), I will just test when it is really necessary. So when they come to this doctor and the doctor says or if it is the clinician, they will not argue with that. And in that way this patient gets to know their status. So I feel PITC is actually a good approach. (Ihuoma, counsellor interviews - Riruta)*

However one counsellor felt that the patients had freedom to opt out of the routine HIV test:

> *They, they have the freedom to choose whether they want to be tested or not because even if you test them by force and somebody lives in denial, you are not going to help that client. Because if it means taking the drugs, it is not me as a counsellor to take the*

drugs it is the patient. So they have the choice (Waithera, counsellor interviews - Mbagathi)

As discussed above, there were several situations where the counsellors did not overtly offer the patients a chance to consent for the HIV test. Likewise, at the time of the observations no patient declined the HIV test offer. In spite of the obvious lack of opportunity to make a choice about the HIV test offer, findings from the patients' reflections presented below show that the majority of the patients did not think anything was amiss. Rather than focus on the lack of informed consent, the patients reportedly felt relieved to have finally been tested and consequently dealt with uncertainties about their HIV status. It was apparent that the provider dominated interaction, the passive patient and the patients' focus on getting treatment worked together to erode the process of seeking consent as recommended in the PITC policy.

Whilst the patients were not necessarily given an explicit choice, ambivalence was apparent in the patient's construction of the decision of whether to test or not. The patients were at the time of the offer of the HIV test put under immense pressure due to the meaning attached to an HIV positive diagnosis:

Worrying. Someone may be tested and that day he just dies. (Alphonso, 42 year old male Pre test interview - Mbagathi)

I don't know... I hear some fear to get that result. They hang themselves or swallow poison (Kimathi, 35 year old male Pre test interview - Mbagathi)

The decision to test towed along other decisions that the patient would have to make in terms of treatment and disclosure versus nondisclosure among others. All these decisions were in themselves life changing especially in view of the negative perceptions associated with an HIV positive diagnosis. In light of the above pre-occupation with the consequences of the impending HIV test result, patients were not in a position to consider the benefits of HIV testing as one would expect in an ideal informed consent situation. The consent situation was a conflicting one: patients were ambivalent about the HIV test and for the most part resistant to it, but they felt that taking the HIV test was for the best.

7.4.3 Patients' response to the informed consent process

In policy documents and guidelines, a key aspect of information giving during the HIV test is to ensure that patients receive relevant information to empower them to make a decision on whether to test or not when given the chance to do so during the PITC consultation. As discussed above, the majority of the patients were tested without the counsellors explicitly obtaining consent for the HIV test. It was therefore necessary to explore from the post test interviews the patients' view on consent during the routine HIV test. In spite of the obvious lack of explicit consent and pressure of an impending HIV positive result, participants expressed a general sense of relief and gratitude for having had the HIV test during the post test interviews.

All patients except two (Lulu and Bosco) said that they were ready to test and had not considered changing their minds about the HIV test even

though the HIV test offer was unexpected. Lulu and Bosco, however both felt that they had no freedom to say no during the consultation:

> *Interviewer: Now when the doctor asked you if he should test or not, did you feel free to say no you don't want to?*
>
> *Bosco: I did not feel free*
>
> *Interviewer: Why?*
>
> *Bosco: I was just afraid*
>
> *(Bosco 26 year old male Post test interview - Mbagathi)*

Bosco expressed the constant battle he faced as he tried to decide whether to go along the test to the extent of considering opting out at one point during the consultation:

> *You didn't hear when I asked, 'can one first try to take TB drugs' at that point I was close to say no (Bosco, 26 year old male post test interview - Mbagathi)*

Despite his initial ambivalence, after the consultation Bosco appeared very happy to have been tested and saw it has an end to his anxiety and indecisiveness. Just like with the rest of the patients who were relieved to have been tested, being coaxed to test did not seem to be an issue. Indeed they focused on the end result of finally being able to rest easy and do away with the uncertainty about their HIV status:

> *Now I do not have any anxiety since I have been tested. I have no worry. (Njeri, 22 year old male Post test interview - Riruta)*

In summary, the counsellor dominated sessions influenced the process of obtaining and seeking consent. Whilst the PITC process formally utilizes an opt-out approach the fact that the patients consistently adopted a passive role and the counsellors an instructive role meant the HIV test was not framed as a choice. At the same time, it was difficult for the patients to differentiate the routine HIV test offer from the process of seeking treatment for their illness. It would appear that in conveying the impression that the patients had no choice but to be tested if they wanted to obtain treatment, the counsellors were achieving institutional objective of testing as many people as possible.

7.5 Conclusion

In conclusion, local cultural conventions that govern communication between a health care provider and a patient as well as those that govern discussion of taboo issues shaped how the counselling sessions unfolded. This resulted in a didactic consultation in which vital topics were either left out or glossed over briefly. In the long run, the structure and sequence recommended by the PITC guideline aimed at contributing to HIV prevention, apt emotional support and referral to relevant services for HIV positive patients was not implemented at the point of service delivery. The recommended sequence left long gaps that were awkward for everyone and needed to be filled with lengthy monologues. There however, seemed to be no attempt to question the recommended sequence or try a different approach. At the same time, the provider dominated passive patient interaction coupled with the patients' primary reason for coming to the health facilities and meanings attached to an HIV positive diagnosis

redefined what patients' autonomy for informed consent meant in this environment.

8 CHAPTER EIGHT: DISCUSSION

8.1 Introduction

The aim of this study was to examine how the PITC process is implemented within the existing social structures in Kenya. The research was undertaken in two public health facilities in which patients were interviewed before and after the routine HIV testing and the consultations were observed or audio recorded. This study has identified the tensions that exist between policy recommendations and the contextual norms that define and shape how informed consent is constructed and how counselling is managed.

This chapter will bring together the findings presented in the chapters above in the context of existing literature, policy recommendations and theoretical arguments about informed consent and counselling.

8.2 Situating PITC in the Kenyan social context

The first objective of this study was to explore patients' perspectives and understanding of HIV and HIV testing and examine how these perceptions of HIV influence their communication and interaction with counsellors during the HIV testing consultation. The study findings discussed in chapter 6 and 7 have illustrated how the prevailing lay constructs about HIV shape the PITC process. Information provided by health professionals is not used objectively but rather sieved through experiential knowledge about HIV. It is this resultant body of lay knowledge that influences decisions about HIV testing, how one constructs their personal risk and

what and how one communicates about matters related to HIV and sexuality.

8.2.1 Tensions between lay and professional constructs about HIV

An analysis of participants' views in my study revealed that stigma continues to be a salient feature in HIV in the Kenyan context. The study suggests that this emanates from the continued association of HIV with death and immorality. This accounts for the enduring exceptionalist view about HIV in the Kenyan context and hinders normalization of HIV in spite of routinizing the HIV testing process through PITC.

However, an analysis of participants' perceptions about the effectiveness of ART paints a contradictory picture. On the one hand, the majority of the participants in this study indicated that ARVs did not necessarily provide a cure but simply deferred death. Therefore, there was no point of having a HIV test and starting ART since death is inevitable either way. This view was held in spite of the wide spread health information about the availability of ART and their vital role in ensuring PLHIV have a long and good quality of life. On the other hand, there were instances of reported positive effects of ART in changing the course of the HIV infection. My study suggests that the two competing views coexist and are perhaps an indication of the tension that exists in lay understandings – as people draw upon diverse bodies of knowledge to make sense of HIV. This perhaps indicates that availability of ART is not necessarily a motivator to seek HTC. At the same time, adherence to medication whose effectiveness is in question may be difficult in this context.

The study finding that HIV is still largely perceived as a killer disease in spite of ARV availability, suggests that the positive impact of early diagnosis linked to access to life saving drugs is not perceived as a reality to many people in this context. Indeed the proportion of patients accessing ARVs in Kenya is about 38-45% in comparison to Botswana with over 80% ARV coverage (UNAIDS, 2012). In light of the current policy on treatment as prevention, the PITC policy implementation in the Kenyan situation needs to be matched with an increased ARV coverage and health education. A cumulative effect of increased ARV coverage may change the association of HIV with death by reducing the observed incidences of AIDS related deaths in the community. It would, however, be simplistic to conclude that increased availability of ART would adequately deal with the longstanding association of HIV with death.

A dualism in participants' constructs about HIV was also identified from an analysis of the moral discourse in HIV from patient interviews. Alongside the morality undertone which was embedded in the participants' narratives in this study, participants also explicitly painted accepting attitudes towards HIV, which were more in line with the content of public health messages. The methodological approach used in this study allowed the uncovering of the complexity of lay attitudes towards PLHIV in Kenya. These findings are similar to those reported by ActionAid International Kenya (2009) but contrary to Chiao et al. (2009) both of which were carried out in Kenya. Presumably, the difference in the findings can be accounted for the differences in methodology between the latter study which used self-reported quantitative methods as opposed to the former study, which like my study, used largely qualitative research designs.

Despite the varied picture and tension of lay understanding of HIV, my study findings suggest that the normative moralizing discourse around HIV has an impact on the implementation of PITC. There was a suggested fear of being blamed and of being seen in a negative moral light in the event that one is diagnosed with HIV. In addition, self-referring for an HIV test was in essence an admission that one had engaged in unacceptable sexual behavior. The need for patients to consider their social and moral standing surpassed the medical advantages of knowing their HIV status. This finding adds to the evidence on the relevance of, and the need for, the PITC approach to testing which does not solely depend on the patient to self-refer for an HIV test following a self-risk assessment. Smith and Morrison (2006) in a qualitative study carried out in a similar setting examining risk assessment and decisions to test for HIV. The researchers in that study found that people's personal beliefs and experiences influenced how they assessed their risk of HIV and decision to test. This finding and that of my study raises the issues about the tradeoff between autonomy and informed consent and the benefits of imposing a PITC approach to HIV testing. This issue has been expounded in section 8.4 further below.

8.2.2 Fear of moral and social contagion

An analysis of this study findings suggest that stigma about HIV is still rife; although there was also a general view that stigma is less now than it had been in the past. Nonetheless, even with the acknowledgement of reduced stigma the participants could not account for why HIV is still viewed with a lot of apprehension and is more often than not accompanied by

discrimination and isolation. This particular finding suggests that stigma is a social construct that is woven within social relationships. Stigma is expressed (or not) depending on the nature of the social interaction at a given time. For example, in social situations where expression of stigma would be considered unacceptable, individuals report little or no stigma to fit into the social expectation at a given time.

My study findings suggest that stigma has evolved from fear of physical contagion to one of fear of moral and social contagion. With the exception of one participant, stigma was rarely referred to in the context of its physical contagiousness e.g. sharing cups. Patients were keen to paint a picture of reduced stigma in their direct reference to stigma in terms of physical rejection e.g. avoiding shaking hands. Instead stigma was embedded in their narrative and emerged as a complex layered discourse in which participants wanted to maintain a moral and social distance from HIV and its related issues. This manifested itself in the counselling sessions and could perhaps explain the stilted communication style observed in the routine HIV testing consultations. It is possible that the prevailing professional information that discourages stigmatization of PLHIV stops participants from expressing overt views on stigma but these ideas continue to be manifested in their narratives. Similar findings have been reported by Gausset et al. (2012). The researchers found that stigma was not universally expressed but rather embedded within the narratives of immorality that are associated with HIV.

The mixed picture about stigma notwithstanding, it is well known that HIV stigma has a major impact on HIV prevention, treatment, care and

support (Karim et al., 2008; Li et al., 2007; Malcolm et al., 1998; Turan, Miller, Bukusi, Sande, & Cohen, 2008; Zhou, 2007). The PITC policy starts from the premise that there is HIV stigma although there are more accepting attitudes towards HIV and PLHIV (National AIDS and STD Control Programme, 2010; WHO/UNAIDS, 2007). However, the PITC policy discourse on stigma is one of homogeneity within and between contexts. Which implies that the reported low levels of HIV stigma in the recent past applies similarly across diverse situations. It presumes universality in how stigma is perceived and expressed across different environments and between and within individuals which is incongruous with realities of social settings (Knight et al., 2014). My study findings and those of other studies show that even within similar contextual backgrounds, different constructs of stigma abound (ActionAid International Kenya, 2009; Chiao et al., 2009; Jürgensen et al., 2013; Winskell et al., 2013).

The PITC policy needs to ensure that its recommendations are reflective of the fluid nature of stigma reported in this study findings. For instance on how to deal with the negative perceptions about HIV so that stigma can be addressed during the routine HIV consultation. Indeed a systematic review has identified gaps in integration of stigma in national HIV/AIDS response strategies (Stangl et al., 2013). Even so, providing information alone is not necessarily adequate since my study suggests that lay people's knowledge draws upon multiple discourses around HIV, including, lay, traditional, observed individual experiences, religious and biomedical. These discourses are woven not only into day to day interaction but also during the HIV testing consultation and thereafter. The enduring negative

perceptions about HIV have largely contributed to continued HIV exceptionalism which has been viewed as a hindrance to HIV prevention, treatment and care efforts. Normalization therefore may not be achievable solely by changing the testing approach, increasing access to ART and providing information.

Indeed, in face of fear of moral and social contagion, the need to maintain a moral face remains extremely important to the patients. For this reason the HIV testing process may not be socially viewed as a 'normal' medical interaction. As a case in point, interestingly, counsellors informally helped patients to save 'moral' face by linking the HIV test offer to the treatment process to remove the notion that it was the result of a question about the patient's moral standing. This approach served a dual role of also ensuring consent for the HIV test offer. Sobo et al., (2008) reported similar findings in an American study. In their study the HIV counsellors presented the HIV test as something routinely done rather than a test that was being offered to the patient solely because they were at risk. Although this study was carried out in a different context, its findings similarly show the counsellor's work in aiding patients' maintenance of 'moral' face.

Similarly, an analysis of my study findings suggests that keeping one's HIV status a secret is an imperative component of maintaining a moral and social face. Indeed disclosure, whilst viewed as a key ingredient in the success of HIV treatment (biomedical lens), in this environment is riddled with stigmatization, blame, violence and a loss of close family and social support (social lens) (Campbell et al., 2005; Nyblade et al., 2003; Stansbury & Sierra, 2004). This challenges the prevailing discourse in

policy guidelines that suggest that a normalization discourse equals disclosure which in turn equals support. Anthropological and sociological literature challenges the biomedical assumption that breaking the silence leads to increase in quality of life and reduced stigma (Hardon & Posel, 2012; Lugalla et al., 2012; Moyer, 2012). In the African context it is silence rather than disclosure that has been used to maintain a sense of normalcy through eliminating discussion about one's HIV status in everyday conversations (Moyer, 2012). This is contradictory to the medical narrative which focuses on expected effects of disclosure in normalization of HIV.

My study findings suggest that PITC is appropriate for an environment where exceptionalist views about HIV prevail and hinder uptake of HTC. I was not able to establish the effect of exceptionalism on uptake of HIV services following PITC or the effect of PITC on reducing HIV exceptionalism. Positive effects of the end of an exceptionalist approach in HIV have been observed in Botswana, where as a result of normalization of HIV, HIV testing coverage and attitudes about HIV has greatly improved (Wolfe et al., 2008). This is deemed an example of the positive effects of a routine approach to the HIV test. Perhaps in the Kenyan situation similar milestones may be achieved once the coverage of HTC is increased further. This is an area that requires further research in the Kenyan context.

8.3 Constructing notions of acceptable social norms of interactions

One of the aims of my study was to examine real time counselling so as to develop an evidence base on the actual translation of counselling as

recommended by the PITC policy. Other observational studies have used check lists to assess the adequacy of counselling but such a methodological approach would not have addressed the intention of my study. Therefore, I adopted a methodological approach that allowed for the examination of the unfolding events as they were during the consultation without predetermining (through a checklist) what good counselling entails.

The data from my study illustrates that the counsellors and patients used several strategies to manage a difficult interaction and help them navigate around the tensions associated with the PITC counselling session. The strategies used include: information control, avoidance, use of euphemisms and a didactic consultation. These strategies were key to ensuring that the participants of the PITC consultation not only respected social norms of interaction but also helped to achieve and drive certain agendas. In the end, the PITC consultation seemed to be a process of managing tensions as the counsellors and patients tried to reconcile the functional aspects of the consultation and the social expectations of the patient provider interaction.

8.3.1 Tensions and complexities of managing competing agendas

Counsellors are tasked with the role of implementing the PITC guidelines and also translating them to the local environment. The study findings suggest that the consultation is a product of a myriad of issues: the functional task of getting through the PITC consultation, dealing with lay constructs of HIV and HIV testing and respecting norms of communication. Consequently the PITC consultation is one of managing tensions between

the prevailing issues and the recommendation of the PITC policy. This was illuminated by the contrast that existed between what was observed in the consultation and self-reports from the counsellor interviews. An analysis of this contradiction suggests that the counsellors were aware of the idealized PITC recommendations. However, the realities of the practice world necessitated an alteration in the process. A diversion from policy recommendations is not a blatant disregard for what is expected but a response to diverse contexts and the constraints that these impose. The methodological approach in my study facilitated the unveiling of this complex situation.

Similarly, Angotti sought to explain when, how and why counsellors in rural Malawi adapt Western testing guidelines in light of the 3Cs (consent, counselling and informed consent) to deal with local needs (Angotti, 2010). The researcher argues that local national guidelines and the international guidelines from which they are derived undergo transformation from the international and national level at the point of implementation. In her view, counsellors are the ones charged with the duty of implementing guidelines which for the most part are not suited for the African context mainly due to its sociocultural variation from the Western countries where they originate. Just as in my study, counsellors in Angotti's study found the strict adherence to the 3Cs recommendations of the PITC policy a challenge (Angotti, 2010). This is because the recommendations as they were did not suit the sociocultural environment. For example counsellors in that study felt that given a choice, patients are likely to decline a HIV test which would impede HIV testing expansion. Similarly, the counsellors felt that maintenance of confidentiality was a deterrent to HIV prevention

efforts as patients rarely disclosed their HIV positive status even when their sexual partners were at risk of being infected. Angotti's findings echo those of my research study.

Interestingly, despite being key gate keepers of policy implementation, [nurse] counsellors are rarely involved in the policy formulation process. In a previous study, exploring the nurses' views on expansion of routine HIV testing it emerged that although nurses were expected to be implementers of the policy, they had been left out in the PITC policy formulation (Evans & Ndirangu, 2009h). Perhaps involving nurses and other health care providers who are in practice in the policy development policy may lead to the development of a policy that reflects the contextual realities of practice. Indeed the analysed consultations in my study were not a sole reflection of the PITC policy recommendations (that counsellors considered unsuitable) but rather a co-construction of an interaction that suited the context.

8.3.2 Professionals writing their own script

An objective analysis of data from the observed consultations in my study reveals a counsellor dominated interaction in which the patients played a passive role. The asymmetrical interaction was achieved interactionally by both participants in the consultation. This finding is similar to that reported in the classic work on patient provider communication by Maynard (1991) and other studies carried out in diverse geographical and social settings (Barry et al., 2000; Vaga et al., 2012). Evidently the ideal of the patient partnership model in medical consultations does not translate easily in practice. It has been suggested that for the most part, patients do not

necessarily want to adopt an active role in a consultation Kumar et al. (2010). Passivity in my study was particularly pertinent as it helped the patients achieve various agendas during the consultation. By being passive, patients successfully managed to keep their personal risky behaviour information a secret, they were able to avoid talking about difficult topics like sex and finally it aided them in feigning ignorance about HIV information to avoid 'blame' in the event their HIV test turned out to be positive.

In contrast to this finding, the PITC policy recommendations imply a more symmetrical interaction in which the counsellor facilitates the patient to disclose and discuss various aspects of his social and personal circumstances. Then using this information, the counsellor is expected to provided adequate guidance that is patient specific (National AIDS and STD Control Programme, 2010). What my study findings suggest is that, whilst the PITC guidelines envision an equal interaction where the patient is an empowered active participant in the PITC consultation, in the real practice world, patients may be submissive in the face of professional dominance of the consultation.

Yet, in spite of the mismatch between recommendations about the nature of the interaction and what was observed, my study suggests that patients were content with the dynamics of the interaction. Perhaps patients did not envisage that an alternative was possible and were thus satisfied because the consultation met their expectations. Indeed the PITC consultation seemed to be rated highly precisely because it was didactic and counsellor centred. Granted the PITC consultation appears brief in

comparison to the VCT one, but it is lengthier and more involved than the everyday medical interactions that patients are used to. However, my study did not compare the routine HIV testing consultation with other medical consultations or health interactions outside the health facility to ascertain the uniqueness, if at all any, which characterised the HIV testing consultation. There is very little evidence from this setting on everyday patient provider interactions outside the PITC situation to provide comparative data from which one can draw inferences from. It might well be that even in the absence of discussions about HIV testing, everyday consultations are no different from what was observed in this study. If that is the case then one can question why the PITC consultation should be any different from the norm.

This is a key area for future research vis-à-vis understanding whether the HIV consultation contains expectations that run outside the realm of what is the norm in health communication in this context. Nonetheless, my study suggests that patients prefer and are comfortable with being passive participants as this fits into the cultural norms that define the patient role as a submissive one. In addition, it helps them achieve one of their hidden agendas: to control information about their personal lifestyles through saying as little as possible. It also assists the counsellors in driving their own agendas through dominating the sessions.

Interestingly, the analysed consultations reveal that the counselling session followed a similar structure across the two study settings. Although it is not clear how the similarity in structure came about or whether it can be generalized to settings beyond the two health facilities

involved in this study, it provides valuable insights into how counsellors in these settings adopt the PITC consultation into one that is contextually appropriate. The adopted structure facilitated glossing over sensitive topics and ensured an asymmetrical patient provider interaction that is in keeping with acceptable social norms of communication in this environment.

The rigid consultation structure observed in my study was generic, not patient centred and did not reflect the need for any specialized skills. This raises questions about whether it is necessary to have a specialized health professional conduct the routine HIV test or whether a trained lay counsellor would suffice. This would free up specialist staff for other functions more appropriate to their skills and experience. My findings suggest task shifting of the routine HIV test from highly trained health providers to lay persons who can follow the rigid testing sequence observed would be essential.

Task shifting is important in a region where shortage of human resources for health care is an issue due to the low patient to nurse ratio, few skilled health workers and the high disease burden that characterizes countries in this region. This situation is intensified by the HIV/AIDS pandemic which affects health workers themselves as well as raising additional roles and tasks required in the prevention, treatment, care and support of HIV/AIDS. Task shifting in HIV/AIDS prevention, care, support and treatment is largely practiced across African countries (Arem et al., 2011; Callaghan et al., 2010; Lehmann et al., 2009; Zachariah et al., 2009). Whilst the initial task shifting happened from a higher cadre to a lower one e.g. doctors to

nurses, task shifting has also been observed between trained professionals and lay workers (Chiambe et al., 2009; Rohleder & Schwartz, 2005). Task shifting has been seen as an avenue of substantially increasing access to HIV/AIDS services particularly in areas where the shortage of trained health workers is a hindrance in provision of key health services (Davyduke et al., 2015; Kennedy & Fonner, 2015). Based on the outcomes of my findings, task shifting of the routine HIV testing counselling from trained [nurse] counsellors to lay counsellors could adequately allow for fair use of the limited available human resources.

Indeed, in one of the health facilities from which my data were drawn, there were two trained lay counsellors whose consultations I observed and which were more or less similar to those of trained counsellors. This finding is consistent with the conclusion of a systematic review that reported marginal difference in the quality of HIV testing and counselling between lay and professional providers (Kennedy & Fonner, 2015). This is a significant indicator of the need for professional and policy changes to regulate the training and use of lay counsellors. Lay counsellors could be used to address key gaps that my study has revealed exist in the current implementation of the PITC policy. For example my study findings highlighted that the post test counselling, which is the focus of the PITC process, is not adequately handled. The abrupt end of the interaction following HIV result disclosure, lack of emotional support, lack of patient-centered HIV result tailored counselling, failure to address an individual's risky behavior and corresponding behavior change communication is detrimental to the foundation of the routine HIV testing aims.

The integration of trained lay persons as counsellors into PITC, can address this gap by involving the lay counsellors in the pre test information giving session and post test counselling. When need arises in complex situations that lay counsellors cannot handle, patients could be referred to a professional [nurse] counsellor for additional counselling. This would ensure that post test counselling takes place after the HIV test results are ready and is thus made relevant to the patient's HIV status. This recommendation would address the observed gap where patients did not receive any post test counselling following their HIV test results as most information was shared generically to fill in time whilst waiting for the test to be ready. A recommendation on the sequencing and flow of the PITC process is presented later on in section 9.2 and illustrated in figure 33.

Other than the use of a scripted and didactic interaction to manage tensions, the analysis of the findings of my study show that linguistic avoidance was a key strategy used in the co-construction of the consultations. It was easier for explicit language of a sexual nature to be spoken in English in the midst of a Swahili dominated interaction in this context. Swahili is considered a local dialect and people are able to closely associate with it and hence they are not able to overtly give explanations on taboo matters using this language. English on the other hand is considered a 'foreign' language and hence use of the vocabulary to explore sexual matters is not perceived as breaking the social distance that the subject matter is accorded. Using English provided a perceived moral and social distance from the local [sexual] social norms and one could with ease make direct inferences even where none would ordinarily be made.

Similar findings were reported in a South African study examining problems of communicative competence in multi-cultural medical encounters (Grant, 2006). Use of foreign dialects may be a vital strategy in assisting in communication of taboo matters in the settings.

The above discussion paints a picture of counselling consultations that do not bear any similarity to the idealised constructs of an empowered and emancipated patient who is an equal partner in the patient provider interaction. This conclusion is congruent with those drawn by Nguyen (2013) in his theoretical exploration of counselling technologies in African settings. He argues that the content of the HIV testing consultation that requires a discussion of matters considered taboo in this context interferes with an honest self-exploration and expression. Indeed as the analysed findings have shown in my study, keeping one's risky sexual behaviour secret is imperative in order for one to maintain face. The counsellors also play part in this process by refraining from indepth exploration of patients' behaviour so as to co-construct a consultation that helps them maintain a moral face and their respectful social standing.

8.4 Interactional strategies for obtaining and receiving consent

One of the objectives of this study was to explore how informed consent is understood by patients and counsellors, and how it is obtained during PITC. An analysis of the process of consent revealed that the provider dominated passive patient interaction coupled with the patients' primary reason for coming to the health facilities (to obtain treatment to achieve relief from symptoms) and the meanings attached to an HIV positive diagnosis

redefined what patients' autonomy for informed consent meant in this environment.

The social norms of interaction were visible in the process of obtaining consent in my study. The findings show that the counsellors chose not to frame the HIV test offer as a choice but rather as an instruction perhaps in order to increase the number of participants who took up the HIV test offer. Additionally they failed to acknowledge patients' right to dissent by ignoring the patient's subtle refusal cues. On the other hand patients did not overtly decline the HIV test offer but rather went along with it. This finding mirrors those of studies on informed consent within research situations in Kenya (Kamuya et al., 2015; Kamuya et al., 2013; Okello et al., 2013). These studies explored informed consent in the Kenyan environment at length in the context of informed consent during research in the Kenyan coast (see section 3.5.2).

These studies illustrated that the process of informed consent in Kenya was largely driven by social norms of interaction which are defined by a passive patient and a dominant health provider. With this power difference in the informed consent interaction patients are not able to overtly go against a request to consent. The focus of the interaction between the patient and the provider is to respect and maintain the social relationship norms. Consequently, patients are less likely to take into consideration information offered impartially and make a value free uninfluenced decision. For instance, patients must do what they are asked to do by a health care provider whilst health care providers must drive the agenda through ensuring everyone consents. These factors are in most instances

left out of policy and guideline documents which focus on a stringent informed consent process without being cognizant of the complexities of consent in localized settings like Kenya.

The tension in the informed consent process was evident in the variance between the observed informed consent processe and self-reports of counsellors about the informed consent process they followed. In spite of the focus on the public health agenda, the findings suggest that the counsellors are aware of the recommended process of consent. This was evident in the mismatch between their narratives about how they obtained informed consent and the findings from the observed process. The tension between the 'official' rhetoric (policy recommendations) and practice has also been reported in an ethnographic study carried out in Swaziland, Namibia and South Africa to explore health workers, antenatal and postnatal mothers' perceptions and experiences with counselling (Buskens & Jaffe, 2008). The researchers found that while in theory the counselling sessions were expected to be non-directive and patient centered, in practice they turned out to be directive/instructive information giving sessions. The aim of the counsellors in that study was to get the mothers tested for HIV and 'force' them to adopt measures to save the baby once it is born. Both this study and mine show that the public health objective of policies takes precedence over the underlying 'human rights' concerns about the patient.

The analyzed findings in this study suggest the tension between the logic of collective responsibility and logic of choice played out in the observed consultations. I devised the phrase 'logic of collective responsibility' to

infer public health benefits that in some instances take precedence over the focus on individual's rights to choice. In contrast, logic of choice refers to a situation where patients are provided with objective information which they consider to make a value free rational decision devoid of external influences. Theoretical debates about these two notions have been explored at length in Chapter three, section 3.5.1. Indeed, the observed consultations suggest that contrary to the recommendations of the PITC policy, in practice the logic of collective responsibility prevails. Counsellors are in everyday practice concerned with making sure that patients maximize the benefits of PITC by ensuring that patients are tested no matter what. Evans & Ndirangu, (2011) likewise found that the quality of the routine HIV testing consultation was secondary to the number of people who accepted the routine HIV test offer. In that case the logic of collective responsibility reflects the reality of informed consent as observed during the routine HIV testing consultation.

In practice and policy the onus of bringing down the HIV prevalence rates and preventing spread of infection lies with the individual as well as the community. However, the policy, which presents official discourse, cannot be seen to place emphasis on public health benefits (common good) of individual testing over the individual's right to say no. Regardless of this, it is a different scenario for health care providers on the ground. In my study, the counsellors presented the HIV test as a requirement as opposed to a choice during the consultation. The counsellor's push for the patients to test was drawn from their need to drive the public health agenda of bringing down the HIV prevalence rates through having as many people as possible become aware of their HIV status.

The PITC policy on the other hand is vague about the thin line between collective responsibility and care. The policy drives the public health agenda by using an opt-out approach which my study suggests inevitably means that patients are not in a position to decline the HIV test offer. The patients' compliance with the health providers' dominance works collaboratively to override the individual's opportunity/entitlement to make an informed choice allowing the unspoken health system's public health agenda to prevail. Importantly, patients were not resentful of this. The consultation met their expectations and the counsellor's management of the encounter appeared to have been seen as appropriate. As my respondents indicated, they were glad that their uncertainty and resistance to being tested had been overridden by the counsellors. They had been relieved of the burden of responsibility for making a difficult decision. Mol deals with this issue. She indicates that patients, especially those in difficult situations, may prefer professional paternalism to personal autonomy (Mol, 2008).

In conclusion, my study suggests that the idealized notion of autonomy that presumes that there are no controlling influences external to the patient's ability to make an informed choice is problematic in the Kenyan context. The limits of patients to exercise choice are constructed and defined by contemporary perceptions of HIV and socio-cultural norms that dictate the format of the health provider – patient interaction. For this reason the Western ideal of what constitutes ideal informed consent is difficult to operationalise in this context. This does not mean that what takes place in Kenya and other developing countries can be considered a

breach of patients' rights to informed consent. It is rather a response to the existing sociocultural norms and expectations of patients and providers.

Using the logic of choice to define good / bad informed consent practices is problematic in view of the multiple factors that influence choice in the social settings in developing countries. Indeed the policy does not in its discourse frame informed consent as a product of other factors beyond the consultation and the individual. What my study has highlighted is that in practice, counsellors and patients translate the policies to suit the reality on the ground. In the implementation of PITC, the obvious tension that exists between the public health agenda and individual rights to consent is manifested.

8.5 Conclusion

The literature on policy transfer makes distinctions between the complete transfer of a policy in its entirety to diverse settings versus drawing lessons from policy issues and adopting them to suit specific contexts (James & Lodge, 2003). My study findings suggest that adopting the PITC policy recommendations about consent and counselling as they are in the Kenyan situation may be ill fitting to the practice setting. For instance, counselling and consent as we have explored at length are defined and constructed in the policy based on Western rhetoric. Yet in the Kenyan context these concepts have different constructs and meanings attached to them and thus do not fit. In the Western paradigm counselling can only take place in a context of a patient centered symmetrical interaction, the achievement of this interaction is not feasible in much of Kenyan society.

Similarly, autonomy and patient choice are not held in the same esteem in this context as they are in the Western context. The social setting has norms providing acceptable guides to roles adopted in an interaction during a medical consultation. In this case patients are not accustomed, and do not expect, to be decision makers of their care but see their roles as being simply following instructions and doing what they are told to do. Notably, the Western ideals of a symmetrical interaction are equally not operationalized in the Western contexts as well (Barry et al., 2000; Maynard, 1991; Mol, 2008; Alison Pilnick & Dingwall, 2011; Vaga et al., 2012).

It is arguable that HIV strategies and measures are often driven by the international agendas and subsequent funding due to slow or absent national responses. It is perhaps in line with this that international HIV policies have been transferred to such contexts. However, examining the actual implementation of the process in this study illuminates the obvious mismatch between what international policies expect and what actually takes place. The 'official' policy discourse does not necessarily fit into the agendas of the health providers and patients particularly in an environment where achieving hidden agendas takes precedence over policy recommendations.

An extensive analysis of policy recommendations about the pre test and post test counselling sessions in European countries shows inconsistencies in the recommendations about the content, process of seeking consent as well as how and when test results should be delivered (Bell, Delpech, Casabona, Tsereteli, & de Wit, 2015; Bell et al., 2016). The authors blame

this on the process involved in the development of policy and guidelines documents which relies heavily on expert opinion as opposed to locally generated evidence. Expert opinion, they argue, whilst invaluable, sometimes diverges from the realities of the practice settings. Further on, they conclude that there is need to carry out research on the procedures followed during counselling and testing and their impact in order to inform policy and guidelines on HIV testing and counselling. My study was able to shed light on the practices of counselling and consent in the Kenyan context. However, the effect of the process that actually took place was not adequately explored. This is an area that requires further exploration.

In sum, there is a considerable distance between policy recommendations and their implementation in practice due to the complexity of the real world. This distance is not occasioned by a deliberate effort by health workers (and patients) to disregard policy recommendations but rather an attempt to adapt to the prevailing environment that is shaped by sociocultural norms. Recommendations for practice, policy and future research in light of the findings and discussion will be outlined in the next chapter.

9 CHAPTER NINE: CONCLUSION

9.1 Introduction

This work has been concerned with the micro practices of obtaining informed consent and providing counselling in the milieu of PITC and normalization of the HTC process in the sociocultural environment of HIV in Kenya. Using the discourse of normalization as a lens through which to understand and critique changes in HIV testing policy and practice, this study sought to examine how the core components of PITC (consent and counselling) are understood and enacted in every day practice. The specific objectives were to: 1) Explore patients' perspectives and understanding of HIV and HIV testing; 2) Examine how patients' perceptions of HIV influence their communication and interaction with counsellors during the HIV testing consultation; 3) Explore how the role of the counsellor is constructed by patients and health professionals, and how 'counselling' is performed during the PITC consultation; 4) Explore how informed consent is understood by patients and counsellors, and how it is obtained during PITC.

Using a social constructionist approach, this study utilized multiple data collection methods in order to uncover the multiple realities of the PITC consultation. This study began with an indepth examination of the patients' perspectives about HIV and HIV testing using interviews prior to the PITC consultation. This was intended to appraise how existing sociocultural factors and perceptions about HIV shape PITC and, in particular, communication and interaction during the routine HIV testing consultation. The study then used observation and recording of the

consultations to examine how patients and counsellors 'perform' counselling and co-construct informed consent within the context of normalization of HIV. This also facilitated the exploration of how the patient and counsellor roles are constructed during the PITC consultation. Subsequently, indepth interviews were carried out with the patients after the routine HIV test to elicit their perspective of the PITC consultation. Counsellors whose consultations had been examined were interviewed to provide their perspectives of the events of the PITC consultations. This methodological approach allowed for the examination of both the meaning and practice of the PITC consultation. Additionally, it facilitated the uncovering of the multiple facets of the PITC consultation and the factors that interact and shape construction of informed consent and counselling.

The findings suggest that there are competing repertories within the normalization discourse in the implementation of PITC. While on the one hand, normalization within PITC guidelines is a biomedical construct (i.e. routinization of the HIV test and treatment process), on the other hand, the response to HIV and the practice of HTC are socially constructed in this environment. This was reflected in the tensions that existed as the counsellors tried to reconcile the functional aspects of offering PITC with the competing agendas. The competing agendas included maintaining a moral face, ensuring patients took up the test, managing a difficult interaction and respecting social norms of communication as illustrated in the diagram below.

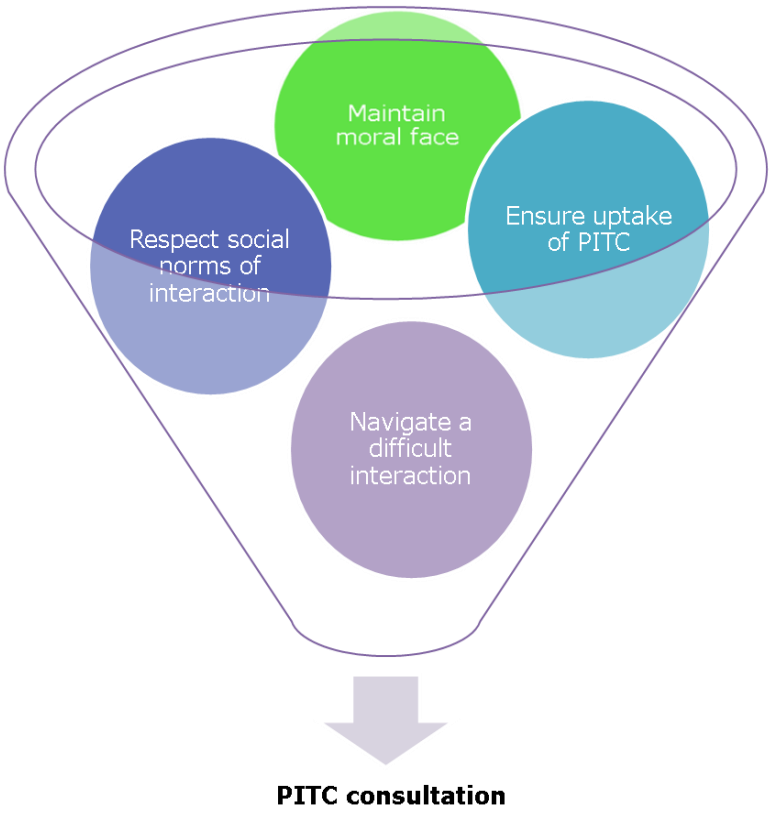


Figure 31: Competing agendas during the PITC consultation

The complexity of the tensions of the PITC consultation was illuminated by the contrast that existed between what was observed and what the patients and counsellors reported about the consultation. Therefore, the study suggested that the practice of PITC is a product of the response to the existing constructs about HIV and social norms of patient provider interaction. Further on, in instances where policy recommendations are far removed from the realities of the practice world, practice is inevitably adjusted to suit the context.

9.2 Implication for training, practice, research and policy

This study makes several contributions to existing knowledge about PITC summarized below.

Key finding	Recommendation
1. HIV exceptionalism is still prevalent and is shaped by social constructs and not biomedical developments 2. Stigma not addressed during the PITC consultation	✓ Policy ✓ Strategies to deal with stigma from a sociological standpoint need to be addressed ✓ Continue expansion of PITC: it helps identify people who, due to continued HIV exceptionalism, will not seek HTC ✓ Training ✓ On how to identify the complex stigma situation and deal with it during the PITC consultation ✓ Research ✓ Extensive sociological and anthropological research to understand the complex terrain of HIV stigma and exceptionalism
1. Pre-test counselling is none specific, generic and not patient centered 2. Pre-test session used to fill-in time for the test to run and labelled 'post-test session' 3. Post-test counselling not done at all. Sessions end abruptly once results are disclosed	✓ Policy ✓ Group pre-test counselling to save time and resources ✓ Removal of the recommendation of risk assessment which is rarely done ✓ Implementation of ultra rapid test kits: reduce the pre-test duration and save time for post-test counselling ✓ Make post-test counselling distinct from the rest of the testing process ✓ Training ✓ Lay counsellors to conduct group pre-test counselling ✓ Reinforce the importance of post-test counselling in PITC ✓ Strategies on how to conduct the difficult task of breaking bad news ✓ Research ✓ Comparative studies on the operationalization of the use of ultra rapid test kits versus conventional rapid tests ✓ Culturally appropriate ways of breaking bad news in the context
1. Distance between policy and practice	✓ Policy ✓ Policy should be drawn from and responsive to the practice setting realities of counselling and consent ✓ Quality assurance measures should be reflective of realities of the practice setting

Figure 32: Summary of key findings and recommendations

First in relation to contemporary lay perceptions about HIV, the findings suggest that HIV is still a highly stigmatized disease. In spite of massive health promotion activities, increase in uptake and effectiveness of ARVs, normalization of HIV testing processes, stigma remains a challenge and needs to be explicitly addressed and understood. Stigma was not addressed in the consultations examined in this study, yet it has impact on

self-referral to HTC and uptake and adherence to HIV treatment and services. This lends weight to the rationale for having PITC in the first place since stigma hinders self-referral for testing. Policy and training needs to be cognizant of the complexity of stigma and lay perceptions about HIV. This can be facilitated through acknowledging the impact of stigma on the PITC process and the influence of lay constructs about HIV on the PITC consultation.

Training of counsellors should include knowledge, skills and attitude that can aid them identify stigma especially in situations where it is not overtly expressed and address it during the HIV consultation. In addition, the counsellor training needs to include the drivers for stigma and how they can be addressed appropriately. For example, previously stigma was largely driven by fear of physical contagion which was dealt with by clarifying the mode of transmission for HIV and debunking myths about its transmission through touch or sharing cutlery. Currently, stigma is constructed around fear of moral and social contagion and therefore strategies that target fear of physical contagion may not be appropriate (Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). Instead counsellor training could include strategies to aid PLHIV live positively and cope with apprehension about stigma e.g. through support groups / networks.

Second, the study findings suggest that the existing HIV exceptionalism originates from how HIV is socially constructed – a disease associated with immorality and death - irrespective of the biomedical advancements of HIV treatment and management e.g. availability of ART, routinization of

the HTC process etc. In spite of these biomedical advancements, the existing perceptions about HIV and its exceptionalism continue to affect self-referral to HTC, the HTC process and uptake and adherence to HIV treatment and services. These findings provide a rationale for the implementation and expansion of PITC since it is a good avenue for identifying persons who would not ordinarily seek a HIV test. In addition, PITC in clinical settings is likely to increase access to testing for men, the majority of whom do not seem to benefit from PMTCT.

However, my study findings suggest that couple testing and counselling within PITC is still minimal. This is partly because health care workers rarely initiate HTC for the couple but rather focus on the 'sick' individual. Perhaps the fact that the counsellors frame the HIV test as part of the treatment process makes it difficult for the HIV test offer to be inclusive of the accompanying partner. Hence it is important for training to emphasis the need for including couple testing and counselling during PITC. The training will need to include strategies on how the counsellors can initiate the routine HIV test offer to a couple during PITC. This should include how the counsellors can deal with patient and partner willingness to be tested and the consent process which may differ from the consent process involving an individual patient. At the same time, the study findings suggest that in this environment, there is a low number of patients being accompanied by their partners when seeking health care. This can be addressed by mainstreaming couple counselling and testing in all models of HIV testing especially those that are not facility based such as home based testing so as to increase opportunities for couple testing and

counselling. For example HBCT can be carried out on weekends and in the evenings when both partners are likely to be available in the homestead.

Third, the findings suggest that the exceptionalist view about HIV, characterized by negative perceptions linked to unacceptable social behavior and death, shapes the construction of consent and counselling rather than the policy recommendations. Arguably, because the policy recommendations do not match and reflect the HIV exceptionalism that is rife in this practice setting, counsellors then seek to modify policy recommendations to suit the realities of the practice world (Angotti, 2010). My recommendation is that policy should be drawn from context realities rather than trying to force the context realities to suit divergent policies. Bell et al., (2015, 2016) argue that the distance of HTC policies from practice results from a heavy reliance on experts rather than indigenous evidence from diverse contexts to inform policy development. They recommend the generation of context specific evidence which can in turn be used to inform policy formulation. A study such as this one, albeit of a small scope, provides valuable insights into the realities of the practice world from which policy should be drawn.

Fourth, this study adds voice to an understanding of the complexity in co-construction of informed consent in the Kenyan context. The study suggests that informed consent is largely a product of expectations and norms of interactions. Therefore, context-free informed consent as found in the PITC policy is not plausible in this context. On the one hand patients largely expect to be told what to do and feel that explicitly declining the HIV test offer would be going against their expected role. On the other

hand, counsellors do not frame the HIV test as a choice so as to enhance uptake of the HIV test offer, and 'ignore' any subtle cues of dissent from the patients. In spite of this, patients appear contented and satisfied with the process - a pointer to the fact that the observed process is in keeping with their expectations and norms.

These findings are congruent with informed consent situations reported in other nonclinical settings in Kenya (Gikonyo et al., 2008; Kamuya et al., 2015; Kamuya et al., 2013). Informed consent in this environment is not a value free, independent process but rather a value laden, dependent process that is a product of social relationships co-constructed during the PITC consultation. The PITC policy and other HIV testing policies may need to reflect this complex informed consent situation. Consequently, the quality of the consent process should not necessarily be viewed from the realm of the idealized autonomous and empowered patient but rather through the lens of the fluid and unpredictable nature of informed consent in specific local contexts. It is vital for policies to be responsive to the complexities of informed consent in diverse settings rather than focusing on a stringent consent process that is ill fitting in the real world contexts of patient care (Gikonyo et al., 2008).

Fifth, in relation to counselling, the study suggests that the patient provider communication in this environment is multifaceted. It is a process of adjusting information and an interplay of scientific and lay information. Counselling takes place against the background of an exceptionalist view about HIV and in a situation where taboo subjects related to sex are not openly talked about. It is therefore not possible to separate lay

information from scientific information. As a result, the study findings reveal an alteration in the structure of the consultation to one that diverges from the PITC policy recommendation, but one that seems to suit the 'hidden' agendas of those involved. The adopted structure impedes patient centered counselling, risk assessment, behavior change communication and post test counselling, but respects social norms of secrecy about sexual behavior and distancing of oneself from behavior considered immoral. Policy needs to reflect a link between the practice of communication and the environment where communication is taking place. This finding has several implications for policy and training.

One, inclusion of risk assessment during PITC seems futile since in practice it is rarely done and when it does occur, it is vague, none personalized and indirect. The study findings therefore, support the exclusion of risk assessment as a component of pre test counselling, as proposed in the most recent HTC guidelines (WHO, 2015). Two, the generic none patient centered interaction suggests that in order to maximize the utilization of available resources and time, it may be more prudent to have a group pre test session. In which case, one counsellor can carry out the group pre test counselling session following which, patients can have an individual HIV test and post test counselling session. This particular session which is generic and does not depend on any professional skills can be done by a trained lay counsellor. This would save the time of save the trained professionals for other tasks in the PITC process that require specialized skills and knowledge.

Finally, the study findings demonstrate a lack of post test counselling since almost all the observed consultations ended abruptly as soon as the results were disclosed. What counsellors labelled as a post test counselling session was actually a pre test session that involved sharing of a myriad of information as they waited for the tests to be ready. It was therefore a session that was drawn on by the need to fill in time and avoid a lengthy awkward silence as the results were running. This gap can be addressed through the implementation of ultra-rapid test kits which are able to run HIV test results in under five minutes. Therefore, the need to impart a load of information to fill in the time is addressed while at the same time shortening the PITC process. This would work well with the proposed patient flow (see diagram) which is aimed at making the PITC process more efficient in its operationalization. There is need to carry out research on the operationalization of the ultra-rapid HIV test such as comparative studies on the use of ultra-rapid HIV test versus conventional rapid tests.

The lack of a post test counselling session has key implications on the PITC process. Patient centered post test counselling is a key component in PITC, specifically in relation to the delivery and receipt of HIV test results, referral to further care and behavior change communication. This finding implies that the post test counselling session needs to be made extremely distinct from the PITC process. One way to do this would be through ensuring that the post test session is done separately after patients have gone through the [group] pre test session. The value of post test counselling needs to be reinforced in ongoing training for the counsellors. Good linkages to care depend on a good post test counselling session that sign posts the patients to available services based on their HIV test results.

Intense post test counselling may be the avenue to prepare patients for uptake of services by making them psychologically prepared to deal with the test results. By saving time during the pre test session through the use of ultra-rapid test kits and reducing the amount of generic content shared, more time can be spent on the post test counselling session.

In addition, specialized skills related to breaking bad news should be included in the counsellor training. This is because for the most part breaking of the news about the test results was done through requiring the patients to interpret the results for themselves. At the same time counsellors avoided engaging with the patients' feelings and emotions towards the HIV test results especially when the test results were positive. Avoidance of engaging in this task suggests discomfort in exploring the patients' situation following a HIV positive diagnosis. Counsellor training may need to focus on strategies to cope with the difficult task of not only breaking bad news, but also engaging with the patients' emotional needs. Separating the pre test session from the post test session may also deal with this problem since a counsellor will be compelled to spend a lot more time with the patient soon after disclosing the test results. Social and anthropological research exploring culturally and socially appropriate ways of breaking bad news would provide indigenous evidence to inform policy and practice.

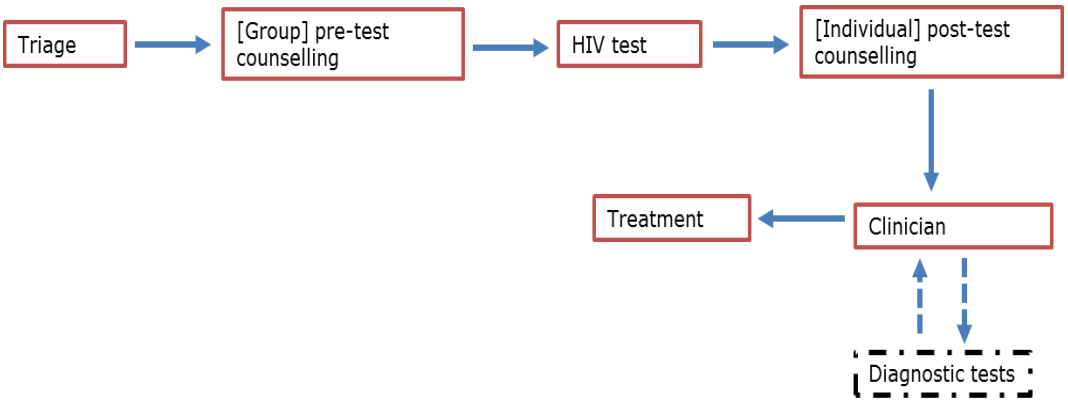


Figure 33: Recommended patient flow

Sixth, the study findings suggest that the implementation of the PITC policy recommendations is influenced by circumstances of the existing health care system. For instance, shortage of testing kits and skilled health care workers to carry out PITC may impact on the number of patients who are referred for PITC. The findings indicate that PITC is an additional task that the health care workers have to deal with in addition to their usual everyday activities. Use of trained lay workers is a viable solution to dealing with the increased workload for nurses who have additional roles to complete. In addition modifying the PITC process through group pre test counselling and saving the counsellors for the much more specialized task of post test counselling would assist in dealing with this concern. Consequently, clear structures for lay counsellor training and monitoring of the quality of testing needs to be put in place. This study did not focus on the quality of the PITC process between lay and professional counsellors. However, it did illustrate very minimal differences in the structure, content and process of counselling and consent between the consultations run by the two cadres of workers. This is perhaps

suggestive of the need not only to carry out further research to explore the role of lay counsellors but also to develop guidelines related to their role within PITC based on context relevant evidence.

Another angle to the shortage of health care workers emerging from observation of the patient flow, was the fact that clinicians who referred patients to PITC, had to see the patient twice. Once at the time of referring the patient for PITC and a second time after receiving the test results. In instances where a patient did not require any other laboratory and diagnostic test then it may not be practicable to send such a patient for PITC. This challenge can be addressed by changing the patient flow so that all patients are offered a HIV test and tested prior to going in to see a clinician. In that way, all patients get an opportunity for a HIV test offer even if in the course of receiving treatment they will not be referred for any other diagnostic tests (as illustrated in figure 32 above). I would recommend that health facility staff [and patients] get involved in redesigning an appropriate patient flow structure in what is referred to as experience based design. Experience based design involves observing patient pathways and understanding experiences of users (patients and professionals) and using this data to improve patient pathways (Bate & Robert, 2006; Donettoa, Pierrib, Tsianakasa, & Roberta, 2015). The impact of the adopted pathway is examined and changed for improvement if need be.

Seventh, my findings also suggest that the poor patient information management system that characterizes the health care system in Kenya impacts on the implementation of the PITC policy. It is difficult for health

care workers to ensure linkages to care and follow up of patients especially those who receive a HIV positive diagnosis. It is also challenging to keep track of those patients who have tested positive and have been referred to other health facilities for treatment and care since appropriate infrastructure does not exist to facilitate communication between health facilities. Lack of appropriate linkages to care leads to limited benefits for those who test HIV positive (WHO, 2015). Additionally, the lack of a proper patient information management system makes it difficult to keep track of 'repeaters' who by virtue of consistently seeking a HIV test, deplete the limited resources particularly the testing kits. This leads to shortages of testing kits and in the process denying those who really require HTC an opportunity to test. These findings suggest that the government needs to invest in a good health information management system in all levels of health care, to strengthen linkages to care and referral systems to the various levels of health care for patients receiving PITC.

9.3 Dissemination plan

Efforts are underway to disseminate the findings of this study to a variety of audiences. The study findings have already been disseminated to the Aga Khan School of Nursing and Midwifery faculty during a faculty research meeting. Abstracts have been written and submitted for the Sigma Theta Tau International (STTI) conference to be held in South Africa on 21st – 25th July, 2016 and the East, Central and Southern African College of Nursing (ECSACON) conference which will take place in September, 2016. An acceptance has been received from the organizers of

the STTI conference; I am awaiting feedback from the organizers of the ECSACON conference. Other conferences will be targeted as the opportunity presents itself. Preparation of articles for submission to peer reviewed journals e.g. *AIDS Care, Social Science and Medicine and International Journal of Nursing Scholarship* is planned. Finally, reports of key findings and recommendations will be shared with the health facilities that participated in this study and other key stakeholders.

9.4 Methodological reflections

Whereas the methodological approach used in this study was invaluable in unearthing the multiple realities of the PITC consultation, a number of methodological limitations were identified.

To begin with the choice of study sites was driven by convenience of health facilities in terms of accessibility to my home town. This was necessitated by the limitations of time and available finance. However, this meant that all participants were drawn from an urban area. As discussed in chapter 2, the majority of the Kenyan population lives in rural areas where resources are limited and scarce. There is a huge rural urban divide in terms of the resources and capacity of health facilities located in these areas. Consequently, the findings of this study may not be reflective of the situation in rural health facilities. However, the two study settings serve a considerable proportion of rural to urban migrants who move to the city for short term, nonpermanent employment.

It is noteworthy that this study had at the onset included one rural health facility (Karuri Health Centre) but the ethical approval and consent process was difficult to navigate. Therefore, a decision was made to carry on with

the two study sites. Findings from these two study sites are not necessarily representative of the Kenyan situation in its entirety. However, the philosophical approach of this study proposes that experiences are socially constructed and therefore different contexts are likely to have unique findings about the PITC process. It would be important therefore, to carry out further research on the implementation of PITC in rural health facilities as well as private health facilities which may have diverse issues and needs.

Another limitation of this study was the small sample size particularly of the counsellors. The counsellors were not the primary target of this study since counsellor experiences with PITC had been the focus of a previous study (Evans & Ndirangu, 2009h, 2011). A decision to add the counsellors was borne from a gap identified in the initial analysis of the patient data which necessitated getting a formal perspective from the counsellors which were not addressed during the reflection sessions with counsellors after the observed consultations. Nonetheless the small number of counsellors made it difficult to compare the PITC consultation between lay and professional counsellors and draw adequate inferences on how the two groups of professionals implemented the PITC process. This is an area requiring further exploration. Additional research is required with a large sample of counsellors (both lay and professional) to explore their perspectives of the observed 'real time' PITC consultation to allow for generalizability of the evidence generated.

A further limitation arises from the very small number of patients interviewed during the follow up interviews. Follow up interviews were a

vital component of this study as they provided invaluable insights into the challenges of linkages to care. A larger follow up sample size particularly including those who had received a HIV positive diagnosis is needed to provide findings that can inform practice and policy on how to improve linkages to care following PITC. This is an area that requires extensive research especially in view of the identified gap with linkages to care following HTC. It would be particularly important to carry out such a study in a context like Kenya that has poor systems of tracking patients and nonfunctional electronic information systems. The high attrition rate at the end of the study is reflective of the high attrition rate of patients in the course of seeking HIV treatment and follow up. Even so, the initial sample size of 30 participants was appropriate for a qualitative study design such as this one which focused on depth rather than breadth of the concepts under examination (Creswell, 2013; Denzin & Lincoln, 2011; Dingwall, 1997).

The fact that the study did not include an examination of the consultation between the clinician and the patient at the point of referral for PITC was another limitation of this study. It was apparent that the process of seeking consent started prior to the patient arriving at the counselling and testing room. It would have therefore been valuable to find out how the clinicians who referred the patients for PITC framed the referral. This is particularly vital in view of the fact that the study findings revealed that some participants did not know why they had been referred to the counsellor and the counsellors reported dissatisfaction with clinicians failing to inform patients they had sent them for a HIV test. With hindsight, when I elucidated this from the preliminary findings, I should have

included a few observations of the clinician interaction with the patient. However, the limitation of time made it difficult to increase the scope of the study. Even so, this is an area that requires exploration since what transpires during this time has an effect in one way or another on the subsequent PITC consultation.

In the same vein, at the initial planning stages of this study, a decision had been made to examine patient provider consultations in situations outside the HIV testing consultation. This was intended to appraise everyday patient provider norms without the added complication of a HIV test. However, as the research project gained shape it became apparent that this would have expanded the scope of the study beyond what was going to be manageable for this PhD project in terms of time and resources. Nonetheless, I have identified this as an area that requires further research since evidence from these interactions would inform policy and practice on the norms of patient provider consultations. This evidence would be key in making recommendations within PITC which are well suited to real practice situation.

The data collection and analysis process of this study faced some limitations. My presence during the counselling session may have influenced the counsellors' practice when carrying out PITC. However, the fact that the sessions were broadly similar across different counsellors in the two study settings may be an indication of the observed practice being the norm. Additionally, there were three counselling sessions where only audio recording was done since the counsellor was not comfortable with me being present. These three sessions were also similar to the rest where

I was present. As a sole researcher, carrying out the interviews, observations and analysis of the data, this study lacked a second eye on the research process. Efforts were made to document the research process so that it is clear how the research findings and conclusion were drawn.

This study may have faced limitations related to translation of transcripts (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015). The data collection was largely done in Swahili with the patient participants and in English for the counsellors. As a researcher, I am conversant with both Swahili (which is the national language in Kenya) and English. Therefore, I was able to carry out the interviews myself. To avoid loss of meaning after translation from Swahili to English, I did coding of the Swahili transcripts so as to maintain the native meanings. I then translated the Swahili transcripts myself with the aim of maintaining the sematic and content equivalent of the original transcript. I paid attention to the unstated meanings of some of the everyday street lingo whose direct translation would have lost meaning. For instance, 'kutembea bila viatu' can loosely be translated to mean 'walking without shoes'. However, the social and cultural meaning is 'having sex without a condom'. An understanding of the sociocultural context and in particular the euphemisms used in everyday language was vital in retaining the intended meanings contained in the indigenous language.

Despite the limitations relating to being a sole researcher, engaging in every aspect of this study gave me an opportunity to pay attention to contextual details. It also facilitated immersion and familiarization with the participants and their journey through the PITC process and the data. It

was therefore easier for me to make informed decisions about the research process as the study evolved e.g. the decision to include counsellor interviews later on to enrich the data.

9.5 At the end of the journey - Personal reflections

The PhD journey has been a long process marked by a lot of learning points and opportunities for self-appraisal. At the onset of this journey, I had begun to realize the impact of HIV on the social wellbeing of individuals and in particular the effect of stigma on the day to day lives of PLHIV (see section 1.3). However, I had not realized the extent to which stigma and prevailing lay constructs about HIV influence the HIV testing process and govern the counselling and testing consultation.

I went into the study setting with certain expectations. Whereas I had an inclination that the PITC policy may be somewhat different in the Kenyan situation, I had expected that it would be a straightforward one dimensional interaction. I expected that the counsellors would be following the PITC recommendations of the consultation to a T and if they were not following this it was because they chose not to. I would never have imagined that the social norms about patient provider communication and the preexisting perceptions about HIV would have such a huge impact on the consultation. It appeared as though the counsellors did not even give the guidelines and recommendations a second thought. What the guidelines were saying did not in any way fit into their practice setting. I felt as though there was nothing like doing the 'right' thing. It was amazing to watch the patients and counsellors work so well together to maintain certain norms and safeguard the patient's moral 'face'. It was

quite intriguing to see how a consultation that was so divergent from the policy guidelines worked so efficiently and seamlessly.

I have struggled with reconciling my thoughts around how we then can determine what constitutes 'good' or 'right' practice. Is it following the guidelines to the letter in practice or is it doing that which befits the practice setting? Before engaging in this study, my response would have been the former: one MUST do what the guidelines recommend. Now I feel that context appropriate care should be the focus. It is inappropriate to force incongruous practices to a situation that is not suitable to the prescribed care. Mol (2008) has extensively presented this misnomer and suggested that good care should recognize the meanings attached to information and the unpredictable real life situations that patients have to deal with in their day to day lives. Similarly, Leon et al. (2013) recognizes that achieving the ideals of informed consent is difficult in certain local settings. Instead they introduce the notion of 'minimum requirements for informed consent' in recognition of contextual differences that may impede implementation of policy recommendations, particularly about informed consent, in diverse settings.

I am now more attuned to the fact that the provider patient interaction is as much a social construct as it is a biomedical process. I feel challenged to look at health care and in particular issues related to HIV/AIDS from a different lens: a sociological one. This is extremely pertinent to my own country where the realities of the practice world which shape implementation of health care are rarely, if at all ever, reflected in policy documents. I feel challenged to continue generating HIV related research

that can produce context appropriate evidence to inform policy and practice. I am more conscious of the need to avoid applying a simplistic point of view to HIV issues, and being aware of the subtleties and multiple realities of an HIV testing consultation. It would be interesting to see if this situation is duplicated in other patient provider interactions outside of the HIV consultation.

I am conflicted about the ethical dilemmas I faced during this research study. Firstly, it was unnerving watching the counsellors 'ignore' the patient's subtle cues of dissent to the HIV test offer and completely fail to obtain explicit consent. I did wonder if it was in my place to point this out and report it or whether I should let the natural order of things prevail. Reflective interviews with the counsellors were quite telling: it was not that the counsellors were not able to pick up the cues or blatantly ignored to seek consent but rather they preferred to ignore these so that they could ensure uptake of the HIV test. Secondly, at the planning phase of this study, I had intended to carry out the post test interviews for participants who received a HIV positive diagnosis two weeks after receiving the diagnosis. However, when I conducted the research, all the participants who received a HIV positive diagnosis wanted to have the post test interview immediately. I felt that to them this was a way of having someone to talk to especially because the HIV testing consultation had ended abruptly after receiving the news of their diagnosis. I felt that failing to respect their wishes would be ethically wrong. Yet it would have been considered unethical to interview patients soon after receiving a HIV positive diagnosis. To me this was a reflection of the complex ethical

dilemma that is often quite gray. I trusted that I had made the appropriate ethical decision.

Looking back I realize that stepping 'out' from a situation and adopting an outsider view is an important process of self-reflecting not only on the practice of others but also of my own. For example I had not realized just how much norms about power differences were a huge part of my everyday life including my PhD journey. I was extremely surprised to find out that I too was tied down by the power relationship norms that characterize the context where I come from. Just as the participants in my study avoided overtly declining a HIV test offer, I shied away from overtly communicating the challenges I was facing to my supervisors. It was easier for me to go quiet than to express that which I needed to say. As one of my supervisors humorously indicated, I was silently refusing. I must say that I have subsequently become much more assertive and open. It is easier for me to communicate about certain things because I now appreciate that giving a different opinion or taking a different stand point does not imply disrespect for my supervisors. This is a valuable lesson for me as I go through my journey as a 'young' academician and researcher.

I end this PhD journey with the realization that it is context that guides practice and how important it is for policy to be reflective of the practice setting. I acknowledge that a lot has to be done to make PITC and HTC in general very context relevant and efficiently operationalized within diverse settings. This is a challenge for me to continue contributing to the small body of evidence about HIV testing emanating from Kenya.

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Appendix One: Ethical Clearance Letters

THE AGA KHAN UNIVERSITY

28th October 2009

Eunice Ndirangu
University of Nottingham
Queen's Medical Centre
Nottingham

Dear Eunice Ndirangu,

Re: **"Communication and interaction in the context of routine provider initiated counseling and testing for HIV: Patient experiences and outcomes in Kenya"**

It is my pleasure to inform you that your submitted research proposal has been approved by the Aga Khan University Research Ethics Committee.

Please note that as the Principal Investigator, you have the full administrative, scientific and ethical responsibility for the management of the research project in accordance with the University policies and guidelines.

You will be required to present the final report of your study to the Aga Khan University Research Office.

Best wishes,

Mr. John Arudo
Chair, AKU (EA) - Research Ethics Committee

KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840 - 00200 NAIROBI, Kenya
Tel: (254) (020) 2722541, 2713349, 0722-205901, 0733-400003; Fax: (254) (020) 2720030
E-mail: director@kemri.org info@kemri.org Website:www.kemri.org

KEMRI/RES/7/3/1 **June 14, 2010**

TO: **MS. EUNICE NDIRANGU,**
AGA KHAN UNIVERSITY, ADVANCED NURSING STUDIES PROGRAMME
Email: Eunice.ndirangu@aku.edu; ntxewn1@nottingham.ac.uk
PRINCIPAL INVESTIGATOR

RE: **NON-SSC PROTOCOL NO. 206 (*INITIAL SUBMISSION*): COMMUNICATION AND INTERACTION IN THE CONTEXT OF ROUTINE PROVIDER INITIATED COUNSELLING AND TESTING FOR HIV: PATIENT EXPERIENCES AND OUTCOMES IN KENYA.**

Make reference to your letter dated May 26, 2010 received on the same date. Thank you for your response to the issues raised by the Committee. This is to inform you that the issues raised during the 178th meeting of KEMRI/National Ethical Review Committee held on 11th May 2010, have been adequately addressed.

Due consideration has been given to ethical issues and the study is hereby granted approval for implementation effective this **14th day of June 2010,** for a period of twelve (12) months.

Please note that authorization to conduct this study will automatically expire on **13th June 2011.** If you plan to continue with data collection or analysis beyond this date, please submit an application for continuing approval to the ERC Secretariat by **3rd May 2011**.

You are required to submit any amendments to this protocol and other information pertinent to human participation in this study to the ERC prior to initiation. You may embark on the study.

Yours sincerely,

RCTKithinji

R. C. KITHINJI,
FOR: SECRETARY,
KEMRI/NATIONAL ETHICS REVIEW COMMITTEE

REPUBLIC OF KENYA



NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams: "SCIENCETECH", Nairobi
Telephone: 254-020-241349, 2213102
254-020-310571, 2213123
Fax: 254-020-2213215,318245, 318249
When replying please quote

P. O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: NCST/5/002/R/1060/5

Date: 13th November, 2009

Eunice Ndirangu
The University of Nottingham
Faculty of Medicine and Health Sciences
School of Nursing, Midwifery and Physiotherapy
Queen's Medical Centre, Nottingham
NG7 2UH
UNITED KINGDOM

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on ***"Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya"*** I am pleased to inform you that you have been authorized to undertake your research in ***Nairobi and Kiambu Districts*** for a period ending ***30th November 2011.***

You are advised to report to ***The District Commissioners Nairobi and Kiambu Districts, The District Education Officers Nairobi and Kiambu Districts and The Medical Officers of Health Nairobi and Kiambu Districts The Hospital Administrators Mbagathi, Karuri and Riruta Hospitals*** before embarking on your research project.

Upon completion of your research project, you are expected to submit two copies of your research report/thesis to our office.

PROF. S. A. ABDULRAZAK Ph.D, MBS
SECRETARY

CITY COUNCIL OF NAIROBI

SHAURI KWA UAMINIFU

MEDICAL OFFICER OF HEALTH
TEL: 2224281/2219849/2218119/2219432/
2210382/2224292/91 Ext. 2390
D/L: 2248316
Website: Citycouncilofnairobi.go.ke

P.O BOX 30108-00100
CITY HALL
NAIROBI.

PUBLIC HEALTH DEPARTMENT

PHD/MOH/R.1 VOL.1 (92)/10

5TH JUly, 2010

EUNICE NDIRANGU
AGA KHAN UNIVERSITY
P O BOX 39340
NAIROBI
KENYA

RE: PERMISSION TO CARRY OUT RESEARCH ON "COMMUNICATION AND INTERACTION IN THE CONTEXT OF ROUTINE PROVIDER INITIATED COUSELLING AND TESTING FOR HIV: PATIENT EXPERIENCES AND OUTCOMES IN KENYA", AT RIRUTA HEALTH CENTRE:

I write to inform you that permission is granted but the following shall apply during your period of your research.

- Payment of **kshs.5,000/=(Five thousand shillings only**) Research fee.
- You will be expected to adhere to the rules and regulations pertaining to the City Council of Nairobi.
- That during the period of research there will be no cost devolving to the Council.
- That you undertake to indemnify the Council against any claim that may arise from the research study.
- A copy of the findings must be submitted to the office of the undersigned.

By a copy of this letter the in charge Riruta Health Centre and DMOH Dagoreti District are to give you the necessary assistance.

DR. ROBERT K. AYISI, HSC
MEDICAL OFFICER OF HEALTH

CC- DMOH/DPHN – Dagoreti District

THE AGA KHAN UNIVERSITY

30th August 2010

Ms. Eunice Ndirangu,
Aga Khan University, ANS Programme,
PO Box 39340, Parklands - 00623
NAIROBI
Tel: +254 20 3747483 / 0734 594551

RE: ACCEPTANCE TO REVISION OF APPROVED PROPOSAL: COMMUNICATION AND INTERACTION IN THE CONTEXT OF ROUTINE PROVIDER INITIATED COUNSELLING AND TESTING (PITC) FOR HIV: PATIENT EXPERIENCES AND OUTCOMES IN KENYA

This is to inform you that the AKU Research Ethics Committee (AKU-REC) has granted your request to revise the initial proposal based on the questions that have been generated from the ongoing research.

REC therefore grants permission to:

- Carry out individual interviews and/or focus groups with counselors whose counseling session(s) you have already observed and/or recorded.
- Trainers and policy makers involved in PITC drawn from Liverpool VCT, National AIDS Control Council and JPHIEGO.
- Collect further background information on each health facility's context and organizational structure.

Yours sincerely,

John Arudo

AKU-REC Chairman

Appendix Two: Participant Information Sheet



Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Name of the investigator: Eunice Ndirangu

Patient participant information sheet

I would like to invite you to take part in a research study. Before you decide whether or not to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and to discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to find out about patient's experience of the routine HIV screening process. Routine HIV testing is a new initiative that involves offering of a HIV test to all patients attending a public health facility irrespective of the reason for the visit. The purpose of this initiative is to increase awareness of one's HIV status to ensure that in case of a HIV positive result, a patient is able to access treatment and support promptly whilst assisting in HIV prevention efforts. I would like to know what people think about having this test and their assessment of how it

was done, and the information and support provided. It is hoped that this project will provide information that can help health providers and policy makers understand the patient's perspective of the HIV testing process and provide the best care possible.

Why have I been chosen?

You have been chosen because you are an individual seeking care in a health facility where a routine HIV test is offered and is likely to be offered to you. Therefore, you are in a position to tell me your views the routine testing process, your experience of this process and if you think any changes should be made to this.

Do I have to take part?

Your participation is completely voluntary - it is up to you to decide whether or not to take part. If you do decide to take part, you will be asked for your consent at the beginning of the study. However, you are still free to withdraw at any time and without giving any reasons.

What does the study involve?

You will be invited to take part in an informal interview before you are offered a routine HIV test. After which I will sit in during the HIV test to observe what is taking place. Later on with, your permission, I would be interested in contacting you for a follow up interview approximately 3 months from today. With your permission, I would like to tape record the interviews and the observation. <u>This is not an intervention study or clinical trial.</u>

What are the possible risks and disadvantages of taking part?

The interview and observations will focus on your views and experiences of the routine HIV testing process. I recognise that HIV is a sensitive issue and can be a source of anxiety. You will not be under any pressure to answer questions or to talk about topics that you would prefer not to discuss.

What are the possible benefits of taking part?

Taking part in the research will not benefit you directly, though some people find it very helpful to talk to others about their experiences and opinions. However the results of this study will provide information that can assist health professionals to improve the quality of the testing process that is reflective of the user's needs and contribute to future policy and service development in this area.

What happens if something goes wrong?

If you are unhappy about any aspects of this research and if you wish to complain, the normal government hospital complaints mechanisms should be available to you. You can also contact me on the address provided below.

Will my taking part in this study be kept confidential?

All your details will be kept completely confidential on a password protected computer. Only the researcher will have access to your interview and observation notes. You will be allocated a project code number, and these notes will not contain any personal or identifying details about you.

The results of the study will be presented in such a way that all individuals and their workplaces will be anonymous. No-one will know who said what.

What will happen to the results of the research study?

The results of the study will contribute to the development of high quality services that take your needs into account. The research results will be made widely available through journal publications and conference presentations, and a report will be sent to relevant health care managers and policy makers. I will send you a summary of the results at the end of the study if you would like.

Who is organising and funding the research?

This is an academic research project that is being carried out as part of the requirements for the completion of the PhD program at the University of Nottingham in the UK. There is no external funding. There are no financial transactions involved in this study.

Who has reviewed the study?

The study has been reviewed and approved by the confirmation review panel at the University of Nottingham. Ethical approval and permission has been obtained from the Kenya National Council for Science and Technology and specific hospital management and department heads.

Next step

If you would like to take part in this study, or would like to discuss this further, please inform me or any of the health workers in the department.

I will then go over the project with you and, if you agree, arrange a time for an interview and later sit in on your routine HIV test.

Contact for further information:

Ms. Eunice Ndirangu, Lecturer,

Aga Khan University, Advanced Nursing Studies Programme,

PO Box 39340, Parklands - 00623

NAIROBI

Tel: +254 20 3747483 Or mobile: 0734 594551

Email: wandirangu@hotmail.co.uk
ntxewn1@nottingham.ac.uk

Thank you very much for taking time to read this information sheet.

With best wishes,

Eunice Ndirangu

Appendix Three: Consent Form (A) – English

The University of Nottingham

CONSENT FORM

Title of Project: Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Name of Investigator: Ms. Eunice Ndirangu

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result.
- I authorise the investigators to disclose the results of my participation in the study but not my name or details about my workplace.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.

Name: ……

Address: ……..

Telephone number: …….

Signature: ……. **Date:** ……..

I confirm that I have fully explained the purpose of the study and what is involved to:

……

I have given the above named a copy of this form together with the information sheet.

Investigator's Signature: ……

Name: ……

Appendix Four: Consent Form (B) – Swahili

The University of Nottingham

FOMU YA OMBI LA RIDHAA

Mada ya Utafiti: Mawasiliano wakati wa uchunguzi wa makali ya ukimwi: Mtazamo na matokeo ya wagonjwa katika eneo la Nairobi, Kenya.

Jina la mtafiti: Ms. Eunice Ndirangu

Tafadhali soma barua hii na utie sahihi baada ya kuwelezwa na kuelewa lengo na utaratibu wa utafiti huu

- nimekubali kushiriki kwenye utafiti huu.
- Nimefahamishwa na nimesoma maelezo ya utafiti huu, nimeona umbile lake, faida zake, madhumuni yake na muda utakaochukuwa.
- Ushiriki katika utafiti huu si wa kulazimishwa na nimeona hauna madhara kwa yeyote na yale yote yatakayotokeya ni mambo ambayo hayatarajiwi kwa jinsi nilivyoelewa kwa maelezo niliyopewa
- Nimepewa nafasi ya kuhoji na kutaka ufafanuzi kwa lolote linalohusiana na utafiti huu, nimehoji, na nimeridhika kwa jawabu nilizopata
- Ikiwa nitakuwa na suali lolote wakati wote wa utafiti huu nitamuona au kuwasiliana na mtafiti
- Nimefahamishwa na ninaelewa ya kwamba ninaweza wakati wowote kujiondoa kwenye utafiti huu iwapo ninataka kufanya hivyo, uamuzi wangu huo hautanipelekea kuadhibiwa kwa njia yeyote ile.

Sahihi ya mgonjwa_____

Tarehe _____

Jina la mgonjwa _____

Anuani ua makaazi _____

Nadhibitisha nimetoa maelezo kuhusu utafiti huu

Sahihi ya mtafiti _____

Tarehe _____

Jina la mtafiti _____

Appendix Five: Patient Pre test Interview Guide

The University of Nottingham

PATIENT PRE TEST INTERVIEW GUIDE

Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Introduction

Thank you very much for agreeing to participate in this project. As I discussed with you earlier I am interested in exploring your perspective on the HIV testing. Please feel free to share with me your view and perception of the HIV testing process. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

Do you have any questions about the interview or the research?

Demographic information

Age	
Gender	
Education background	
Occupation	
Marital Status	
Date of HIV test	

Existing knowledge / Perceptions on HIV testing

1. Can you please tell me if you have heard of routine HIV testing
    - What have you heard/know about? (if the participants is not aware of PITC explain what it entails and then obtain his/her view on it)
    - What do you think about it
    - Had you been consulted about taking the HIV test prior to attending the clinic?

- Did you have any worries and anxieties about this
- Were you expecting to be offered a HIV test?
- Had you decided in advance what decision to make?
- Do you feel you will be able to say no?
- How comfortable/confident do you feel about discussing issues about HIV testing with the health provider?

2. Have you had or considered having a HIV test before attending the clinic?
    - If yes, tell me how that experience was like
    - If no, why not.....
    - Do you about other people's (friends/family) experiences of the test?
    - Has this had an influence on your own attitude of the routine HIV test?
    - What do you think are some of the barriers to HIV testing
    - What do you think are some of the facilitators of HIV testing
3. In your view what you think are the benefits of doing a HIV test?
    - What are the disadvantages?
4. How do you feel about a HIV test being done routinely in comparison to VCT?
    - What are the possible benefits
    - What are the possible disadvantages
5. Please share me with me what people in the community say about HIV and HIV testing
    - How are people with HIV or suspected to have HIV treated?
    - Please give me examples of this?
    - Do you think this has an effect on the routine HIV testing process?
    - Does this affect your own attitude to HIV testing?
        i. Whether you will have it done?

Is there anything else you would like to add on your views about routine HIV test or HIV in general?

Conclude interview

Thank you so much for talking with me. If it is alright with you I would like to sit in during the counselling session. If you have any further queries do feel free to get in touch with me in the number I have provided.

Appendix Six: Patient Post test Interview Guide

The University of Nottingham

PATIENT POST TEST INTERVIEW GUIDE

Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Introduction

Thank you very much for agreeing to participate in this study. As I had discussed with you earlier, I am interested in exploring your experience with the routine HIV testing process. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

Do you have any questions about the interview or the research?

Demographic information

Age	
Gender	
Education background	
Occupation	
Marital Status	
Date of HIV test	

Understanding voluntariness of the routine test

1. What did you think about being offered a HIV test?
    - Before coming to the hospital did you expect to be offered a HIV test?
    - Would you rather you had not been asked (worries, anxieties etc.)?
2. Please explain to me how the HIV test was offered to you?
    - Did you accept to be tested?

- Did you feel that you could say no? Why?
- How confident did you feel about discussing HIV and HIV testing with the nurse during the pre and post counselling session?

3. How did you feel about the decision you made
    - Why did you accept/refuse to be tested
    - Did you the pre and post test sessions meet your needs?
    - Did it prepare you for the test result?

Communication between the patient and the provider

1. What information were you given during the test (before and after the HIV result)
    - Did you find the information useful? What did you think about how it was delivered?
    - Was it enough?
    - Did you learn anything new about HIV? Please explain to me what that was?
    - Has going through the HIV test changed how you view HIV?
    - For patients who are HIV negative: was the issue of behaviour changed raised in the pre counselling session?
        - Were able to explore it with the nurse? Did the nurse explore this
        - How did you feel about it?
    - What other information would you have liked to be included during the counselling session?
    - Did you feel comfortable during the session?
    - Were you able to express yourself?
        - Ask questions and say what you felt. Please give me an example of some of the things/questions you wanted to talk about or ask
2. How were you informed about the result?
    - Please explain to me how that was done
    - How did you feel about that? What did you think about it?
    - What does the test result mean to you?
3. Please tell me what you think about the HIV testing process now that you have under gone it
    - What did you like about the process
    - What would you have liked to see done differently?
    - What did you think of the nurse who provided the test?
    - Would you recommend the routine HIV test to others? Why? Why not?

Is there anything else you would like to add about your experience with the routine HIV test process?

Conclude interview

Thank you so much for talking with me. If it is alright with you I would like contact you for a follow up interview approximately 3 months from now. If you have any further queries do feel free to get in touch with me in the number I have provided.

Appendix Seven: Patient Follow Up Interview Guide

PATIENT FOLLOW UP INTERVIEW GUIDE

Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Introduction

Thank you very much for agreeing to participate in this study. As I had discussed with you earlier, I am interested in exploring your experience with the routine HIV testing process. I will be asking you to look back at the HIV test process as well as your experience after the HIV test over the past couple of months. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

Do you have any questions about the interview or the research?

Demographic information

Age	
Gender	
Education background	
Occupation	
Marital Status	
Date of HIV test	

Outcome after routine HIV test

1. How do you feel about having had a HIV test three months on?
    - Did you have any worries before and after the HIV test
    - How did you feel about the result?
    - What have been the consequences of the (positive/negative) test result?
2. What does the HIV test result to mean to you now?

- Has anything changed since you had a HIV test? Please give me examples
- For a HIV positive result participant: have you been able to access any services, treatment and support?
- For a HIV negative client: have you been able to adopt /change your way of life based on what you were told? Please give examples of this
    i. What have you found most challenging/helpful in maintaining a HIV negative test result?

3. It is a while since you had the HIV test, looking back on the process is there anything you feel could have been done differently? Added? Removed from the process?
4. What did you think of the information you received about the test?
    - What information would you have liked included in the pre test and post test session
    - What information would you have liked excluded from the pre test and post test session
    - Let us focus a little on how that information was delivered. What did you think about the way the information was given to you by the nurse doing the test?
        i. What about how you were informed about the test result?
    - How would that have changed or helped you in handling the HIV test result
5. What have been the advantages / disadvantages of having had a HIV test routinely?
    - If you were to go back would you still accept the HIV test? Why? / Why not?
6. Have you talked to anyone else about having the test - have they tended to conceal the test and its results? Etc.
7. Would you recommend that others have the test?
8. What would you recommend to those offering the routine HIV test in order to make the patient's experience or uptake of the test result better?

What recommendations would you make to the nurse doing the test?

Is there anything else you would like to add about your experience with the routine HIV test process?

Conclude interview

Thank you so much for talking with me and sharing your experience with me. If you have any further queries do feel free to get in touch with me in the number I have provided

Appendix Eight: Key Informant (Counsellor) Interview Guide

Communication and interaction in the context of routine provider initiated counselling and testing for HIV: Patient experiences and outcomes in Kenya

Key Informants - Counsellor's Interview Guide

Introduction

Thank you very much for agreeing to participate in this project. As I discussed with you earlier I am interested in exploring your perspective on the HIV testing and in particular PITC. Please feel free to share with me your view and perception of the HIV testing process and the type of interaction you have with the clients you meet in your day to day work. I would really appreciate if you could give me examples and stories from your experience as this would assist me in understanding the context better. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

1. As we all know, in Kenya, there is a high level of HIV, yet many of the patients who come into our health facilities do not know their HIV status and have most likely not had a HIV test done.
    a. What do you think are the reasons for this?
    b. Why is it in that in a number of cases clients are not asked to come back for a repeat test after 3 months?
        i. Do patients tend to return for their 3 month test? If yes/no, why?
    c. Do you have patients who keep coming to test again and again over time
    d. In your view do clients tend to disclose their test results to their sexual partners?

2. What is your typical day at work like?
    a. Number of patients you see in a given day on average
    b. Challenges? Good points?

3. Let us now focus on routine provider initiated counselling and testing (PITC) for a while. What are your views on PITC?
    a. What do you think about this policy?
    b. What is the aim of PITC?

   c. What is your role as a counsellor in PITC?
   d. What are you achieving with the testing process?
   e. What is your view of the PITC process? Are you satisfied with what you do? Anything you would want done differently?
   f. What are the pros and cons? (does it put people off seeking health care? explore voluntary informed consent, confidentiality and privacy, patients' ability to opt-out, post test counselling, dealing with stigma)
   g. What are the challenges in implementing this policy in your own workplace?
   h. Do you feel you have the flexibility of how you implement the policy/guideline?

4. Let us reflect a little bit on the PITC counselling approach you use? Are you satisfied with what you are doing? Is it the right approach?
   a. Interestingly you all seem to use a similar approach in your counselling session for PITC. Why is that?
   b. Is there any reason in particular why you include a variety of information ranging from ARV counselling to nutrition among others?
   c. Did the training program you attended state what should be included in the counselling session?

5. What other models of HIV testing are you involved in?
   a. Pros and cons of implementing each/ trying to fit each into the practice setting
   b. How do they compare to PITC? How does PITC fit into all these?
   c. Generally, how are new policies introduced to you?
   d. From your experience, do you have room for flexibility in the implementation of various HIV testing policies? Explain

6. From your experience, when a patient is offered a HIV test, what do you think their needs are at this time?
   a. In what ways are you able to address these needs?
   b. What are the challenges you face? (in communicating with clients and how do you address them)
   c. Is the situation different if the patient is a man or a woman?
   d. What is your experience with breaking the news of a positive test result?
      i. Reason for encouraging clients to see the results for themselves and how does this compare to you telling them what the results are?
   e. Is there anything that could be done differently?

7. From my observations I noticed that you tend to use individual counselling as opposed to group counselling. Is there any particular reason for that?
   a. What is the aim of individual counselling?
   b. What is the aim of group counselling?

8. Can you think back and tell me about a patient who you have recently tested and whose counselling and testing process is memorable to you (whether the test result turned positive or negative). Kindly share with me how that experience was like.

9. With regard to HIV testing, are there any areas in which you feel you need more support?
    a. How is PITC evaluated?
    b. Do you get supervisory visits?
    c. Training?

Appendix Nine: Profile of the Patient Participants

Code	Pseudonym	Facility	Age	Gender	Education Background	Occupation	Marital Status	Date of HIV test	Test Result	Pr	Ct	Pa	Pb
P1	Alphonso	Mbagathi	42	Male	Primary	Farmer	Married	06/01/10	Positive				
P2	Bosco	Mbagathi	26	Male	Primary	Hotelier	Married	07/01/10	Negative				
P3	Chepkwony	Mbagathi	26	Male	College	Policeman	Married	07/01/10	Negative				
P4	Kimathi	Mbagathi	35	Male	Standard 7	Hawker	Married	11/01/10	Positive				
P5	Nasike	Mbagathi	29	Female	Form 2	Housewife	Married	11/01/10	Negative				
P6/P7	Kwamboka/Wamugunda	Mbagathi	22/25	Female/Male	Secondary	Office work	Single	11/01/10	Negative				P6
P8	Wayua	Mbagathi	28	Female	Primary	Unemployed	Single	12/01/2010	Positive				
P9	Salim	Mbagathi	38	Male	College	Policeman	Married	13/01/10	Positive				
P10	Ameka	Mbagathi	26	Female	Secondary	Saloonist	Married	13/01/10	Negative				
P11	Chacha	Mbagathi	29	Male	Standard 7	Unemployed	Single	13/01/10	Negative				*
P12	Gakere	Mbagathi	29	Male	Standard 4	Casual	Married	14/01/10	Negative				
P13	Nyamai	Mbagathi	45	Male	Primary	Messenger	Married	14/01/10	Negative				
P14	Makau	Mbagathi	21	Male	Form 2	Jua Kali (Artisan)	Single	14/01/10	Negative				
P15	Imani	Riruta	26	Female	Secondary	Saloonist	Married	14/07/10	Negative				
P16	Kanoni	Riruta	30	Female	Standard 6	Business	Single	14/07/10	Negative				
P17	Lulu	Riruta	41	Female	Form 2	Tailor	Married	14/07/10	Negative				
P18	Khamisi	Riruta	24	Male	Primary	Casual	Single	15/07/10	Negative				
P19	Idowu	Riruta	33	Male	Secondary	Watchman	Married	15/07/10	Negative				
P20	Mariamu	Riruta	23	Female	Standard 7	Unemployed	Single	16/07/10	Negative				
P21	Adhiambo	Riruta	33	Female	Form 1	Business	Single	20/07/10	Negative				
P22	Nangila	Riruta	29	Male	College	Hairdresser	Married	20/07/10	Negative				

P23	Makori	Riruta	72	Male	Primary	Watchman	Married	20/07/10	Negative				
P24	Obuya	Riruta	40	Male	Primary	Farmer	Divorced	21/07/10	Negative				
P25	Kamau	Riruta	53	Male	Form 2	Jua Kali (Artisan)	Married	22/07/10	Negative				
P26	Ekirapa	Riruta	40	Male	Standard 7	Casual	Married	22/07/10	Negative				
P27	Njeri	Riruta	22	Female	Secondary	Business	Married	26/07/10	Negative				
P28	Muna	Riruta	19	Female	Standard 7	Housewife	Married	27/07/10	Negative				
P29+1	Yusufu/Shiku	Riruta	30/32	Male/Female	Secondary/ Standard 7	Chef / housewife	Married	28/07/10	Negative				
P30+1	Ekweme / Bahati	Riruta	30/25	Male/Female	College	Business	Married	28/07/10	Negative				

Key:

Pr – Pre test interview

Ct – Counselling and testing consultation

Pa – Post test interview

Pb – Follow up interview

Appendix Ten: Profile of Counsellors Interviewed

Code	Pseudonym	Facility	Interviewed	Age	Gender	Years of experience	Years of experience in HIV testing	Role	Qualification
C1	Maria	Mbagathi	No		Female			Nurse Counsellor	Diploma in nursing. Degree in counselling psychology
C2	Hazina	Mbagathi	No		Female			Nurse Counsellor	Diploma in nursing Diploma in counselling
C3	Bhoke	Mbagathi	No		Female			Nurse Counsellor	Diploma in nursing & higher diploma in counselling
C4	Waithera	Mbagathi	Yes	49	Female	24	5	Nurse Counsellor	KECN & Higher diploma in counselling
C5	Jelimo	Mbagathi	Yes	48	Female	22	7	Nurse Counsellor	KECN & Diploma in counselling
C6	Opiyo	Riruta	Yes	34	Male	1	1	Lay Counsellor	Certificate in counselling
C7	Ihuoma	Riruta	Yes	31	Female	2.5	1.5	Lay counsellor	Diploma in HIV testing & counselling in clinical & community settings
C8	Abdul	Riruta	Yes	36	Male	3	1	Lay Counsellor	Diploma in counselling

Appendix Eleven: Sample of Synopsis (Early Memo)

A SYNOPSIS ON OBUYA

Introduction
Obuya had been married twice: the first wife, with whom he had two children, was mentally ill and had left while the second one walked out on him. He had gone for VCT two months ago after his second wife had walked out on him. He said he went for the HIV test because he felt that his wife had not been faithful. However, the fact that he waited several months after the wife had left, the fact that he was falling ill often may have tipped the balance and thus 'forced' him to take the initiative to visit a VCT.

Pre test interview
Obuya says he was ready for whatever the doctor would ask him to do including when he was asked by the doctor to go for the HIV test. Even so he says he expected to be sent for a HIV test because he has not been feeling well. At this point he gives the impression that he was ready to be tested so that he can know his status.

I did venture to find out from him what the doctor had told him when sending him for the HIV test and he explains that the doctor had sought to find out if he has multiple sexual partners. In this case the doctor seems to be giving the impression that HIV is due to promiscuity which matches the widespread society perception of HIV. As such health workers could be doing little to change these perceptions as they too belong to the same society as the lay persons.

Obuya seems suspicious of his HIV status because his second wife had left him and he supposed that she was unfaithful. This coupled with his frequent illnesses made him feel that he needs to be tested. Having said that though, Obuya did not come for a VCT but rather came for treatment for his illness but was sent for PITC. If indeed he felt that he needed to know his HIV status why had be not taken the initiative to get tested prior to today? However, his previous HIV test some two months ago was done via VCT when he took himself after his wife left him. Even so he had not sought a HIV test with his current wife or during the time they were together but rather several months after she had left him. Perhaps because he had started getting sick coupled with the suspected unfaithfulness may have tipped the balance towards encouraging him to get a HIV test. This is one of the few cases where suspicion of a possible HIV positive test result acted as a motivator for seeking a HIV test.

In his view many people avoid testing because they do not want their secret known by others. As such there seems to be an obvious believe that once one is tested and found to be HIV positive then his/her results will be known by others. Why is there a distrust that HIV test results will be kept

confidential by the health care workers? Issue of mistrust of health care workers seen in other cases e.g. authenticity of test kits/results, risk of being infected during a HIV test.
Although PLHIV are isolated, Obuya feels there is no need for this since HIV is a disease just like any other and so PLHIV should be accepted as they are. This isolation inhibits people from testing who chose to remain unaware of their status rather than risk testing only to be found HIV positive.

Counselling Session
Abdul, the counsellor, begins the session by getting some background information on the patient's testing history and even manages to get information on his wives including where they are. He also obtains information on his health history and finds out that he has been coughing so the counsellor refers him to the TB clinic where he is asked to go through after taking the results to the doctor.

The counsellor follows a different structure in this session. After establishing that the patient had only been tested a couple of months ago, Abdul goes straight into explaining the test kits and how he was going to about doing the HIV test. It is when waiting for the test results that Abdul provides the patient with information on how to live with HIV or what is next if one is HIV negative and things that put one at risk of contracting HIV. This is the typical PITC approach. After a short description on how to interpret the results, the counsellor asks Obuya if he is ready for to check the HIV results to which he responds in the affirmative.

Interestingly Abdul calls the participant by the wrong name on two occasions without the patient pointing this out to him: I am the one who makes him aware of this fact. Perhaps the subservient role of the patient in the consultation norms in this context make it difficult for Obuya to correct the counsellor or make him aware of this error.

Just like in the other sessions, reading of the test results signals the end of the counselling session.

Post test Interview
Prior to the HIV test, Obuya says he was not anxious about the impending test or the results that he might get, he was ready for whatever would come out. He was happy with the process and the information given to him was appropriate although he indicates that he did not learn anything new from this process which he says was similar to the VCT one. Considering the approach used by Abdul during this session was a typical PITC approach, it is expected to be somewhat different with the VCT approach with which Obuya was tested previously.
Obuya says that if he gets another sexual partner they he will go for a HIV test together with her although as we have seen above he had not done so with his previous wife despite being in doubt about her faithfulness. Similarly he says that he will now encourage his friend to go for a HIV test although he had not previously told anyone of his HIV results when he got

tested. He had considered what he would do in case of a HIV positive or negative result.

Appendix Twelve: Questions and thoughts on issues emerging from the data

1. What is counselling? Does what is happening in the PITC context fit what is defined as counselling?
    - Looking at the focus of PITC, ideally it was expected that the focus will be on post test counselling yet from the interaction it is quite clear that all the information is being bombarded on the patient before the HIV test.
    - Session seems to end abruptly after the results are given
    - Purely information giving
2. Routinization of the process
    - Is it because the counsellors have little time?
    - Are they trying to fit in everything in one session because it is not clear whether the patients will turn up again for follow up?
    - Process appeared to be very medicalized i.e. little exploration of patients feelings rather more like information giving
    - Checklist approach
    - Could it be linked to the training program (see 3 below)
3. Training
    - What is the content of the PITC training materials?
    - Why do the counsellors seem to be saying more or less the same things during the counselling sessions despite not using a script in the counselling room?
    - How are the counsellors assessed?
    - Do they all undergo similar training in terms of duration and content?
4. There seems to be an assumption of ignorance on the part of the counsellor towards the patients
    - Patient being viewed as guilty i.e. assumption that the test results will turn positive as evidenced from the information being given which is based on the assumption that the test results will be positive
    - There is also an assumption that the patients are an uniformed even when the patients do seem quite informed about HIV and the process
    - Hence the question is if patients are actually quite informed do the counsellors need to spend so much time giving information that the patients do not really require?
    - Is it possible to have an individualised approach to each participants rather that routinized checklist approach (no. 2 above)
5. Patient's concealing their knowledge
    - Patients appear to be concealing their knowledge and instead expressing their ignorance. Perhaps this could be due to the fact that the patients are trying to fit into a particular role that is seen as the norm in this context. *Could this be linked to the culture of the consultation? (see 7 below)*

- On the other hand counsellor's do not try to explore the patient's previous knowledge and perceptions
- Counsellor's also seem to be making an assumption of the patient's knowledge especially when the patient has been tested before
- By discounting having any knowledge about HIV are the patients distancing themselves from accountability i.e. ignorance is an excuse so as not to follow behaviour change.
- Or are they using this to avoid 'blame' if they got infected because it would be because they did not know the appropriate thing to do to prevent being infected.

6. The role of the patient
    - Patients seem to be adopting a typical patient role 'uninformed/unresponsive/cooperative'. Is it a hindrance to the PITC (counselling) process
    - Is the adoption of the behaviour by the patient due to the expected role of the patient in this context or is it just particular to HIV?
    - How does the counsellor work around this role (or not)?
    - Pressure between the patient's role and the roles of social engagement e.g. using strategies to engage in a relationship with the patient. This is challenging for various reasons:
        - PITC is a one off meeting,
        - The relationship involves talking about sensitive issues some of which are difficult for both the counsellor and patient to infer to directly,
        - The process is highly routinised with little room to make changes based on the participants situation
        - Existing patient's role i.e. quite unengaging (Challenges of doing counselling in an area where the patient role is submissive)
    - How do patients view health care workers and what are their perceptions of health care services?
7. Culture of the consultation / The counselling model – linked to point 1 above
    - Think generally about the consultation and the patient's role
    - How do the patients understand it? How do counsellors look at it? What about the stakeholders?
    - There does not seem to be much on general consultations in other settings hence we do not know whether what goes on in the HIV setting is unique to HIV or similar to what happens in others
    - If this is what happens generally why do we expect HIV to be different? Isn't this trying to change the organisation culture?
    - Review literature on consultations and communication in Kenya and other African countries in both HIV and none HIV settings

8. Professional model
    - What do the counsellors think they are doing?
    - What do they think they are expected to be doing and to achieve?

- What do they think PITC is supposed to be doing?
- What is their view on the process?
- What is their view on breaking the news i.e. giving a positive test result
- There seems to be different agendas for testing and how does this compare with what the policy says
- Counsellors are using different strategies to initiate the HIV test as well as provide a rationale for why the client is being asked to test. What are some of these strategies?

9. What is the overall ethos towards patient care?
    - Is PITC focused on HIV prevention? i.e. looking at the process there is little focus on the emotional care of the patient who is being counselled the focus seems to be more on getting the patient tested and pumping the patient with so much information which he may not make use of later
    - Again look at the counselling role outside HIV
    - Compare pressures in the work setting and how they influence the PITC process
    - Counsellor's views on their role in PITC? How do they see themselves in the PITC process
10. Distancing self from HIV / Concealment about HIV
    - Is it possible not to have heard about HIV in an area that has such a high prevalence and HIV is not only discussed every other day but happens to be all over the media as well?
    - Why are majority of the participants not referring to HIV by name and instead using words like 'that thing' or 'it' or 'that disease' or even 'that HIV'
    - Why do the participants seem to set themselves apart from HIV?
    - What is the sociocultural background of HIV in terms of how HIV was perceived and treated? Review anthropological papers on this from Kenya and Africa in general
11. Doubts about the HIV results
    - Does it give a sense of comfort that the results are not correct and hence one is not HIV positive i.e. the results will change if tested again?
    - Why do patients feel they need to reconfirm their results just to be sure?
    - Does accepting one is HIV positive also mean accepting that one has been immoral or promiscuous?
    - Or does reconfirming a HIV negative result give one a sense of security just to be sure that the results will remain the same?
        - Possible mal adoption of behaviour change and hence seen as a relief that one has not been infected despite behaviour
    - Does this have to do with the uncertainty of the viability of the test kits?
    - Why doubt the motive of the HIV test?
12. Question on the nature of knowledge
    - Information versus emotional needs

- Emotional arguments with self-i.e. what one knows about HIV versus personal fears
- Interplay between lay knowledge and professional knowledge
- Patients obviously aware of the professional knowledge but seem deep rooted on lay knowledge
- Are counsellors able to separate the two even within themselves?
- Could this contribute to the ambivalence seen and the mismatch between what participants seem to be saying and what they actually do?
- Lay knowledge seems to be based on past professional knowledge in some instances. But why does it take so long to correct the lay perceptions even long after the professional knowledge has changed?
- Knowledge / information about HIV versus the client's personal fears or emotional needs related to HIV
- Effect of sociocultural perceptions about HIV in shaping lay knowledge and in the uptake of professional knowledge

13. Communication norms about sensitive issues are reflected in the interaction even with the counsellors
    - Use of encrypted and coded language to imply certain meanings
    - Does this allow for a scope of ambiguity that gives the counsellors and even the patients some sense of comfort?
    - Does it allow those involved to talk about sensitive issues without feeling that they are breaking the communication norms?
    - The counsellors and patients do seem to share the meaning and understand each other. Could this be because they come from the same context with similar understanding of the language being used?
14. Impact of the HIV test on social relationships
    - Symptoms such as weight loss may be seen by others and make others suspicious of a HIV positive result a fact that the patient may be very well aware of
    - Spouses hiding the results from each other or working hard to keep the diagnosis a secret
    - Impact of the HIV results on social relationships and norms considered important e.g. wife inheritance, ability to marry and have children
    - How about the extended family that tends to be involved a great deal in the care of the sick family member
    - Review literature on interrelationships in the context of HIV

Appendix Thirteen: Participant 4 Analysis Notes

Participant 4 (P4) just like Participant 1 (P1) and Participant 2 (P2) sees HIV testing as a normal thing and verbalises the importance of having a test on the one hand but expresses that there is fear associated with testing to the extent of people committing suicide when they learn they are HIV positive. It is also a bit questionable that there is any chance that P4 has never talked about HIV with anyone ever. Once again some double speak and inconsistencies where HIV and HIV testing is concerned. I feel as though for most of the participants there is awareness of what is expected as well as the ideal situation but there is some underlying fear which is deep rooted on the long-established views and perceptions about HIV and which are more real to the participants.

Perceptions about HIV: I find it interesting that P4 on the one hand says he has heard about PITC on the radio but on the other hand has no information on how HIV is spread. At the same time he seems to deny knowing what other people are saying about HIV by emphasising that he stays alone and strictly confines himself to the work place and his home. Yet at other points during the interview he does explain to me what people say about HIV only for him to revert to 'I don't bother myself much with what people say'. It is as if he is trying quite hard to set HIV apart from his life. I wonder whether this is a way to make himself feel safe by looking at HIV as something apart from his daily life which revolves around work and home. Likewise he does not link the information he has heard on routine testing with himself he says he did not bother with that information (to get a HIV test) because it did not apply to him because he had not seen any signs of HIV. Yet at the same time he sees HIV testing as important if there are drugs – ambivalence. On the hand he says he had not come for routine testing since there is no need to come to hospital when one is not sick, that is 'bothering' the doctors and yet one is healthy. These two points highlight the tendency of linking the possibility of being HIV positive with physical illness and signs and symptoms. And once again we see a client who is actually HIV positive viewing himself and not likely to have HIV just as was the case with P1. This on the other hand is opposite of

Decision to test: P4 views the HIV test as something he has been asked to do by the doctor and thus has no alternative but to do it which is similar to P1 and P2. He further says that the doctor is 'like God in intelligence and thus one cannot know what he is thinking'. Unlike P1 and P2 who in one way or another showed an inclination of having second thoughts about HIV testing, P4 does not at any point express this either during the interviews or counselling session. It is as if he had resigned himself to the fact that he will be tested anyway since the doctor had said so. Counsellor 2 (C2) does not seek consent from P4 but rather asked him to move to the table for the HIV test.

Assess of risk: P4 did not expect a HIV positive result; 'he felt the way he lived his life could not have resulted to a positive result'. Looking back at the interview sets I get the feeling that P4 probably had a good idea that there was likelihood he could be positive and that he knew more about HIV than he was letting on to me and the counsellor.

Accepting the test results: P4 does not seem to have accepted the test result. He says he is not scared about the positive test result and yet at the same time again refers to the fact that he does not believe that his test results could have been that way. He even goes ahead to say that he can come back at a different time for a test and the results end up negative. This is similar to what P1's wife talked about when she said she had not believed her first test result and had to have a second one to believe her test results. The question I have on this where P4 is concerned is whether indeed the counselling session prepared him at all to handle his test result and actually own it. There is a chance that if indeed he is in doubt about the result then he is likely not to take up any on the information given to him by the counsellor.

Interpersonal relationships: P4 says he is unaware of whether his wife has been tested or not. However, since his children are quite big there is a chance that she did not have access to antenatal HIV testing. All the same it is rather odd that P4 claims not to know if his wife goes to the hospital for family planning (another avenue for PITC) because he leaves for work in the morning and comes back in the evening. Is it really possible that P4 is that detached from his family life? And if so why? Likewise if this is the relationship he has with his wife then there is a chance that he may not disclose his test results when he goes back home.

Relating with Counsellor 2 (C2). P4 still insists he was in the dark about HIV and cites this as the reason he was not able to freely talk to the counsellor. However, he says that the second time round he would be able to talk more. It is quite interesting that when P4 is asked by C2 what results he expects he says, 'I am not God: how can I know?' And he continues to express the same idea as P2 that what happens in the counselling room is beyond him and rather depends on God. Once again C2's approach is very medicalized and routinized – she plunges into providing a variety of a lot of information to P4. When P4 reads the test results C2 ends the session almost immediately as I had observed with Counsellor 1 (C1). In my view, both C1 and C2 appear to have a more or less the same approach to the counselling session. Interestingly during the post test reflection session with C2, it appears that she suspects that P4 would not disclose his test results to his wife. However, she did not venture to explore this further during the counselling and testing consultation after disclosing the HIV test results to P4.

Appendix Fourteen: Memo on 'HIV Talk'

HIV Talk

'HIV talk' refers to the play of words that the participants and the counsellors engage in during the PITC process as well as during the interviews. The interactions between the counsellors and the patient and between the participants and I are characterised by a particular 'language' that portrays the social context of HIV in this environment. By exploring the interplay of words, one can get an idea of the underlying and often unstated suppositions about HIV and the social structures in which it occurs. HIV talk extensively involves the use of euphemisms and coded language.

Use of euphemisms facilitates the discussion of topics and issues that are generally considered a taboo or sensitive by using words that are polite or less sensitive. For example, words such as having friends outside marriage rather than 'sexual partners', are repeatedly used because the former sounds more palatable. This type of talk highlights the existing communication norm where sex and HIV are normally not discussed explicitly and openly within the African context. Nonetheless, this modification facilitates the handling of an otherwise uncomfortable discussion between the counsellor and the patient. It also allows those involved to talk about sensitive issues without feeling that they are breaking any communication norms. Equally, individuals seem to find it hard to refer to HIV by name and in its place use terms such as: 'it', 'that thing', 'that disease' and 'that HIV'. By doing so the participants are detaching themselves from HIV and revealing the apprehension associated with it.

At the same time language that is coded and highly metaphoric allows the participants to avoid the tension and difficulty that comes with making a direct reference to the sensitive issue they are discussing. In some cases the coded language is highly encrypted and has to be deciphered to elicit the hidden meaning. Let us take the example of Bosco. He indicated that now that he is HIV negative, he will become a 'child of God' because before he was not 'very much a child of God'. In this situation he is referring to taking up morally upright behaviour and deviously admitting to have engaged in risky sexual behaviour in a rather ambiguous manner. In spite of this metaphoric language, both the counsellor and the patient understand each other partly due to the fact that a large proportion of the language is borrowed from everyday lay interactions.

Besides ambiguity, HIV talk is in other cases laden with claims of unawareness which participants use to avoid talking about HIV. For instance, Kimathi consistently insists that he has neither heard anything about HIV nor has he talked to anyone about the disease. This is highly unlikely in an environment where HIV is talked about extensively in both formal and informal situations. By taking this stand, he is covertly implying that he is neither involved in any behaviour considered unacceptable nor is he likely to be infected. Historically a feared phenomenon is respected through verbal avoidance which gives the

individual a false sense of ease that he is no way linked to the phenomenon in question (Wood & Lambert, 2008). Ambiguity and vagueness gives the participants a lee way to distance themselves from HIV and risky sexual behaviour.

HIV talk is not just confined to language that is vague and ambiguous. Individuals can adopt words and phrases that are used by health professionals or health promotion messages in the media and incorporate them into their talk. For instance 'VCT' is used on a number of occasions to infer a HIV test rather than its actual meaning which is a model or approach to the testing process. This idea is referred to as dissociating language (Lambert & Wood, 2005). The term VCT has time and again been used in a myriad of HIV prevention campaigns. Other phrases used by the participants such as 'know your status' (jua hali yako) and '[out]side arrangement' (mpango wa kando) were reflective of the most recent media campaigns which focused on encouraging people to get tested and discouraging multiple sexual partners. At the same time lay discourses regarding HIV depict the local perception about HIV and issues related to it. For example words like 'fear', 'death', 'shock' and phrases like 'not a disease like any other' are used by all participants. By looking at these terms it is possible to provide a context on local perceptions about HIV and HIV testing.

Overall, the category 'HIV talk' is closely linked to vagueness, ambiguity and avoidance. I need to follow these ideas further to discern how they relate to this category and whether they best fit as sub categories or categories.

Appendix Fifteen: Memo on 'maintaining moral face'

'Maintaining a moral face' refers to the intricate process of patients presenting themselves as moral individuals of upright social standing by controlling and managing the information shared during the consultation. In one of the earlier memos, I explored the category of the 'passive patient'. After much reflection on the data, I am beginning to think that the passive role of the patient was not just confined to the little or no active participation during the counselling session. It would appear that in the expression of their awareness of HIV or lack of it thereof, patient were feigning ignorance as a means of preserving their moral integrity.

The majority of the participants presented themselves as uninformed during the interviews with me on various issues. Firstly, some asserted that they have not heard anything about HIV, and neither do they discuss HIV with anyone or even know of someone who has been diagnosed with HIV. The same scenario played out during the counselling session where the patients told the counsellors that they did not know how HIV is spread. In a context where HIV is talked about in the media both print and audio, it is difficult for a person not to have heard anything about HIV. Moreover, with a high prevalence of HIV, the majority of the Kenyan population knows someone or has heard of someone who has or is suspected of having HIV. Indeed anecdotal information shows how much lay people talk about HIV informally and it is these hidden discussions that spread and sustain the existing negative perceptions about HIV (link with memo on lay perceptions about HIV). By claiming unawareness of the HIV infection including how it is spread the patient is painting a picture of a person who is uninformed and therefore if he is HIV positive then he is blameless. At the same time, patients were trying to create a distance between themselves and the behaviour associated with HIV. By doing so the participants are trying to present a face of a good patient who not only does not associate himself with a disease that is discriminated against, but one who is devoid of behaviour associated with it which is usually frowned upon. Maintaining this face is vital in a society that has strong views on people who are seen to contravene the acceptable moral behaviour associated with sex.

Feigning ignorance from the very beginning of the session assists the patients to espouse a lower position in the interaction in which the counsellor who has more information automatically becomes more powerful than the less informed patient coming in for the HIV test. As a less informed participant of the consultation, the patients can comfortably withhold information they deem 'incriminating' to their social standing by being passive.

Although there were some similarities in the level of feigning ignorance between what took place in the counselling session in comparison to the pre and post test interviews that I carried out, there were some distinct situations where the patients were more open to me than the counsellors. For instance the majority of the patients told the counsellors that they had

no idea why they had been referred to them by the doctor despite having discussed with me earlier about the impending HIV test and in some cases wanting clarification on why the doctor had thought it necessary to send them for a HIV test. In other cases, a few patients brought the queries they had failed to raise during the counselling session and raised them during the post test interview with me. For example, Alphonso sought to clarify with me why it was important for him to use condoms had not clarified with the counsellor why it is important for him to use condoms despite the fact that he and his wife were HIV positive. From his inquiry it emerged that he was not comfortable or even ready to use condoms, an important aspect in HIV prevention that was missed out during the counselling session because he was not willing to open up to the counsellor.

There were also instances where participants withheld information about engaging in risky sexual behaviour during the consultation. However, on receiving a HIV negative diagnosis, they discretely, using euphemisms (link to memo on 'HIV talk') admitted to having been in risky situations. This could be due to the fact that, following the HIV negative diagnosis, a patient felt freer to 'admit' to risky sexual behaviour since the HIV negative diagnosis meant they were blameless. After all they could not be stigmatized now that they had not been infected with HIV. Control and managing of information has been discussed at length by Goffman.