The London School of Economics and Political Science

Exploring the psychosocial barriers to children's HIV services in western Uganda: A case study of social representations.

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Abstract

Despite the clinical need for children living with human immunodeficiency virus (HIV) to access and adhere to antiretroviral treatment (ART), rates globally remain roughly half that of adults. Although the structural barriers to accessing HIV and health services are well studied, further research into the psychological and social factors underscoring children's limited access to HIV care is needed to facilitate scale up amongst health service users and providers. Using a social representations theoretical approach, this thesis examines the interplay between psychological and social factors concerning children's HIV service uptake in a community setting. A qualitative research study was conducted in Kabarole district, Uganda with 60 adults, including 15 health care workers (HCWs) and 45 adult carers of children, and 82 children (N=142). Methods of data collection were individual interviews, focus groups, a draw-and-write exercise, and participant observation in the main local health clinic setting. A thematic content analysis reveals multiple cross-cutting factors which mediate HIV service usage.

For HCWs, despite challenging working conditions, the impact of ART has been positive both professionally and personally. Adult carers, however, continue to be negatively impacted by social stigma against HIV, and fears of potential negative consequences resulting from revealing an HIV-positive status influence their uptake of HIV services. For children, the pervasiveness of HIV in their society, and its negative personal and social impact, has created a sense of fatalism and resignation over potential HIV infection and future suffering. At present, the clinical practice environment does not provide a supportive space for these representations to be openly addressed by health service providers or users. Drawing from these findings, the thesis concludes that in order to increase children's ART access and adherence, more supportive clinical and social environments will need to be jointly created by health service users and providers, through the building of social capital and increased social trust and cohesion between stakeholder groups. Failing to do so may result in continued low or even decreased HIV service usage for children, particularly in light of recent national legislation which may lead to further entrenchment of HIV stigma against socially vulnerable groups.

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Figures in Chapter 7 are draw-and-write pictures produced by research participants, who are acknowledged by code in this thesis for anonymity purposes. Figure 2.1 was designed by the author for illustration purposes. The map of Uganda under British Protectorate administration (Figure 4.1) is licensed under public domain and used in accordance with Creative Commons and Wikimedia licensing.

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ANC	antenatal care
ART	antiretroviral treatment
CBO	community-based organization
CHW	community health worker
CIHR	Canadian Institutes of Health Research
FBO	faith-based organization
FG	focus group
HBM	Health Belief Model
HCW	health care worker
HIV	Human Immunodeficiency Virus
IDI	in-depth interview
JCRC	Joint Clinical Research Centre (Uganda)
KAP	knowledge attitude practice
NGO	non-governmental organization
NRA	National Resistance Army (Uganda)
PEPFAR	The US President's Emergency Plan for AIDS Relief
PIASCY	The Presidential Initiative on AIDS Strategy for Communication to Youth (Uganda)
PMTCT	prevention of mother-to-child transmission
SIT	Social Identity Theory
SR	social representation
SRT	Social Representations Theory
SSA	sub-Saharan Africa
TASO	The AIDS Support Organization (Uganda)
TNA	Thematic Network Analysis
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNCST	The Uganda National Council for Science and Technology
UNICEF	The United Nations Children's Fund
WHO	World Health Organization

Overview of the thesis

This thesis explores the psychosocial barriers to children's HIV services in Kabarole district, Uganda. Here, "psychosocial" refers to both personal, psychological aspects of the lived experiences of participants, and the external, social implications of HIV infection within their community. The research uses Social Representations Theory (SRT) and qualitative methodological approaches to explore the meaning and sense making about children and HIV, as understood by local stakeholder groups who have a direct involvement in children's HIV care and treatment, specifically children, adult carers, and health care workers (HCWs).

In the *first chapter*, I outline my background and research interest in undertaking this study, and discuss the biomedical and clinical rationale for children's HIV service provision. Current research on the psychosocial aspects of children's HIV care access and adherence within a sub-Saharan African context is also reviewed, and the Research Questions for this thesis are outlined.

Chapter 2 explores the choice of the theoretical framework underlining this research, SRT, and positions it against an alternate theoretical approach, the Theory of Reasoned Action/Theory of Planned Behaviour, which is more widely used but makes certain assumptions which may prevent it from fully capturing the complex picture of human behavior and HIV. This chapter problematizes this theory and positions SRT as a more appropriate theoretical paradigm for this study.

The methodology and research design for this thesis is discussed in *Chapter 3*. The methods and procedures used in this study for data collection, as well as information on participants and research team members are provided, and the corpus of research material is outlined. Data analysis and interpretation is discussed using examples from the corpus. Ethics approvals and broader social considerations in working with potentially vulnerable populations are also discussed.

In the *fourth chapter*, the historical social context of the study setting, Kabarole District, is discussed at length, including a historical overview of HIV/AIDS in

Uganda as it relates to the present day. Historical social representations (SRs) of children, health and health services, and HIV, are explored with attention given to their potential influence on present-day SRs, which will be discussed in subsequent chapters.

The first empirical chapter of this thesis is the *fifth chapter*, where the data findings from the HCWs are explored. Key themes and SRs which emerge suggest that despite significant practice challenges, such as materiel and personnel shortages, and against a social backdrop of continuing HIV stigma, the emergence and use of antiretroviral treatment (ART) has been a positive experience for HCWs. However, this positive experience with ART is not widely shared with affected children, as their adult carers are seen as reluctant to use health services at the local clinic.

In contrast, *Chapter 6* explores the data findings from participating adult carers of children, who hold differing SRs of HIV, children, and health services. For them, health services are seen as ineffective and unreliable due to structural shortages. HIV is positioned as a major threat to a positive social identity and status within the community, with HIV stigma continuing to have a very negative impact, particularly on children's HIV service uptake. Carers feel unable to cope with the threat of HIV and related stigma, and so may not acknowledge children's HIV risk or actual infection, which contributes to low HIV service uptake.

In *Chapter 7*, the data findings from participating children are examined. Here, SRs of HIV and health services are overwhelmingly negative, with health services seen as being unhelpful to those suffering with HIV, who become very ill and die as a result. The resulting negative social impacts on children and families are vividly portrayed, with the children resigned to living in a world filled with HIV, and an uncertain future filled with the risk of infection.

Chapter 8 discusses participant observation findings from a focused clinical ethnography undertaken at the local government-run health clinic. Analysis suggests that the clinic is an intimidating and unwelcoming social environment, where HCW practices inadvertently foster HIV stigma, which discourages HIV service uptake by potential users. Procedural limitations and resource shortages

also impact negatively on clinic service uptake, and frustrate service providers and users alike.

The *final chapter* of this thesis draws together and synthesizes the data findings and SRs of the previous chapters, and reflects on the historical progression of the SRs, up to the current social situation of low HIV service access for children. Unresolved historical social strife, and a lack of underlying social capital, social cohesion, and trust between stakeholder groups in this community combine with negative SRs as impediments which underscore low HIV service access for children. In light of recent regressive national legislation related to HIV infection and human rights, potential future scenarios and their implications for children's HIV care access and adherence are discussed. Concerns over the potential for increased HIV stigma, resulting in continued low or further decreased children's HIV service access are explored. Given this recent legislative trend, the possibilities for facilitating broader social dialogue and changes related to improving children's HIV care access and adherence appear minimal.

In order to preserve the anonymity of the participants in this study, the sub-county area of Kabarole district in which this research took place will be referred to as "Amooti" throughout the thesis. The name "Amooti," which can be translated as "royal" or "noble," is a common nickname or pet name in regions where Rutooro is spoken, and reflects a cultural use of pet names or nicknames as a term of endearment or respect (The Kasiisi Project, 2014).

Chapter 1: Current research concerning children & HIV in Uganda

Introduction

My interest in conducting this PhD research came out of research undertaken for a Master's degree conducted in Kabarole district, Uganda, in 2009-10. Whilst working on a quantitative, biomedically-based study, reports emerged that pediatric antiretroviral treatment (ART) medication was going to waste both in the district and across Uganda, despite observed and reported need (IRIN, 2009; Baguma, 2010). I was intrigued by this disconnect between the health system and society, which ultimately resulted in children not being tested for HIV or treated with ART, despite local availability of both. As a Registered Nurse coming from Canada, my lived experience had been that of generally good rapport between health service providers and users, resulting in a good uptake of services and positive outcomes for clients, and overall, an effective use of the health system by citizens. The situation locally appeared to be the opposite of that, but I was not sure why. I wanted to find out how such a disconnect between a health system and the people it serves could occur, and what impact this had on children's access to and adherence to HIV testing and treatment. What caused this to occur, and what could be done to improve the situation for children, led me to undertake this research study as a PhD.

Against this background, this PhD study will use a qualitative, multi-method study design to explore potential barriers to children's HIV service access, as well as potential facilitators of improved access, by engaging three main groups of "stakeholders," groups which have direct control over, and a vested interest in, children's HIV and health service access. These groups are children and adult carers of children, who are the health service users, and health care workers (HCWs) who are health service providers. As this study seeks to discover their lived experiences regarding children, HIV, and the health system, qualitative methods are used to capture this data, as will be described further in Chapter 3, Methodology & Research Design.

This first chapter will provide a review and overview of key recent biomedical and clinical research findings on children, HIV, and ART in section 1.1, with additional biomedical and clinical research relevant to the participating stakeholder groups reviewed in sections 1.2-1.4. Research focusing on HCWs and their facilitation of children's access and adherence to HIV care will be undertaken in section 1.2, with research on issues surrounding adult carers and children's access and adherence to HIV care reviewed in section 1.3. Section 1.4 will explore research focusing on children as related to their access and adherence to HIV care, with the Research Questions, which will guide and focus this thesis, outlined in section 1.5.

For this study, children are defined by the UNICEF (2013) age demarcation of 18 years old or under. However, as the teenage years of 13-18 may be considered adolescence or even adulthood in some cultures globally, the term adolescent will be also be used in this chapter, particularly section 1.4, to denote a teenage child who may be engaging in sexual behaviors, as this reflects the majority of research studies into adolescent health which tend to focus on sexual and reproductive health needs. In this chapter, HIV research covering both children and adolescents up to age 18 has been considered for review, and included as relevant to the goals of this study.

This chapter serves to frame the research findings discussed in subsequent chapters by reviewing both the biomedical aspects of children's access and adherence to HIV care, and the psychosocial aspects of HIV service utilization. Here, "biomedical" refers to the clinical and biological aspects of HIV infection, including recent statistics as relevant to HIV programming challenges, the biological course and impacts of the illness in children, and the logistical issues in HIV care provision, as they relate to the study location. The term "psychosocial" in this thesis will refer to an examination of both the personal, psychological aspects of the lived experience with HIV infection, and the external, social implications and impacts of HIV infection and having an HIV-positive status in the community.

These psychosocial aspects will be further examined in Chapters 5-7 by looking at the interplay between the social representations of HIV, children, and health services, and the social identities of the stakeholder groups, here HCWs, adult

carers of children, and children themselves. The theoretical framework which will underlie this research will be outlined in Chapter 2, with study methodology outlined in Chapter 3. In Chapter 4, the broader social, cultural, and historical context of the study setting will be explored, focusing on historical factors which link to current social dynamics and representations. Chapter 8 will discuss ethnographic observations of current clinical practices and the clinical social space, to reflect on the day-to-day lived experiences of participants in the health care setting, with Chapter 9 reflecting on the data findings in light of potential future scenarios and possibilities to improve children's access and adherence to HIV care within the community.

For this literature review, the electronic database Scopus was chosen, as it is the largest database of peer-reviewed journals which combines both biomedical and social sciences content, appropriate to the biomedical and psychosocial focus of this research (Falagas, et al., 2008). Multiple searches were conducted for the terms listed below, with no date range or language restrictions used, however, the most relevant hits were returned from the year 2000 to date. In addition, previously-acquired documents were also included where appropriate and if unavailable online. Search terms included: HIV, AIDS, HIV/AIDS, child, children, pediatric, paediatric, health care worker, nurse, clinician, clinic, carer, caregiver, parent, guardian, Uganda, sub-Saharan Africa, and Africa.

The relevant articles which were returned as database hits were reviewed, with a further review of the references cited in the selected works. These were also included if deemed relevant to the study. The geographic focus of the results was kept on Uganda and Africa whenever possible, and it was found there is a significant body of research on HIV/AIDS in Africa upon which to draw. As 90% of children who are HIV-positive globally live in sub-Saharan Africa (SSA) (UNAIDS, 2013), and as the research studies returned were highly relevant and of sufficient number and scope, these limitations on the database search were deemed to be acceptable, based on the quality and quantity of articles returned. On occasion, non-African HIV research studies, which had direct relevance to this thesis were also included.

1.1: Overview of current biomedical research on HIV & children

In this section, a brief overview of the current clinical research concerning children and HIV/AIDS will be given, as relevant to this research study's goals of examining the barriers to and facilitators of, children's HIV care access and adherence in a western Ugandan setting. Studies will look at both global and SSA findings, as well as findings from a national Ugandan context, and will focus on the biomedical and clinical aspects of children's HIV access and adherence.

1.1.1: Global findings on clinical aspects of HIV care access & adherence for children

The history of children's HIV care in Africa, particularly drug treatment, only dates back to the late 1990s-early 2000s, with 2004 noted as a watershed year when ART for the prevention of mother-to-child transmission (PMTCT) became more widely available across the continent (Lowenthal, et al., 2014). However, despite over 10 years of increasing clinical availability of children's ART, significant practice challenges remain, with a corresponding need for further research into children's access to and uptake of HIV services including ART. Further research is needed into discovering, creating, and sustaining the personal and social factors which will support a massive uptake and usage of HIV care. As recent international policy advocates for global "universal" access to ART, defined as an 80% coverage rate, there is significant international political and financial support for the current UNAIDS campaign to reduce HIV infections and increase ART treatment numbers, particularly for children, called "Getting to Zero" (UNAIDS, 2013, 2010a). Whether this will translate into local support and improved health outcomes at the community level remains to be seen. This PhD thesis therefore seeks to contribute to this growing area of research, by exploring the barriers to, and facilitators of, children's access and adherence to ART and HIV care.

According to the most recent statistics (UNAIDS, 2013), globally, over 35 million people are HIV-positive, with 25 million, or roughly 70% of this population living in SSA. This includes an estimated 3.3 million children under the age of 15 years who are HIV-positive, with over 2.9 million, or about 90%, living in SSA (UNAIDS, 2013; Barlow-Mosha, et al., 2012; Lowenthal, et al., 2014). Recent statistics also suggest that in the 21 highest-burdened countries around the globe, only 59% of HIV-

positive pregnant women receive PMTCT, resulting in about 1000 infants being infected daily (UNAIDS, 2013). This results in an estimated 370,000 children being infected annually in the SSA region alone (Barlow-Mosha, et al., 2012). Whereas adult drug treatment rates are currently at 10.6 million adults able to regularly access ART for 64% coverage, the rates of children accessing ART globally are roughly half that, at 34% coverage for children (UNAIDS, 2013; UNICEF, 2013). This results in a treatment gap where 1.9 million children globally qualify for HIV drug treatment, but only 650,000 receive it (UNAIDS, 2013).

Despite relatively low treatment numbers for children, the advent of ART usage has improved the health situation for children who can access it, as before ART, children who were infected with HIV at birth had only a 50% survival rate to age 2 (Brahmbhatt, et al., 2006; Kekitiinwa, et al., 2008; Newell, et al., 2004). Further clinical research has since shown that HIV infection in children may follow either a fast or a slow progression to clinical illness in the body (Lowenthal, et al., 2014). As many as one-third of HIV-infected children may end up having a slow progression infection (Ferrand, et al., 2009), which results in many children surviving for years without treatment, only to be found HIV positive in their adolescent years when they become extremely ill with the disease (Ferrand, et al., 2007; Walker, et al., 2006). Current research suggests that children infected with HIV at birth may have a 20-30% chance of being able to survive up to 10 years without drug treatment (Marston, et al., 2011; Ferrand, et al., 2007), with one study suggesting that children with a slow-progressing course of HIV infection may survive for up to 16 years without ART (Ferrand, et al., 2009).

However, despite this lag time in progression to major clinical illness, untreated HIV infection can cause significant harm and detriment to the growing child, particularly in terms of decreased immune system functioning, poor growth and development, and an increased risk for illness and death from susceptibility to opportunistic infections, often exacerbated by a poor nutritional status (Lowenthal, et al., 2014; Kekitiinwa, et al., 2008; O'Hare, et al., 2005). As HIV infection causes significant biomedical and psychosocial effects which are detrimental to children as well as to their families, the clinical rationale for scaling up children's access and adherence to

ART is sound and logical; the question then becomes how to optimize and support this, which will be considered by this thesis.

1.1.2: Challenges to clinical HIV care access & adherence for children in Uganda

In terms of the setting for this research, Uganda is often cited as a "success story" in the global fight against HIV/AIDS, given its early and proactive governmental programming in mobilizing an initial health education response (AVERT, 2014a; Barnett & Whiteside, 2006). However, the fight here is far from over. At the peak of the epidemic in the 1980s, Uganda had an adult HIV prevalence of over 30%, which reduced to a low of 6.5% in 2009, with current district HIV prevalence rates varying from 4-12% (AVERT, 2014a; Kipp, et al., 2007). The current national adult HIV prevalence rate has risen slightly to 7.2%, and the rate in Kabarole district, the setting of this study, remains on the high end of the district range at 11.3% (AVERT, 2014a; Kipp, et al., 2007; Kabarole District Local Government, 2010). Nationally, recent statistics suggest there are about 1.4 million adults who are HIV-positive in Uganda, with a drug treatment coverage of 62%, which is roughly on par with the global ART coverage average for adults of 64% as referred to above (AVERT, 2014a; UNAIDS, 2013).

However, as also happens globally, the rates of children using ART in Uganda is roughly half that of adults, with less than 32% on ART, of a total estimated HIV-positive population of 190,000 children (AVERT, 2014a; UNAIDS, 2013). According to reports released at the start of this study, in 2010, about 16,000 children per year died from HIV in Uganda in 2010, which actually outnumbered the total receiving ART treatment at the time (Baguma, 2010; UNICEF, 2010). This occurs despite the increasing availability of, and funding for, children's ART at local health centres across Uganda, which provide children's ART programming alongside adult ART programmes (IRIN, 2009), and which is the case for the study setting in Kabarole district (Kipp, et al., 2007).

In addition to local Health Centre ART provisions for children, treatment in Uganda can also be accessed through a network of faith-based organizations (FBOs), and community-based organizations (CBOs) such as The AIDS Support Organization (TASO), which are active in many districts, and which have been shown to achieve

very high adherence rates (95%) for children's ART, even after 1 year on treatment (Kiboneka, et al., 2008). This illustrates how the potential to provide children's ART is there, at both governmental and non-governmental service levels, yet there appears to be a disconnect between what is possible and what happens, or is probable for children. This thesis will therefore also investigate such gaps between the potential within the system, and the practice realities "on the ground," in this case at the local government health centre as will be discussed in Chapter 8. It will be the focus in terms of the clinical provision of ART drugs for children, as it is currently the only organization providing children's ART in this community; no CBOs or FBOs at present provide additional ART services in the local area.

A clinical factor which may complicate children's ART access is the availability of child-friendly medication formats and dosages, which is still uneven across Uganda's districts. Consistent access to children's ART formulations, in the form of child-specific dosages and formats such as syrups over pills, can be hampered by funding, as pediatric drug formulations can cost up to 10 times higher than adult formulations (Barlow-Mosha, et al., 2012), and by drug stock-outs, as all government Health Centres are supplied from the national Uganda Medical Stores in Kampala. As will be discussed further in Chapters 5 and 8, supply provisions, including children's ART, from the National Stores have been erratic and unreliable in the past, resulting in a potential structural barrier to ART provision. This has been overcome in this community by recent assistance and funding support for children's HIV programming from Uganda's Joint Clinical Research Centre (JCRC) and an American university. In other rural clinics, HCWs cope with drug stock-outs by using adult ART drugs for children, cut up to the appropriate dosage based on children's body sizes (ibid). This has been practiced in other countries with similar supply problems, most notably Thailand, and has been confirmed to be both feasible and clinically safe (Barlow-Mosha, et al., 2012; Collins, et al., 2010). Such logistical coping practices suggest that, despite latent supply problems, there are ways in which children's ART access and adherence can be met across Uganda.

Finally, another factor which may also complicate children's ART access from a clinical perspective relates to parental HIV infection and PMTCT access and usage. In the general population of Uganda at present, women's HIV infection rates remain

higher than men's, at about 60% versus 40% of HIV infections recorded (Nassali, et al., 2009). One study found that mother-to-child HIV transmission accounted for 95% of pediatric HIV cases at the time (Uganda AIDS Commission, 2008). This high rate of mother-to-child HIV transmission may well be linked to low rates of HIV-positive mothers accessing PMTCT services, including low access to antenatal care (ANC) services during pregnancy and postpartum as follow up visits after birth (Karamagi, et al., 2006; Uganda Ministry of Health, 2005). The personal and social reasons for children's caregivers, particularly mothers, not accessing HIV or clinic services are significant and will be discussed further in section 1.3, as well as in Chapters 6 & 8. As the psychosocial factors underlying HIV care access choices made by adults also appear to play a role in mediating children's access to HIV services (Bakeera-Kitaka, et al., 2008; Birungi, et al., 2008), current research will be reviewed here, and further discussed in Chapters 5-8 in relation to the data findings.

The biomedical and clinical research into children's HIV testing and treatment explored here, suggests that clinical treatment outcomes could be expected to be better than they currently are in Uganda. This gap between what is possible medically and what is probable and actually happens in real life situations is problematic and deserves further study, and is what has led me to conduct research into this problem. Given the medical possibilities for successful pediatric HIV treatment which are available in Kabarole district, conducting research into the non-medical reasons for the low rates of HIV treatment access and adherence for children, could provide additional insight into this failure to connect children to services. This is best investigated through qualitative research with the three stakeholder groups most directly involved in children's HIV and health service access, namely children, adult carers, and HCWs, to understand their lived experiences and the ways in which they make sense of this problem. Whilst their own lived experiences will be covered in Chapters 5-7, current research which provides a more in-depth background to these findings, will be discussed in the following sections.

1.2: Health care workers, HIV & children

In this section, research on HCWs and children's HIV care provision will be reviewed to provide insights into conditions that impact on the ability of HCWs to

provide good quality care to their patients, with some similar findings noted across SSA (Ehlers, 2006). Four areas emerge as being particularly relevant to this research study. Many HCWs feel they are unsupported in their clinical practice, in terms of HIV knowledge and skills, despite research which advocates for a well-supported staff, which can then facilitate improved pediatric HIV service delivery and care. This is also linked to a lack of HIV-specific skills training, particularly HIV test and treatment counselling for families and children, from which staff would benefit in terms of their day-to-day practice. Although HCWs face significant challenges from burnout and the personal and social effects of stigma, the use of ART has been a positive and encouraging professional experience for them overall, which has helped them to provide better care to clients.

1.2.1: Issues in supporting HCWs to provide HIV services

In terms of HCWs providing HIV care to children, one South African study (Yeap, et al., 2010) examined the structural and social factors influencing children's access to HIV care as seen by children's caregivers and HCWs, and found that service-related factors such as high clinic demand, and poor quality of care including negative staff attitudes, were cited by carers as reasons for decreased clinic access for children. Despite such barriers, however, many carers still access HIV services, and HCWs remain committed to caring for clients, often facing difficult professional and structural challenges in doing so, which impacts on the quality of care they are able to provide (Campbell, et al., 2011a). Other significant issues in terms of HIV service provision by HCWs, include a lack of HIV-specific education and skills, particularly HIV counseling (Salyer, et al., 2008; Horwood, et al., 2010; Myer, et al., 2006), as will be discussed further in section 1.2.2.

One Ugandan study found a discrepancy between the type of health information HCWs provided to HIV-positive adolescents, and the type of information the adolescents needed and wanted, particularly in the area of reproductive health, HIV transmission, and contraception (Birguni, et al., 2009). Whilst this may be due to staff knowledge levels, it may also be due to broader cultural constraints and considerations, which may influence HCW intervention decisions, despite Ugandan HIV national policy guidelines allowing HCWs to test children over the age of 12 for HIV without parental consent or knowledge (Rujumba, et al., 2010). As the authors

(ibid) also note, most HCWs in Uganda need structural and system-based support to acquire the clinical skills needed to provide better care to children living with HIV. Continual opportunities for in-service training can help staff keep up with changing pediatric HIV care guidelines, and staff at all service levels could benefit from such support (Rujumba, et al., 2012). Maintaining or even improving staff morale, which can be done through increased staffing, training, and resources and supplies, was seen to have a positive effect which improved HIV care provision in one study (Nuwagaba-Biribonwoha, et al., 2007).

Creating a supportive clinical environment is also seen as a way to improve HIV care outcomes, and involving HCWs as stakeholders in HIV and health service decision making processes would be beneficial to staff morale and service provision (Kapiriri, et al., 2003). Examples include working with staff to adopt a family-centered model for HIV care, which allows HCWs more flexibility in providing services to HIV-positive children and related family members, and can result in faster and easier service provision for them (Luyirika, et al., 2013). However, if not implemented properly, HCWs may see a change in service programming as an additional burden to their workload, which may result in a lack of enthusiasm and unfriendly attitudes to clients (Msellati, 2009). This unfriendliness can then act as a barrier to service users, particularly to underserved groups such as adolescents (Varga & Brookes, 2008). Programme implementation and changes should ideally be undertaken with the support of staff, which will be discussed further in Chapter 8.

1.2.2: Issues of HCW service capacity, education & training
A major concern to HCWs, as will be seen in Chapter 5, is the lack of resources available for them to do their job effectively, such as critical medical supplies and drugs, as well as employer support for professional development (Nuwagaba-Biribonwoha, et al., 2007). One Ugandan study (Rujumba, et al., 2010), found that amongst HCWs working in general practice, 63% had received no formal training in counselling patients at all, whereas with HCWs who specialized in HIV care, 62% had attended some form of training course related to HIV counselling. As HIV testing and treatment in this study setting in Uganda, as well as in other countries globally, is increasingly carried out in non-HIV specific health service settings, such as local health centres, this highlights a serious oversight in staff capacity and

training, and a resulting service gap, which will be discussed further in Chapters 5 & 8.

In terms of facilitating HIV status disclosure to children, HCWs often are caught in the middle between parents and children, and may feel uncomfortable in this position if they do not have the counselling skills to mediate these tensions (Myer, et al., 2006; WHO, 2011; Lowenthal, 2014). Work by Brouwer, et al. (2000) points out that HCWs are not only counselling the HIV-positive child, but are having to counsel the adult carer as well, who may also be HIV-positive, and may not be coping with his or her own diagnosis, let alone that of the child's. In addition to carer reluctance to disclose, HCWs also cited time constraints and heavy patient loads as constraints on counselling children about HIV (Rujumba, et al., 2010). However, one South African study found that clients who had access to a clinic-based, specialized HIV and ART adherence counsellor were significantly more likely to remain in care than those who did not, suggesting that the development, or deployment, of staff with such training could help increase clinic use and ART adherence, and decrease loss-to-follow-up of patients, with resulting negative health outcomes (Igumbor, et al., 2011).

The use of innovative clinical models of practice and intervention can help improve children's HIV care provided by clinic staff in several ways. A recent Ugandan study recommended a move to family-centered HIV care practice models to improve clinical practice, in conjunction with task-shifting towards nurse-led clinics with community outreach programming, as it provided improved access and ART adherence by children and families (Luyirika, et al., 2013). When properly staffed, a combination of nurse-initiated HIV care with home-based peer counselling follow up has proven to be as effective at maintaining good ART adherence as doctor-provided care, and is a feasible option for many SSA countries (Kiweewa, et al., 2013). However, community health workers and peer counsellors must be appropriately trained and educated to ensure appropriate care interventions and health assistance occurs, as one Ugandan study found that inappropriate care actions were taken when this was not the case (Alamo, et al., 2012). In Mozambique, a trial program which assisted staff in providing enhanced HIV care through the use of quality improvement measures was effective in increasing the

numbers of women accessing early infant diagnosis and returning for follow-up care, with no correspondingly negative impact on other areas of care provision or staffing (Ciampa, et al., 2012). Unfortunately, broader social issues, in particular HIV stigma, were seen to inhibit follow-up care return, and undermined the ends achieved by such innovative programming (ibid).

1.2.3: Issues of burnout & stigma relating to HIV care provision
As a result of barriers to good HIV care and clinical practice, as discussed above in sections 1.2.1 and 1.2.2, HCWs often experience high levels of moral conflicts and moral distress which can impact negatively on their provision of care, and even on their remaining in the profession altogether (Fournier, et al., 2007; Harrowing & Mill, 2009; Horwood, et al., 2010). These conflicts are often a result of a clash between their professional and personal values, and are exacerbated by an unsupportive or constrained clinical practice environment (Harrowing & Mill, 2009). Continued clashes over time can lead to compassion fatigue, often followed by burnout, yet many HCWs choose to stay working as they are often the primary income earner in their extended family and cannot afford to change careers or quit to remove the burnout (Harrowing, 2011). This can further exacerbate poor coping and even depression, which can result in even worse care provision at work for clients (Davhana-Maselesele & Igumbor, 2008).

HIV care provision, particularly in underfunded health systems, is often seen as being particularly high risk for compassion fatigue and burnout, due to poor working conditions, high patient acuity and loads, high personal risk for HIV exposure, low wages, and a lack of external practice support in the form of unions or practice legislation enforcing good clinical standards, such as minimum staffing (Turan, et al., 2008; Harrowing, 2011). The additional psychological burden of having significant numbers of patients die, although lessened by increased access and adherence to ART therapy, remains and continues to impact on HCWs (van Dyk, 2007). Although HCWs need support to ensure that HIV service provision does not burn them out further, this often does not occur in an underfunded system (Msellati, 2009). The emotional nature of HIV care, particularly in regards to counselling clients who have tested HIV-positive for the first time, can be further exacerbated by the social context in which HIV may have been acquired, such as through rape or

spousal or child abuse (Mavhandu-Mudzusi, et al., 2007). When coupled with poor or no training for HIV counselling, as discussed in section 1.2.2, HCWs may be further traumatized and have difficulty coping emotionally and psychologically, often experiencing depersonalization and emotional exhaustion (Engelbrecht, et al., 2008).

Untreated compassion fatigue, trauma, and burnout can also lead to stigmatization of clients by HCWs. Negative, judgmental and unsupportive attitudes and actions to HIV-positive parents, particularly HIV-positive pregnant women, can trigger feelings of stigmatization in the service user, and result in them not returning for health services (Harries, et al., 2007; Msellati, 2009). Such stigmatizing attitudes often result from underlying burnout and frustration with clinical practice realities, which can also be exacerbated by frustration at clients who engage in high risk behaviours, or who don't comply with the requirements of ART therapy (Horwood, et al., 2010; Ngyuen, et al., 2007). In addition, HCWs themselves may also face secondary stigma from the community for having to work with HIV-positive clients, which not only deprives them of the social support which would help them cope with work challenges, but can actually exacerbate or worsen burnout (van Dyk, 2007).

1.2.4: Impact of ART on HCWs
Despite significant practice challenges, and the risk of burnout as seen here, HCWs do remain committed to their work and patients, as the advent of ART has led to increasingly improved patient health outcomes, and is a challenge to social stigma and negative representations of HIV, which benefits both patients and nurses (Stein, et al., 2007; Kyakuwa, 2009; Holzemer, et al., 2009). The dramatic impact of ART on a client who has almost died from HIV/AIDS, often described as the "Lazarus effect" (Castro & Farmer, 2005; Pisani, 2008) cannot be underestimated in its capacity to inspire clinicians, HIV-positive patients, and the public alike. HCWs often cite such dramatic improvements in patient health outcomes as inspiring hope for the future, and as a motivating factor for them to keep working despite significant practice limitations, shortages, and challenges (Stein, et al., 2007; Campbell, et al., 2011b).

Given the clinical benefits of ART medication, as seen above and in section 1.1, the move to task-shifting in order to support HIV service and ART scale up has seen many challenges in implementation, including shortages of clinical education, supportive management and logistics, and appropriate role assignment and delineation (de Wet & du Plooy, 2012). Despite these challenges, positive patient outcomes and a greater sense of control and professional capacity to be able to respond effectively to the health challenge of HIV may help to revitalize and reinvigorate HCWs who have suffered from compassion fatigue in the past (Harrowing, 2011; Stein, et al., 2007). When linked with successfully implemented task-shifting to facilitate increased HIV and ART programming, one study found that HCWs reported increased feelings of accomplishment and satisfaction at work, however the authors point out that further research is needed in this area (Iwu & Holzemer, 2013). From a psychosocial perspective, interventions which could help to boost morale and improve HCW satisfaction would not only help service providers, but could also benefit service users as well through improved service delivery, which will be explored in Chapters 5 & 8.

1.3: Adult carers, HIV & children

In a review of the literature concerning adult carers and children's HIV care access and adherence, four key areas emerge which are relevant to this study. First, issues surrounding children's HIV service access are often linked to perceived quality of care by the adult carers, with system engagement playing a role in the uptake of care services. Second, the challenges of caregiving and family interpersonal dynamics are often exacerbated when HIV enters a household. Stigma continues to be a major negative factor mediating HIV service uptake, and has both personal and social consequences for adult carers and children alike. And finally, issues surrounding HIV-status disclosure have an impact on children's caregivers and the health care decisions made for their children and family.

1.3.1: Need for quality health services & engagement with the system

As discussed in section 1.1.2, there are health system barriers in the provision of HIV care which remain and are inhibitors of children's access and adherence to HIV care. Although HIV programming, particularly PMTCT, is a key part of the response to children's HIV care needs as it has the potential to stop HIV transmission to

children altogether, service access still remains low across SSA (Friberg, et al., 2010; Horwood, 2010). In Uganda, one study (Mbonye, et al., 2010) suggests that only 15% of health facilities offer the full components of PMTCT programming, from HIV testing for mothers and children, through to counseling and ART provision. Other limitations in SSA which are well-researched include financial costs to access health care, and transport difficulties (Mukhtar-Yola, et al., 2006; Barnett & Whiteside, 2006).

Interestingly, one Ugandan study (Kapiriri, et al., 2003) found that stakeholder support for PMTCT programming may actually be determined first by the availability of local resources, and only then by evidence in support of the intervention. Such limitations are found globally as well, as Spaar, et al. (2010) show in an analysis of 27 ART programmes, where service uptake reflected the extent of the programming activities, which was ultimately dependent on funding, staffing capacity, and mandate. However, despite the local clinic in this research study setting having all components of PMTCT programming, from HIV testing for mothers and children to post-test counselling and free ART drug provision (Kipp, et al., 2007), access here remains sub-optimal for children. This discrepancy suggests there may be other factors at play besides structural barriers such as a lack of service provision or mandate, which in this setting is not the case.

In examining additional barriers to the uptake of HIV services globally, interpersonal barriers such as language, social stigma, and negative staff practices and interactions can prevent children and their carers from accessing services (Ngyuen, et al., 2008; Painter, et al., 2004). A lack of public education about HIV services, combined with rapidly changing and contradictory clinical practices, which can result in a lack of continuity in service provision, may have additional negative impacts on service uptake (Harms, et al., 2005; Homsy, et al., 2010). In Uganda, psychosocial barriers for carers which may hamper HIV service access and uptake further, include a real reluctance of some women to partake in services that do exist, particularly PMTCT. One Ugandan study (Dahl, et al., 2008) found a 15% mean refusal rate for HIV testing by women at the clinics studied, with the main refusal reasons being: wanting to first discuss testing with the male partner, fear of the male partner's reaction to the test result, and the belief that ART drugs are not

available, affordable, or effective. As will be explored further in Chapters 6 & 7, the women's fears and concerns in that study (ibid), are valid and reasonable, as many adult carers here not only echoed the conclusions of this study, but added more.

Given this, a likely determinant of poor HIV service access may therefore be the extent to which services are perceived to resonate with the needs and interests of potential users, and in the case of children, those of their carers or guardians (Leach, et al., 2008; Campbell & Cornish, 2010; Campbell, et al., 2011a). In short, if health services are perceived as being useful and relevant to the needs and lived experiences of system users, they are more likely to access them. This goodness of fit, between user perceptions of health services, and those of service providers, is therefore key to optimizing the likelihood that people will access the services they need (Leach, et al., 2008; Campbell & Cornish, 2010).

In this thesis, Chapter 8 will examine the clinical aspects of this goodness of fit, or lack thereof, by observing and exploring the local clinical setting in which health service provision and uptake occurs in this community. When considered in connection with the data from Chapters 5-7, a broader picture of service user and provider perceptions of the HIV and health service setting will emerge against the day-to-day interactions seen within the clinical setting. The implications of this match or disconnect of representations, for children's access and adherence to HIV services locally, will then be discussed in Chapter 9.

1.3.2: Issues of caregiving & HIV within families

For adult carers and families, HIV caregiving presents a series of challenges, particularly in terms of children's HIV care access and adherence. From a Ugandan perspective, studies recognize the importance of HIV caregiving in families as reinforcing familial, social, and cultural bonds within communities, but also that this can come at a high cost for those involved, in terms of decreased income with increased living expenses (Kaler, et al., 2010), changes in normative power and gender relationships within families (MacNeil, 1996), and increased psychosocial stressors from handling constant health crises and needs, often at the expense of the carer's own health (Kipp, et al., 2007).

Elderly caregivers, typically grandparents caring for their grandchildren or other related children who are orphaned by HIV, may face a unique challenge due to their age, as they may take on the role of primary caregiver for young children at a time when they are at a relative disadvantage to perform the physical, financial and psychosocial work related to raising children, with many facing a double burden of care in caring for both their ill adult children and young grandchildren at the same time (Ssengonzi, 2009; Kamya & Poindexter, 2009; Skovdal, et al., 2011a). The challenges faced by elderly carers, and the negative impact of HIV on children and families, are vividly depicted in the children's draw-and-write data in Chapter 7, and will be discussed in further detail there.

Chapters 6 & 7 also reflect other findings where, despite the will and capacity of carers of all ages to look after their families, supportive health, educational, and social resources are often in short supply, not only in poorer countries but also in richer ones (Ssengonzi, 2009; Kipp, et al., 2007, Nicholson, et al., 2006). This is particularly so when there are no additional non-medical services to help caregivers, such as socioeconomic support programmes, including cash transfers, support groups, or home-based services (Skovdal, 2010). In this study setting, there were no FBOs or CBOs operating such programming in the area, unlike other parts of Uganda which are served by such organizations (TASO, 2014a), as participants here typically rely on extended family members for such support, where possible.

The role of interpersonal dynamics in the family may have an impact on children's access and adherence to HIV care and services. Studies suggest that strong parental relationships with, and trust in their children, helped to support ART adherence for children (Bikaako-Kajura, et al., 2006; Rwemisisi, et al., 2008). In contrast, adults who did not trust their children, and did not disclose the children's HIV status to them, often had to force them to take their ART medication, by resorting to threats, bribery, and verbal or physical abuse (Bikaako-Kajura, et al., 2006). Such tactics could undermine family trust and result in long-term issues regarding parent-child trust over time (Abadia-Barrero & Castro, 2006).

A lack of open disclosure can create also confusing and distrustful social conditions for children, which may have further negative impacts on their health outcomes, and

put them at risk for behaviours which could spread HIV (Abadia-Barrero & Castro, 2006; Rwemisisi, et al., 2008). The role of inter-generational interpersonal dynamics in supporting children's HIV care access and adherence is deserving of further research, as strengthening and supporting families in coping with HIV could lead to better long-term outcomes for children and carers alike (Skovdal, et al., 2011a).

1.3.3: Issues of stigma for adult carers

Stigma, which is composed of both the fear of social censure, and the psychological internalization of shame, guilt, sadness, and "otherness" (Goffman, 1963; Joffe, 1999, Campbell, et al., 2005) remains a significant inhibitor of HIV care and service access across countries. However, women may face particularly strong gender-role and psychosocial barriers which can prevent them from accessing PMTCT and HIV services, which are often linked to a fear of stigmatization that can come with an HIV-positive status (Mast, et al., 2006; Msellati, 2009; Hejoaka, 2009). This has been documented in Uganda and elsewhere in SSA as having long-term negative health impacts on the woman and her children (Homsy, et al., 2007; Mast, et al., 2006).

In association with non-disclosure of HIV-positive status to family members, stigma has been cited as a main reason for ART default and loss-to-follow-up in HIV programming in Malawi, with roughly half of the adult and child defaulters dying within 2 months of therapy discontinuation (McGuire, et al., 2010). Given these serious consequences, further research into keeping children and their carers on effective ART in the face of stigma is needed, and it is hoped this study will contribute to this area. The impact of stigma on children's access and adherence to HIV care in this setting will be examined in Chapters 5 & 6, as seen by HCWs and adult carers.

Further, the bigger problem may in fact be the social consequences of disclosing one's HIV-positive status, which are linked to stigmatization by friends and family members, including a lack of, or withdrawal of, social support (Campbell, et al., 2005; Jones, et al., 2005). In one Ugandan study, there was a good rate of HIV testing during PMTCT when only mothers were being tested (77%), however, the acceptance rate dropped significantly to 41% when HIV testing with a partner was

enforced (Nassali, et al., 2009). Following up, only 42% of the individually-testing mothers disclosed their HIV status to their partner, due to a fear of the negative social consequences which could result (ibid). The women's fears were justified, however, as of the mothers who did disclose their HIV status, 14% reported adverse interpersonal effects including violence, divorce, and withdrawal of social or financial support (ibid). Unfortunately, similar findings have been seen in other studies in SSA looking at disclosure of HIV-positive status (Gaillard, et al., 2002), particularly adverse social events from disclosure (Jones, et al., 2005). As mentioned in section 1.3.1, such themes emerge in the data from HCWs and adult carers participating in this study and will be discussed more in depth in Chapters 5 & 6.

1.3.4: Issues of disclosure for adult carers

Disclosure of a child's HIV positive status is difficult for parents universally (Rwemisisi, et al., 2008; Wiener, et al., 2007), but is seen by both parents and health care staff as being important to the child's understanding of HIV and adherence to medication regimes (Bikaako-Kajura, et al., 2006). However, within many social contexts in SSA, including that of the study location in Uganda, it is not culturally acceptable to talk about sexual matters between family generations, especially to children (Whyte, et al., 2008). This can create problems regarding HIV education, given its continued representation as an illness which is a stigmatized punishment for sexual behaviors (Joffe, 1999; Kyaddondo, et al., 2013). A lack of disclosure can also create interpersonal and intrapersonal conflict, as HIV status disclosure is important in supporting children's ART adherence, to help mobilize social support and allow for open conversations about living with HIV, particularly between parent and child (Bikaako-Kajura, et al., 2006).

As discussed above, not discussing HIV and disclosing a child's positive status can create a context of secrecy, mistrust, and confusion and put the child at risk for negative health outcomes (Rwemisisi, et al., 2008). In addition, HIV status disclosure is often necessary to gain access to medical and socioeconomic supports via HIV programming (Whyte, et al., 2010). However, as will be seen in Chapter 8, the physical layout and care procedures of the local health clinic do not

allow for much privacy, which may lead to inadvertent disclosure of one's HIV status, and as such, may be intimidating and prevent service uptake.

For many carers, the fear of having to explain one's own past personal and sexual actions, which may be judged and seen as being immoral or promiscuous, is too much of a threat and prevents disclosure (Rwemisisi, et al., 2008). Carers may be reluctant to disclose their own HIV status due to fears about their "losing face" in the children's eyes, and may have concerns over the child's level of maturity to understand and "keep the secret" private (Kyaddondo, et al., 2013). This was a particular issue for fathers and male carers, who fear rejection, blame, and a backlash against their promiscuity, particularly when they have multiple partners concurrently (Kyaddondo, et al., 2013; Rwemisisi, et al., 2008).

More generally, parents and carers were also fearful to disclose the child's own HIV-positive status to them due to lingering guilt over having infected their children, and the potential social stigma and discrimination which could result (Kyaddondo, et al., 2013). In many studies, carers were often afraid to disclose both their own, and the child's HIV-positive status, for fear the child would then tell others, "outing" them socially (Vaz, et al., 2008; Vreeman, et al., 2010; Skovdal, et al., 2011a). This is still strong in communities where fear and ignorance about HIV continue to drive social stigma (Campbell, et al., 2005; Hejoaka, 2009). In this regard, the personal fears of carers often outweigh the potential familial benefits of HIV-status disclosure, creating a culture of secrecy and denial (Hejoaka, 2009), which will be discussed in Chapters 5 & 6.

1.4: Children & HIV

For children themselves, less research has been done to capture their voices and document their own accounts of the lived experience of HIV/AIDS in comparison to adults, but this is an area of increasing research to which this study will contribute. Four key areas emerge from current research conducted with children. The impact of HIV on children and their families create significant challenges in terms of coping and interpersonal dynamics. Disclosure of a child's HIV-positive status often results in increased adherence to ART and increased agency in terms of the child actively monitoring his or her own health. Whilst research has been done on HIV health

services for children, this has been mainly in the area of adolescents and HIV and sexual health education, with less work done on the HIV service needs of younger children. Finally, issues of growing up with HIV, particularly in relation to longer-term ART adherence, is an area requiring further research, to which this PhD will contribute.

1.4.1: Psychosocial impact of HIV on children and their families

For children, the life-long impact of HIV infection on both the family unit and themselves is increasingly being researched. The effects of coping with HIV are numerous in terms of personal and social impacts, and are often cumulative or recurrent over a span of time, such as the child's entire childhood, as opposed to discrete, singular events (Lowenthal, et al., 2014). Children often have to face the long-term illness and death of family members including their caregivers and their family's main income providers (Nyamukapa, et al., 2008; Petersen, et al., 2010; Skovdal, 2010). As a result, they may themselves become responsible for other family members, such as siblings or elderly relatives either through caring work or paid employment (Bachmann & Booysen, 2003; Skovdal & Campbell, 2010).

Children in families where multiple family members are affected by HIV may also experience orphanhood, which carries with it significant risks for economic and social distress, including a higher risk for transactional sex for survival due to economic pressures (Cluver, et al., 2011; Samara, 2010). A risk of dropping out of education, due to having to look after others or being unable to afford the fees or costs of schooling, may threaten their future and potential career and life choices (Nyamukapa & Gregson, 2005; Skovdal, 2010). This can alter their whole life trajectory, resulting in long-term personal and social impacts as they grow up.

Children can also experience poor mental health outcomes from stress and trauma (Nyamukapa, et al., 2010; Betancourt, et al., 2011; Cluver, et al., 2012), which may exacerbate underlying mental health and developmental problems if they are infected with HIV but have not been able to access ART (Mellins & Malee, 2013). A lack of supportive psychological and social environments have also been seen to undermine children's access and adherence to HIV care and ART, particularly when

exacerbated by family social and economic difficulties (Mellins, et al., 2004; Nyandkio, et al., 2006).

As children and adolescents who are HIV-positive have needs specific to their own development, which differ from the needs of HIV-positive adults, they thrive when they have mentoring and positive adult role models in their lives (Steele, et al., 2007; Onuoha et al, 2008; Kaggwa & Hindin, 2010). These supportive psychological and social environments are seen as factors which can help to bolster and maintain children's access and adherence to ART, often in the face of social and economic difficulties (Mellins, et al., 2004; Nyandkio, et al., 2006). The role of social capital in encouraging HIV resiliency in children, families, and communities, in order to support improved access and adherence to HIV care for children (Campbell, et al., 2012a; Seeley, 2014), will be explored in Chapter 9.

1.4.2: Issues of disclosure, agency & adherence to ART medication
Research suggests that children need disclosure of their HIV status in order to help them understand their illness, and to be an active and informed participant in their own care (Biadgilign, et al., 2011; Domek, 2006). In some instances, children who are uninformed about their HIV-positive status and who are on ART may refuse to continue taking their medication until they are told what disease they have, and why they are taking the medication they are on (Kyaddondo, et al., 2013). Despite these findings, as seen in sections 1.2 and 1.3, there is a general reluctance to disclose a child's HIV-positive status from both caregivers and HCWs alike, who often cite fears of causing the child psychological distress, as well as wanting to avoid the difficult task of discussing how the child was infected with HIV, as their reasons for non-disclosure to the child (Moodley, et al., 2006; Vaz, et al., 2010).

One Ugandan study found varying levels of disclosure to children, from complete disclosure, to partial disclosure, to non-disclosure, with the best overall ART adherence and health outcomes resulting from full disclosure of the child's HIV status, as children were more motivated to adhere to their medications and often took proactive responsibility for their own medication use (Bikaako-Kajura, et al., 2006). Adverse outcomes of partial or non-disclosure, included decreased trust between child and caregiver, refusal to take the medication or subterfuge to get rid

of it without taking it, and feelings of fear, anxiety, and resentment towards both the medication and the parent (ibid). Vaz, et al. (2010), found that disclosure rates in developing countries ranged from 19-62% of children, with increasing rates of disclosure seen with increasing age of the child.

In one study in the Democratic Republic of the Congo (Vaz, et al., 2010), parents were not only reluctant to disclose to their children, but they were also not proactive in their communication about the child's HIV status. Children, after hearing about their HIV-positive status had reactions which were a mix of sadness, feeling hurt, worry over potential stigma if found out to be HIV-positive, and also relief at being told why they were feeling unwell and were on medication (ibid). However, they also reported that most clinical communication took place between HCWs and parents, with only 1 of 7 child respondents reporting a direct conversation with a HCW (ibid). One study found that no children were told of their diagnosis before age 10, and were only told as adolescents, despite almost all of the respondents (88%) stating it was better for them to know their status early, as knowing their status would help them protect themselves and others (Vaz, et al., 2008). However, adolescents themselves are also reluctant to disclose an HIV-positive status to others, with fears of stigma and rejection playing a large role in these decisions (Siu, et al., 2012).

Despite the challenges faced in disclosing children's HIV-positive status, it can inspire them to counter the effects of social stigma by "flipping" stigma around, and developing a positive social identity as someone who has found out their status and is therefore a "responsible" person, as seen through ART adherence, keeping healthy and being pro-social by not passing on their HIV infection (Midtbo, et al., 2012; Campbell, et al., 2011c). Disclosure may also provide children an amount of control and agency over their illness, and help to encourage effective health system use in the future (Midtbo, et al., 2012). This could help to develop a form of "therapeutic citizenship" (Ngyuen, et al., 2007), within the context of creating a new normality for one's identity as a person living with HIV (Wekesa & Coast, 2013). Such a realignment of social identity has been seen in Zimbabwe (Campbell, et al., 2012a), as a coping mechanism used by adults in dealing with HIV stigma in their community. However, such normalization also carries with it a risk of complacency

over HIV infection and treatment, the implications of which will be discussed in Chapters 5 & 7.

1.4.3: Issues of HIV service access for children & adolescents

In terms of research on children's HIV service access, there are a few studies which have been done focusing on children, which will be reviewed here, however the main focus of much research is on the sexual health needs of adolescents, typically from around age 14 or 15 up to age 18 when legal adulthood begins, as it is a time when puberty is occurring and when first sexual behaviours may be undertaken (UNICEF, 2013; Gregson, et al., 2002; Cheney, 2007). Unfortunately, research also suggests that children may be sexualized earlier than this, often due to sexual violence within the family or community (Cheney, 2007; Samara, 2010), and that the sexual and reproductive health needs of HIV-positive adolescents are often not fully considered by HCWs, as seen in section 1.2.1. Health clinics and outreach programs targeting adolescents in Uganda often do not address their sexual health risks or needs well or at all, creating a service gap which may impact on their health service uptake (Birungi, et al., 2009b; Bakeera-Kitaka, et al., 2008), and which will be considered in connection to children's access to HIV services in Chapters 7 & 8.

In Uganda, as will be discussed in Chapters 4-6, a lack of HIV and reproductive health service access is complicated by a long-standing cultural reluctance to discuss sexual matters with youth across the generations, as it has traditionally been taboo for parents and caregivers to discuss sexual matters with their children (Taylor, 1998; Whyte, et al., 2008). This taboo still occurs despite youth needing to learn how to negotiate their sexuality as they grow up through childhood, particularly if they are HIV-positive (Birguni, et al., 2009b). Two Ugandan studies have shown how social and health service supports are needed by HIV-positive youth in negotiating safer sex and condom usage, as well as for other psychosocial challenges such as peer pressure, alcohol and drug use, and HIV disclosure (Birungi, et al., 2008; Bakeera-Kitaka, et al., 2008).

Further complicating the issue of adolescent sexuality and HIV in Uganda is a strong cultural emphasis on having children, which often places significant personal and social pressure on older adolescents if they are HIV-positive, as they are

caught between the cultural and personal desire to bear children and the risks of passing on HIV infection to their partner or child (Taylor, 1998; Birungi, et al., 2009b). In one major children's HIV clinic in Kampala, roughly 10% of adolescent girls attending for ART had been or became pregnant whilst on therapy, with 1% of boys attending having fathered children whilst on ART (Lowenthal, et al., 2014), suggesting a not insignificant need which remains to be addressed and met.

In addition, the social circumstances regarding youth sexual activities can present difficult psychosocial challenges for children and adolescents, as these may include early or forced sexual debut, multiple sexual partners, wider social risks for sexual violence, and transactional sex (Samara, 2010; Cluver, et al., 2011; Fatusi & Blum, 2009). Learning how to negotiate these social situations is a significant maturational task, and one in which additional supports would be beneficial for children as they grow up, such as in the form of supportive and non-judgmental health services, as will be discussed in Chapter 8.

Although there is a large literature focusing on school and peer-based HIV education interventions across SSA, including research on available local programming (see Kilian, et al., 2007), some Ugandan studies suggest that adolescents' health education needs are not being met by these programs, in terms of sexual education and HIV prevention negotiation strategies, which can be constrained by social and gender role contexts in regards to cross-generational or transactional sex (Jacob, et al., 2007; Mutonyi, et al., 2010; Norton & Mutonyi, 2010; Samara, 2010). Whilst this study will briefly examine the role of the Ugandan national HIV/AIDS curriculum as it pertains to the findings from child participants in Chapter 7, a more detailed analysis of school-based interventions is outside the scope of this thesis, as recent research from Zimbabwe (Campbell, et al., 2014), questions the role schools can play in HIV education, particularly when facing significant structural and social limitations, including poor funding, staffing, and non-supportive social contexts. As the study location does not have any formal school-based assistance programmes for HIV-positive children, the clinic remains the main formal social space for support, and as such will be the focus for this research in Chapter 8.

1.4.4: Growing up with HIV & ART adherence challenges

There is a growing body of research on pediatric ART adherence in SSA (Biadgilign, et al., 2011; Biadgilign, et al., 2009; Arrive, et al., 2005; Polisset, et al., 2009), which has found that children on ART and their families face many of the same adherence challenges as children in richer countries. These issues include role and responsibility conflicts for medication administration, continued stigma and a lack of support from family members and friends, the need for further HIV and ART education and simplified medication regimes, in addition to support in overcoming barriers such as finances or drug availability (Katko, et al., 2001; Brackis-Cott, et al., 2003; Martin, et al., 2007).

Clinical research into ART adherence for children and adolescents has shown that, whilst young children and adults have the highest rates of ART adherence and correspondingly good clinical outcomes (Shroufi, et al., 2013), adolescents have poorer rates of ART adherence and correspondingly worse clinical outcomes in terms of viral load and virological failure (Nachega, et al., 2009; Bygrave, et al., 2012; Evans, et al., 2013). One study in Uganda speculated that this may be due to psychosocial challenges such as poor social support for adherence and poor access to health facilities, particularly for boys (Bakanda, et al., 2011). Older children and adolescents may also face stigmatization from peer groups or extended family, and a desire to blend in with their HIV-negative peers may also hamper ART adherence (Campbell, et al., 2005; Lowenthal, et al., 2014). Further, "drug fatigue" resulting from long-term ART medication usage may also put the child at risk for non-adherence, particularly as they grow into adolescence (Bikaako-Kajura, et al., 2006).

However, some Ugandan studies suggest that a supportive family environment, particularly a strong and trusting relationship with parents or a primary caregiver is associated with good ART adherence amongst children and adolescents (Bikaako-Kajura, et al., 2006), but that increased secrecy about HIV status puts children at risk for non-adherence to ART treatment (Nabukeera-Barungi, et al., 2007). As good adherence to ART is also important clinically to prevent the development of drug resistance, which has already been seen in children's ART, even from the early 2000s on (Barro, et al., 2011), further research into creating supportive social

environments which will help children's ART access and adherence is warranted, to which this study will contribute.

1.5: Research questions for this PhD study

The above findings have shown how despite the numerous biomedical and clinical advances of the past 20 years, ART access remains an elusive goal for many children globally. Despite significant research and the best efforts of health service providers and users alike, real life disconnects are occurring and hamper efforts to ensure children have access to HIV testing and treatment. For HCWs, research suggests that a lack of structural support from the health system has a negative impact on their ability to provide good quality care, despite the positive personal and professional effects of ART. Adult carers face significant social challenges in terms of stigma, guilt, and mistrust, which hinder their own health service access and HIV status disclosure, as well as that of the children in their care. Children appear to face difficulties in negotiating HIV and health service access within the family unit, due to HIV-related interpersonal tensions between themselves and their carers. Examining the lived experiences of participants in this study against this research background will help to further address why children in Kabarole district face difficulties in accessing HIV testing and ART treatment.

The focus of this PhD will therefore be to examine the barriers to, and facilitators of, children's access to HIV services in the "Amooti" sub-county area of Kabarole district, Uganda. This pseudonym will be used throughout this study to protect the anonymity of participants, and is a Rutooro nickname or pet name which means "royal" or "noble" (The Kasiisi Project, 2014). Whilst the structural barriers to children's HIV care access are well-known and well-researched, as seen here, findings suggest that social and psychological and factors play an important role underlying the decision to access HIV care or not, and deserve further research and attention (Kapiriri, et al., 2003; Spaar, et al., 2010; Bakeera-Kitaka, et al., 2008; Birungi, et al., 2008). In order to focus on these factors, as will be discussed in further detail in Chapter 2, this research study will use a social psychological theoretical framework of Social Representations Theory (SRT), to investigate the social representations (SRs) of children, HIV, and health services (Moscovici,

2000), as held by the main social actors and health service users or providers in this local context, specifically, adult carers of children, children, and HCWs.

A main assumption underlying this research is that service access is mediated by the extent to which the worldviews of health service providers resonate and align with the needs and interests of health service users, namely children and their adult carers (Campbell & Cornish, 2010). A goodness of fit between the SRs of these groups would facilitate good health service usage and support, with a poor alignment facilitating poor service usage and support. As reports from Uganda at the start of this research suggested that children were not being tested for HIV due to a lack of service user uptake (Baguma, 2010), and that available pediatric ART had gone to waste due to a lack of service user demand (IRIN, 2009), examining the SRs held by these main social actors about children, HIV and health services, could help us to understand why this is the case and what can be done to facilitate better access and adherence to HIV care and ART treatment for children.

The Research Questions for this study are therefore the following:

- What are the social representations of HIV, health services and children, as held by health care workers, children's carers, and children in the Amooti sub-county area of Kabarole district, Uganda? (Discussed in Chapters 5-7.)
- What are the areas of tension or overlap in these sets of representations? (To be examined in Chapters 5-7.)
- In what ways do these representations serve to facilitate or hinder HIV service access for children? (To be explored in Chapters 5-8.)
- How can a Social Representations theoretical approach give us greater insight into why children are accessing HIV care less than adults? (To be examined in Chapters 2, 4 & 9.)
- What are the implications of these findings in relation to promoting children's HIV service access and adherence? (Discussed in Chapter 9.)

Conclusion

As explored in this chapter, despite the clinical need for ART access and adherence for HIV-positive children as seen in section 1.1, there are still practice gaps in terms

of creating supportive social contexts for their treatment and care. Upon reflection, prior research on children and HIV care in SSA, as seen in sections 1.2 to 1.4, tends to have 3 main areas of focus for the majority of research studies surveyed here. Research has been done on issues surrounding HIV service access and service provision, primarily between HCWs and adult carers of children, but also amongst adolescents. Research has also highlighted issues around HIV disclosure, particularly to younger children, in light of continuing social stigma over being HIV-positive. Finally, issues concerning access to ART, including adherence to ART within the first couple of years of initiating treatment, have seen increasing research since this PhD study began in 2010.

Based on this literature review, although there has been an increasing research focus on issues surrounding children's HIV care access and adherence in SSA, there are still areas where further research is needed. Further study on children's engagement with the health system and their perspectives on service provision and potential quality improvement, could help service providers to better understand their needs and inform system change. Continued research on SSA-based family and interpersonal dynamics related to health services use and provision, could help to inform and shape a more family-friendly HIV and health service response. Research which captures more insights into the lived experience of children and adults on ART will be vital to supporting adults and children on life-long therapy in the future, by capturing what it is like to live with HIV and ART in a resource-challenged setting. The research questions for this study, as outlined above, will attempt to address these areas throughout this thesis.

Given these future directions for children's HIV research and the research questions presented in section 1.5, this thesis will use SRT as its theoretical framework, to be discussed in Chapter 2, to map out the representations held of the day-to-day lived experiences and realities faced by key stakeholder groups, in regards to children's HIV care access and adherence. Participant data will be discussed in Chapters 5, 6, and 7, with the methods used in obtaining this data explored in Chapter 3. The historical social context of the study location is outlined in Chapter 4, with ethnographic observations considered in Chapter 8, and the ramifications of these findings considered in conclusion in Chapter 9.

Chapter 2: Theoretical research perspectives on children & HIV

Introduction

As theory is a tool chosen to support, focus and orient research (Graue & Walsh, 1998), the role played by theory in research needs to be considered as well. As will be explored in this chapter, current theoretical perspectives in use in research may not be capturing the whole story of children and HIV/AIDS, and so miss key elements which could better facilitate the social changes needed to support and increase children's HIV treatment access and adherence around the world. This chapter will explore these shortcomings and advocate for the use of an alternative theoretical paradigm for children's HIV research, that of Social Representations Theory (SRT), which allows for alternate voices to be heard and findings to emerge.

In choosing which theoretical framework to use for this PhD research, several disciplines were considered as possible conceptual options to guide the research process. Although I have a biomedical background and my previous research on children and HIV was situated in this perspective, I wanted to work from an alternative theoretical framework for this research, as I felt that the biomedical perspective did not have sufficient theoretical rigour to frame and explore the deeper social and psychological issues and concerns which may impact on people's health choices. Whilst the Social Determinants of Health framework (Labonte & Schrecker, 2007) developed for population health studies is a notable theoretical advancement in the field, it focuses mainly on social factors, and does not fully consider how personal or psychological aspects of the individual may impact on the health choices they make for themselves and their family, which was what I wanted to explore in this study.

Anthropology, particularly medical anthropology, was also considered as a theoretical discipline from which to work, as it focuses on exploring the symbolism and cultural meanings of health and illness within a society, as seen in social practices related to health and illness (McElroy, 1996). It has a sound theoretical tradition and uses a social constructivist position to explore issues related to the

construction and function of cultural and social processes (Berger & Luckman, 1966). However, its overall focus is again more on the societal level and not on the individual level, whereas I wanted to explore how the psychology of individuals impacts on their interactions with society at the health system point of contact, so that findings on HIV service provision for children could be related to future clinical service applications, to support increased HIV service usage for children.

The use of a sociology-oriented framework was also considered but rejected, as sociology explores the broader social processes and organizational factors in a society using a more top-down approach, where the impact of social structures on the individual is the focus of research (British Sociological Association, no date). Again, I wanted to use a theoretical framework that examines the interplay between the individual and society on a more equal footing, to see if one can influence the other, and whether this is a dynamic or a static and unidirectional process, as such findings could suggest how children and families could be better supported to use HIV services in their community.

After much consideration, it became clear to me that social psychology was the theoretical perspective which best fit with the overall goals of my research, namely, to explore the interplay of internal personal and psychological factors with external social factors and choices, in order to better understand how individuals make and mediate health choices related to children's HIV service uptake. Recognizing from my previous research experience that there were two components, namely the individual and society, which appeared to interact and influence each other, I realized that social psychology offered the theoretical perspective which would best capture both these aspects, and allow me to explore how the individual was situated in society, and how individuals and the society in which they live impact on and influence each other. As HIV is a personal disease with significant social components and impacts, exploring both the personal and social sides of this illness is key to gaining a better understanding of the barriers faced by children in accessing the HIV services available in this community.

2.1: Current social psychology perspectives underlying research
Within the discipline of social psychology, however, there are differing frameworks

from which research can be conducted, in terms of the conceptualization of how individuals and society interact. Differing schools of thought within the discipline have emerged over time, and have split along two orientations or lines of thought: a more Behaviourist and Social Cognition-oriented framework most frequently found in the American social psychology tradition, and a more Social Constructivist-oriented framework found in European social psychology (Moscovici, 2008; Markus & Plaut, 2001). Although both schools explore the interactions between the individual and society, their underlying assumptions about those interactions differ and have a major impact on how their research is framed and conducted. This translates into different research orientations, processes, and even findings, as will be explored in this section.

2.1.1: Social psychology perspectives and research on HIV/AIDS

Regarding research into HIV/AIDS, the American Behaviourist and Social Cognition-influenced school has been frequently used as an adjunct to biomedical research studies. Theoretical models such as the Health Belief Model (HBM) and the Theory of Reasoned Action/Theory of Planned Behaviour (TRA/TPB) reflect these Behaviourist and Social Cognition traditions by focusing on individual volition as the main factor influencing health choices, assuming the individual has the ability and opportunity to fully act on their wishes in regards to health behaviour choices (Abraham, et al., 1998; Trafimow, 2009). However, critics argue that for HIV, such models are inappropriate to use, as they do not capture social context, which can impact on health decisions by limiting behaviour choices, such as in circumstances where people may be unable to choose their behaviours freely or are forced into behaviours which they would not choose of their own volition (Launiala, 2009). Issues of reliability and efficacy have emerged, and critics question the ability of these models to predict or modify health behaviours (Joffe, 1996; Launiala, 2009; Ogden, 2003; Parkhurst, 2012). Despite these critiques, these models are still used in many research studies, the implications of which are discussed below.

2.1.2: Exploring the HBM, TRA & TPB theoretical models

The origins of these theories lie in the development of the Health Belief Model (HBM) in the United States during the 1950s (Glanz, et al., 2008; Smith & Stasson, 2000). HBM developed out of public health research which sought to explain why

people do not use health programmes, particularly for disease prevention (Glanz, et al., 2008). Its key underlying concept is that if people believe they are susceptible to a disease with serious health consequences (perceived susceptibility and severity), and believe that potential action to mitigate this health threat are beneficial and outweigh the barriers to undertaking this action (perceived benefits and barriers), then they will choose to engage in this course of action (Glanz, et al., 2008; Smith & Stasson, 2000). Its conceptual roots lie in American Social Psychology, in particular Stimulus-Response Theory (Waston, 1925, in Glanz, et al., 2008), Cognitive Theory (Lewin, 1952), and later Social Cognitive Theory (Bandura, 1977), which attempts to directly link mental or cognition processes with resulting behavioural outcomes by linking attitudes, beliefs, behaviours and practices (Glanz, et al., 2008; Launiala, 2009). Over time, the role of health knowledge was added, with an assumed linearity that, if people have health knowledge, this will engender healthy attitudes and beliefs, which will result in them choosing healthy behaviours and practices, with survey methods including "KAP surveys" and scales developed as research methods for this theoretical outlook (Joffe, 1996; Launiala, 2009; Glanz, et al., 2008).

HBM has slowly been replaced by the TRA conceptual model (Glanz, et al., 2008), which was developed out of work by Fishbein and Ajzen (1975) and attempts to more explicitly link the attitudes, beliefs, and subjective social norms held by the person to the likelihood of enacting a certain behavior, typically a health-promoting one (Glanz, et al., 2008; Smith & Stasson, 2000). The goal of TRA is for researchers and health practitioners to be able to both explain and "predict" the health behaviours of individuals, and to then be able to influence them to enact health-enabling behaviours when they are presented with a range of behavior choices, some healthy, others not (Ajzen, 1991). Health education campaigns are a key component of this attempt to influence individual health behavior in wider society (Smith & Stasson, 2000). Building on the linearity of the HBM, TRA also implies a causal relationship between its components, with an assumed linear progression which suggests that if people are educated or provided with health information about a healthy behavior, it will sway their attitudes and beliefs in favour of that behavior, predisposing them to choose to act in a rational, logical, health-

promoting or health-enabling way (Ajzen, 1991; Ajzen & Fishbein, 2003). This major assumption of the model is illustrated below in Figure 2.1.

Figure 2.1: Assumed Linear Causality of HBM & TRA-TPB
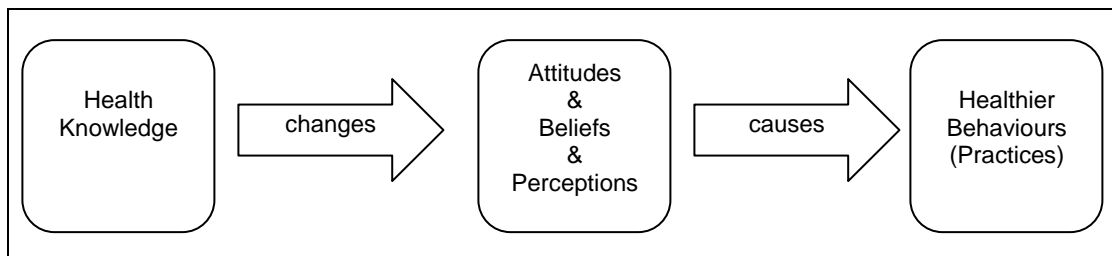
Researchers using TRA operate under the assumption that individuals have perfect control over their environment, and that they are able to make choices independently from their social context and environment. This led to early criticisms about the model, regarding health choice situations where the individual may not be able to exercise personal, volitional control, which were ostensibly addressed by the authors (Ajzen, 1991; Smith & Stasson, 2000) and led to the revision of TRA into the Theory of Planned Behaviour (TPB). This added in the concept of "perceived behavioural control," where the individual's "perceptions" of being able to enact the health promoting behavior is also assessed (Glanz, et al., 2008; Smith & Stasson, 2000), although criticisms of the feasibility and applicability of this model within a wider social contextual setting remain (Launiala, 2009; Ogden, 2003).

To date, however, TRA-TPB remains a predominant theoretical model underlying much HIV research, and is often used with quantitative surveying methods involving 5- or 7-point scale questionnaires, or elicitation interviews (Glanz, et al., 2008). This occurs despite significant criticisms having been raised as to the validity, applicability, and relevance, not just in the health promotion field, but particularly in regards to HIV/AIDS research, which will now be examined below.

2.1.3: Problematizing these theories in regards to HIV research
There are several major problems in regards to the use of the TRA-TPB theoretical model in HIV/AIDS research, particularly in sub-Saharan Africa (SSA), which has ultimately lead to its rejection as a theoretical model for this research study.

The first problem is that there are inherent conceptual flaws in the model, due in part to nature of the ideological assumption behind it, that knowledge precedes attitudes and beliefs, which precede behaviours in a neat, linear fashion as illustrated in Figure 2.1 (Launiala, 2009). It assumes a direct linear progression between attitudes and beliefs and resulting actions undertaken by the individual. This linearity has even been recognized by the theorists themselves as being problematic, in that the theoretical model fails to adequately predict or explain many findings, often to the bafflement of researchers using it (Ajzen, 1977; Ajzen & Fishbein, 2003). This is often seen in a related methodological and statistical concern which arises from meta-analyses and systematic reviews of TRA-TPB, in regards to the measurement of the Crohnbach's alpha, with variances seen from .53 and .62 in Sheppard et al. (1988), to .66 and .68 in van den Putte's (1991) review (cited in Albarracin, et al., 2001). Crohnbach's alpha is a statistical measure of internal consistency and reliability commonly reported in psychometric testing and quantitative research (George & Mallery, 2003; Kline, 2000). The preferred score range is typically held to be .70 or higher, suggesting that the test and the constructs measured have high consistency and reliability across settings, but this threshold is not seen in the systematic reviews of TRA-TPB (Albarracin, et al., 2001). Insignificant p-values are also often reported in the statistical data, which may be linked to poor or low internal consistency and reliability, or may be reflective of low statistical power (George & Mallery, 2003; Kline, 2000; Jemmott, 2012). Such inconsistencies suggest the theoretical model may not be capturing relevant information to account for the results, and many studies point this out quite openly in their findings sections (Smith & Stasson, 2000; Munoz-Silva, et al., 2007; Abamecha, et al., 2013).

This second problem, that TRA-TPB does not account for the complexities in real-life human interactions between people outside of a laboratory or experimental context or setting, has been widely criticized both by researchers who do and do not use this model (Joffe, 1996; Launiala, 2009; Gillespie, 1997; Vissman, et al., 2011). This criticism is particularly strong for HIV/AIDS research and interactions related to sexual behavior, where the intimate and interpersonal nature of such actions is not well captured by the model. TRA-TPB appears to work moderately well for health behaviours for which there is a high level of individual control over the behaviour,

such as dieting or quitting smoking, but less well for health behaviours which are jointly negotiated between people, such as occurs in sexual situations (Michielsen, et al., 2012; Kashima, et al., 1993). The socialized, interpersonal context is not adequately captured or explained by this model, nor does it reflect the often illogical, arbitrary, and "messy" nature of human relationships (Kashima, et al., 1993; Vissman, et al., 2011; Abamecha, et al., 2013). Many studies also note that their findings do not actually directly translate into actual behaviours or behavior changes, which is also concerning (Michielsen, et al., 2012; Kashima, et al., 1993; Munoz-Silva, et al., 2007).

Finally, a significant flaw in relation to this research, is that TRA-TPB model also does not account for the impact of social contexts and constraints, including power differentials, in individuals negotiating complex social behaviours in a wider society (Kashima, et al., 1993; Gillespie, 1997; Munoz-Silva, et al., 2007). The model explores past and present attitudes and behaviours, and attempts to link these to future actions, but does not account for the social context or setting. In this regard, social context needs to be examined to determine who has power and influence, and how it is manifested both in regards to personal choice and health decision-making, and in greater society, in the case of overall health system access and usage (Fisher, et al., 1995; Kashima, et al., 1993; Abamecha, et al., 2013). If social context can hinder or promote positive health behavior, the role of social change to support a health-enabling context should also be considered, which is not a part of this theory. Power and social constraints can be seen in sociocultural aspects of society, such as gender roles or norms, and cultural practices, which are also not addressed in this model but which can play a significant role in shaping and influencing HIV health behavior choices (Vissman, et al., 2011; Munoz-Silva, et al., 2007; Gillespie, 1997). Additionally, for HIV research, the impact of emotions, such as social stigma and feelings of shame and guilt over one's HIV status, continue to play a role in health behavior choices and are also not well captured by the cognitive focus of this model (Vissman, et al., 2011; Michielsen, et al., 2012).

2.1.4: Relevance for children's HIV access & adherence
An additional concern in relation to the focus of this study, specifically children's HIV care access and adherence, is that most TRA-TPB studies concerning HIV/AIDS

are adult-focused and linked to adult behaviours, with condom usage intent being well-studied using this theoretical perspective (Kashima, et al., 1993; Albarracin, et al., 2001; Munoz-Silva, et al., 2007). Resulting from a Scopus search in March 2014, only three studies have used this theory in researching children and HIV, two discussing HIV disclosure between HIV-positive youth and caregivers (Noroski, et al., 2010; Jemmott, et al., 2013), and one studying antenatal HIV testing (Mirkuzie, et al., 2011), all of which feature adult participants. There have also been no studies to date using TRA-TPB to examine children's HIV care access & adherence.

However, given its individualistic focus as seen above, the TRA-TPB model does not appear well-suited to the examination of external social dynamics or internal family dynamics, which would be highly relevant for studying children's HIV service access. Therefore, this study requires a theoretical model better-suited to capturing the interpersonal, social complexity of families and societies as well as individual behaviours within these contexts. As will be seen below, SRT holds at its theoretical core a social constructivist perspective, which underscores how SRs are used by individuals to "make sense" of and give meaning to their lived experiences, with SRs mediating the impacts of social contexts, social behaviours, and social identities through the meanings ascribed to them by the individual or group (Campbell, 2003; Jovchelovitch, 2007).

2.2: SRT as the better theoretical paradigm for this study
As discussed in section 2.1, in conducting research on HIV, there is a need to move beyond studying the knowledge, attitudes/beliefs, and actions of individuals, to examining the broader social contexts in which social behaviours and interactions occur, how social settings impact on the choices available and the corresponding decisions taken by the individual, and how the individual makes sense of it all for his or her life. If the social environment hinders healthy behaviours, then the need for and role of social change should also be considered. For children and HIV, interpersonal dynamics play a key role, as health care access is negotiated within and across social settings, namely the family setting and the broader social setting of the clinic. One starting point is to explore how the socially constructed ideas about children and HIV, situated within a broader sociocultural space, and internalized or rejected by individuals, impact on decisions to access HIV services

or not. This can be seen by examining the SRs used within a society, considering the impact they have on social identities, and exploring the broader social contexts of the society in which they are situated (Belton, 2011). As SRT allows for the exploration of these three factors, it will be the underlying theoretical paradigm used for this thesis.

2.2.1: SRT as the theoretical paradigm for this study
SRT was developed by Serge Moscovici in France, and introduced in his 1961 book, "Psychoanalysis: Its image and its public" (Moscovici, 2008). Drawing inspiration from the work of Durkheim, Moscovici sought to examine how knowledge of a specific new phenomenon, in his case psychoanalysis, was being developed and used across French society in the late 1950s (ibid). Although having its conceptual roots in Europe, psychoanalysis was seen at the time as being an imported American phenomenon, and was derided in the French press and by the public as being a foreign imposition on the French way of life and a social threat; Moscovici sought to understand how this reaction happened and why this was the case (ibid). His study led him to question how common sense knowledge was produced in and used by society, and what purpose was served by its generation and use.

Whilst it was Durkheim who originally coined the term "social representation," to reflect how "the social has primacy over the individual" in influencing thoughts, images, and the actions resulting from them, it was Moscovici's work which led to the development of a school of social psychological study which is most closely linked to this concept (Moscovici, 2008, p. xxix). SRT holds as its central tenet, that a social thought or henceforth representation (SR), is essentially a "modality of knowledge, and its function is to shape inter-individual behaviours and communication" (ibid, p. xxx).

Moscovici (1973, in Duveen & Lloyd, 1990), further defines and delineates SRs as:

> "systems of values, ideas and practices with a two-fold function; first, to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social

exchange and for naming and classifying the various aspects of their world and their individual and group history" (p. xiii).

Here, SRs form a symbolic field in which actions, or in this study, the possibility of children accessing HIV services, are negotiated and implemented. In SRT, knowledge is socially mediated, dynamic, and fluid, and is constantly being created and re-created, interpreted and re-interpreted, by the members of a society, to suit their changing circumstances, needs, and contexts (Moscovici, 2000). SRs may be shared across different social groups within a society, or they may also develop and use different SRs at the same time, particularly as a new phenomenon, or knowledge, presents itself into their world (ibid). How such knowledge is dealt with by a society, and how the society, particularly its constituent groups, shapes out a unifying social representation or doesn't, is the main interest of SRT research (ibid). As "systems of values, ideas and practices," SRs can facilitate or hinder social connections across and within social groups (Moscovici, 1973, in Duveen & Lloyd, 1990). As such, their study can reveal much about a society's inner workings and spaces for individual actions, making them well suited to studying a nuanced illness such as HIV/AIDS.

In contrast to TRA-TPB as seen in section 2.1, SRT research actually suggests there is a disconnect between knowledge, attitudes and practices, and reflects the observation that many people "are influenced mainly by their situation" and by the meanings they construct for it, which has repercussions for health services research and interventions (Moscovici, 2008, p. 123). From an SRT theoretical standpoint, there is therefore no link between knowledge, attitudes, and practices, in terms of a linear progression towards health behavior choices (Moscovici, 2008; Joffe, 1996; Launiala, 2009). Further, attitudes are typically seen as being fixed, internalized and personalized, and independent of social context (Laljee, et al., 1984), but dependent on broader underlying SRs for their formation, as attitudes depend on SRs for their formation, but SRs are maintained independently of personal attitudes (Tafani, cited in Abric in Deaux & Philogene, 2001). This is because SRs are social constructions collectively constructed by members of a social group, as they engage with their daily life challenges within specific social settings (Jovchelovitch, 2007). To differentiate further, whilst SRs permeate through all parts of society from the outset, SRT posits that individual knowledge, attitudes and practices are later

selectively grafted onto pre-existing SRs, to make everything fit the greater context of the individual's life in society. Therefore, uncovering the fundamental SRs used by individuals and groups within their social context, is the key to uncovering how people are positioned and able to operate within a society, and allows for a more nuanced understanding of how individual and group health choices and behaviours are made within a social context.

2.2.2: SRT & the role of social identity within this study

In using SRT in this thesis, 3 theoretical aspects will be considered in concert with each other. First, the content and function of SRs in this social setting will be explored, as discussed above. Second, the role and function of social identity must also be considered, to the extent that it shapes and is shaped by the SRs in a society (Howarth, 2002a). And third, the role of the broader social context, against which SRs and social identity act and interact (Campbell, 2003), must be considered in building up a picture of how children's access and adherence to HIV care can be improved. In this study, therefore, as seen in the research questions in Chapter 1, SRT, social identity & social context will be jointly used to determine: how the SRs held by stakeholder groups frame the likelihood of children's HIV service access, how the SRs may be linked to the social identities of the stakeholder groups, and what role underlying social contexts may have in shaping behavior choices within this community at large. It is hoped that by studying these components under an SRT theoretical paradigm, that the current lived realities of children and their caregivers in regards to HIV care will emerge, and that factors which hinder or facilitate increased HIV care access and adherence will also be exposed. The data chapters of this thesis, Chapters 5-8, will contain detailed findings and analysis. The potential for social change and community needs in negotiating these changes to improve children's access and adherence will then be considered in Chapter 9.

Although Social Identity Theory (SIT), developed by Henri Tajfel, is itself a distinct theory from SRT, there are some areas where concepts of identity overlap (Abrams & Hogg, 1990). According to Tajfel (1981), an individual's social identity consists of the knowledge that one belongs to a particular social group, and the associated emotions, values, and practices which go along with that knowledge. In terms of

SRT, the concept of identity is seen as being as much about being identified by others, as making self-identifications of yourself by yourself (Duveen in Deaux & Philogene, 2001). Identity is seen as a function of the social existence, a self-representation constructed both from external influences, and internal actions and reactions by the individual or group, in order to develop as a social actor within the larger social context, and is in effect, a way of "making sense" of the world and your place in it (ibid). In this regard, there is a congruence between the SRT view of identity and that of Tajfel's SIT, in that identity is developed through comparison with others by identifying with a group and valuing membership in that group (Abrams & Hogg, 1990). In this regard, social identity and the need for positive group identity and membership may influence and shape health related behaviours, as will be explored in Chapters 5 & 6, in the data findings from health care workers (HCWs) and adult carers of children.

This also concurs with Self-Categorization Theory, developed by Turner but based on Tajfel's later work, where people seek to shape themselves into the norms and forms of the social category in which they have situated themselves, and in so doing, attempt to create a positive identity for themselves and their group (Abrams & Hogg, 1990; Turner, 1987). In this sense, SRs may be used as a sort of scaffold, against which identity is constructed or reconstructed, and reproduced or transformed in the process. If the SRs and corresponding social identities are positive and affirmative, group members may choose to uphold and reproduce them, however if they are negative, social competition and insecurities between groups may lead to social tensions and result in a need to transform and recreate both the SRs and the social identities in use in that society (Reicher in Turner, 1987; Howarth, 2002b). The capacity to do this, however, may be negated by asymmetrical power relationships within a society (Duveen in Deaux & Philogene, 2001), which can result in a lack of choice for component groups negotiating social change. However, open dialogue and the use of community spaces can assist in challenging and changing these identities (Campbell & Jovchelovitch, 2000). Chapter 8 will use a clinical ethnography to explore the main social setting and space for HIV in this community, which is the local government-run health clinic.

In considering the role of social identity and SRs on how social groups interact with health care further, there are 3 main stakeholder groups which will be participating in this research, namely HCWs, adult carers of children, and children themselves. Although more detailed discussions of the impacts of SRs, social identity and social context will occur in the relevant data chapters (Chapters 5-7), as well as in the historical social context chapter (Chapter 4), a brief overview of current SRT-based theoretical research on identity issues for these groups will be presented here as an introduction.

In terms of social identity for HCWs, the professional identity of being a health care worker is highly relevant to how they provide health care services to clients (Campbell et al., 2011a). HCWs have both a personal and professional interest, and so both a self- and a social interest, in being seen as safe, competent, and ethical health care providers, as this constitutes being a "good" health care provider to them (ibid). Potential threats to this identity, which may come from difficult external practice realities, or internal emotional reactions to these challenges, such as burnout, can be damaging and impact negatively on social identity, and have a negative impact on care provision resulting in poor quality services (Horwood, et al., 2010; Harrowing & Mill, 2009). As will be seen in Chapters 4, 5 & 8, a protective factor which has helped to strengthen a positive social identity has been the positive SRs connected to the advent of antiretroviral treatment (ART) in their practice setting. The connections between these SRs and the social identity of HCWs will be explored in Chapter 5.

For children's adult carers, their social identities as people who look after children are influenced by wanting to see themselves and be seen by others as being a "good" carer to their child or children, by providing for the child's needs and keeping them safe (Kitzinger in Markova & Farr, 1995; Campbell, et al., 2005). The impact of HIV on that identity will be particularly important to consider, not only in terms of carers seeking to avoid social stigma, but also in terms of the effects of personal shame, distress and possible guilt over the child being HIV positive (Harrowing & Mill, 2009; Campbell, et al., 2005). As the majority of HIV positive children acquire the infection through birth, women's identities may be particularly affected (ibid), the implications of which will be explored in Chapters 6 & 8, by examining the SRs

generated by participating carers and their implications for women within the social context of the community (Chapter 6) and the social setting of the clinic practice environment (Chapter 8).

Children, as will be discussed further in section 2.3, occupy a unique social position, in that their identities are formed through their experiences of childhood (James, et al., 1998). In this regard, one must consider not only the child's own perspective of his or her identity, but also the wider social identities and perceptions of children as constructed by adults, who influence these through holding the more dominant social positions in society (D'Alessio, 1990). This presents a research challenge, as it is often the adults in children's lives which influence and structure the creation of their identity, through socialization processes such as formal schooling (Corsaro, 1990). Although many theorists consider childhood itself to be a social construction, influenced by particular cultures and contexts, even from this theoretical perspective, children can still be seen as "social actors shaping as well as shaped by their circumstances" (James, et al, 1998). For SRT, Duveen & Lloyd (1990) posit that children access and engage with the SRs of their community through the socialization process, via the ontogenesis and microgenesis of SRs as further discussed below. This will be explored primarily through the data findings in Chapter 7, as well as through an examination of the wider social and cultural roles of children in this community and in Uganda generally (see also Cheney, 2007).

2.2.3: SRT & the role of social context within this study
The broader role of social context is also important to consider in connection with SRs and social identities, in mapping out influences on children's HIV care access and adherence. For the purposes of this research, social context is best conceptualized as having three components: the immediate and day-to-day social conditions as seen in Duveen & Lloyd (1990), local social spaces which are both physical and symbolic for community residents (Campbell, 2003; Jovchelovitch, 2007), and the intersection between global and local social contexts, which is often one of conflict and contradictions (Moscovici, 2008; Campbell & Cornish, 2010).

The role of social context in terms of "place," where the day-to-day social conditions and interactions of community members are reflected by the SRs and social

identities in use, was developed by Duveen & Lloyd (1990) and is explored in this thesis in Chapters 4-8. Here, day-to-day social conditions, perspectives, and contexts in which SRs are used, transmitted, or transformed act as the social context of their research, which outlines three aspects of how social place or placement impacts on SRs, via sociogenesis, ontogenesis, and microgenesis. Sociogenesis refers to the social conditions at the time which produced the SRs (ibid), and is seen in this thesis in Chapter 4 through an examination of the social history and SRs in use in the local area. Ontogenesis reflects the use of the SRs in the socialization process through either imperative or contractual obligation of a society's members (ibid), as will be explored in Chapters 5-7, through the SRs directly generated by participant data. Finally, microgenesis refers to the day-to-day use and constant change of the SRs through interpersonal social interactions and conventions (ibid), which will be seen in Chapter 8 which uses ethnographic research to explore the day-to-day clinic setting.

Moving to consider the physical and symbolic spaces in a community, the works of Campbell (2003) and Jovchelovitch (2007) reflect on SRs as they are constructed within community contexts, which are always situated in a particular space, time, and cultural orientation. Researchers need to consider these particular contexts and how they resonate with local residents when conducting research, to better understand the social entities where SRs are generated and used, particularly if working on community-based interventions (ibid). In this thesis, the historical social context of this community, in effect its historical "space," situated in a broader Ugandan historical context, will be considered in Chapter 4. Also, as will be seen in Chapter 8, examining the local health clinic through a focused ethnography will help to provide an immediate social context for the SRs and social identities in use in Chapters 5-7, as the clinic will be evaluated as a space which either hinders or promotes health and HIV service usage by community members (ibid). This will help to contrast the daily practices of the clinic against the SRs of health services discussed by participants in Chapters 5-7, and to speculate on the potential for change and improvement within the health system and community, as will be discussed in Chapter 9.

A final theoretical consideration relevant to this study is the impact of the intersection between global and local social contexts, and the resulting tensions or conflict which may occur. In SRT, this has been seen as far back as Moscovici's original study (2008), where the social context at the time was that of a society in transition: France after World War II was very much creating and re-creating itself, and was opening up to a new variety of influences on its culture and social structure, as well as trying to salvage parts of its past from before the war. As will be discussed in Chapter 4, a similarly fluid social context exists in Uganda, where decades of civil war and social anarchy were compounded by the appearance of HIV/AIDS and an attempt to rebuild and stabilize society (Barnett & Whiteside, 2006), which both disrupted and reinforced aspects of local culture and social structures. Work by Campbell & Cornish (2010), Skovdal, et al., (2011a), and Campbell, et al. (2012a) further conceptualizes three sets of social-contextual factors which impact on how people access health services. The material context, refers to available resources, such as transport or money; the institutional context, which refers not only to health service availability and efficiency, but also to the wider social hierarchies and structures which can impact on people's social positioning and lives; and the symbolic context, which examines the extent to which health services are offered in ways that resonate with the perceived needs and interests of service users or not (Campbell & Cornish, 2010). These contextual factors will be considered against the data findings in Chapters 5-8, and will also be reviewed in Chapter 9, in terms of a consideration of what broader social changes may be needed, to improve children's HIV care access and adherence.

2.2.4: SRT research on health services & HIV/AIDS relevant to this study
As discussed above, SRT is a useful lens with which to examine how societies interact with knowledge, and each other, within local and global contexts (Moscovici, 2000; Jovchelovitch, 2007). In addition, there has been much useful research conducted on HIV/AIDS and health services. Even the theory's founder has reflected on how SRT can be used to better understand the social impacts of HIV/AIDS infection on a society (Moscovici & Markova, 1998). Using SRT, this study will examine how the SRs held by key social actors of health services, HIV, and children in western Uganda, impact on children's HIV service access and use. A brief overview of key SRT research into health services and HIV/AIDS will be

discussed here as relevant to the data findings and analysis which will be further explored in depth in Chapters 4-8.

The first SRT research to examine the role SRs play in concepts of health and illness, was done by Jodelet, whose seminal work focused on the SRs of mental illness in France (in Farr & Moscovici, 1984). Here, using an SRT approach revealed a disconnect between the positive SRs generated by villagers about the mentally ill, and the negative and stigmatizing actions carried out towards them in the research setting (ibid). In this study, contrasting the SRs generated by participants in Chapters 5-7 with their actual practices in Chapter 8, reveals both disconnects and congruence between the SRs expressed and the health behaviours performed.

Divergence between SRs and health behaviours performed is also seen in the work of Wagner, et al. (2000), who explored the impact of the wider social context on SRs of mental illness in India, where "traditional" SRs are challenged by new ones, as a result of modernizing social processes or globalization. In this study, a change in SRs is seen in Chapter 5, in regards to HCW perspectives and SRs on the changing nature of HIV care and ART treatment. Also, Chapter 4 provides a historical perspective on the SRs used locally, particularly in regards to perspectives on children which are being challenged by modern schooling practices. Adult carers in Chapter 6 comment on this phenomenon, reflecting how multiple competing SRs are possible within a social group (ibid).

Such competition between multiple SRs was also the focus on work by Gervais & Jovchelovitch (1998), who found that individuals often have to negotiate between highly divergent, competing SRs, such as in choosing between alternate cultural systems of medical treatment available. This is discussed in Chapter 4, with a review of local and Ugandan medical history and development in the area, as well as in Chapters 5-7, where participants discuss their health system options for care, none of which fully resonate with them in terms of quality of service provision.

Turning to SRT research involving health service providers, they too are often facing similar difficult situations and representational choices, as they are often

caught "between worlds", specifically the worlds of professional best practice and the very different lived realities experienced by their patients (Flick, et al., 2002). The SRs held by HCWs were found to be influenced by regulatory frameworks and profession-specific definitions and concepts, which had no resonance with health service users (Flick, 2000; Flick, et al, 2002). In the context of this thesis, Chapter 4 explores the historical social context of HIV for HCWs, who face different challenges and burdens of care than health service users, related to their position as service providers. Chapters 5 & 8 here turn attention to the SRs and social identity used by HCWs, in contrast with their social context practice realities in the clinical setting, and find there to be a gap between them. This can also be seen in findings from Campbell, et al. (2011b), regarding the motivations and frustrations of HCWs providing HIV care in Zimbabwe and the resulting negative impacts on the care setting.

Concerning SRT and research on HIV/AIDS, the seminal work is that of Joffe (1993, 1996), who not only examined the SRs of HIV/AIDS as it was becoming a globally-known disease, but who also examined it in a cultural context that included a SSA country, namely South Africa. The SRs of HIV at that time were often centered on shame, guilt, fear, social deviance and carelessness, and served to further stigmatize those who were HIV positive (Joffe, 1999). As will be seen in Chapters 4-8, those initial SRs remain and still have major impact on the health behaviours of the participants in this study. Joffe's (1999) later work on HIV focused on individual risk perceptions of HIV infection, and surmised that these SRs of HIV risk were influenced by the extent to which HIV infection is represented as something that happens to particular "others", such as minority social groups within a society. In an interesting divergence from Joffe's findings, as will be discussed in Chapter 7, child participants in this study now felt that HIV infection was inevitable and to be expected in their society.

Children's SRs of HIV in the study also continue to reflect the findings of Kitzinger (1995), whose work on media images of HIV in the late 1980s suggested that the SRs which had the most impact and so were retained most strongly in people's minds, were the images of extreme illness, suffering, physical wasting and potential death. These images were very prominent in the children's draw-and-write

exercises, as will be discussed in more detail in Chapter 7. As also discussed by Kitzinger (1995), the SRs of adults being infected with HIV as a sort of punishment or suffering for past immoralities was also seen in Chapters 5 & 6, where participants continued to hold SRs that contrasted HIV-positive adults' guilt with HIV-positive children as innocent victims suffering "for the sins of their fathers or mothers" (ibid, p. 52).

The continuing challenge of HIV stigma in seen in the SRs used by parents in South Africa about their children (Campbell, et al., 2005), and between children in Zimbabwe (Campbell, et al., 2014, 2010), and are particularly salient to the SRs and findings discussed in Chapters 5-7. The role social spaces play in the perpetuation of HIV stigma, as explored by Campbell, et al. (2011c) will also be considered in Chapter 8, which explores the social setting of the local health clinic in this community.

SRT research on HIV and health service access and usage has been undertaken by researchers such as Joffe (1996), and Campbell, et al. (2011a), in terms of examining how health care interventions and programme design may in fact, also act as a barrier to access and use of HIV and health services in SSA. Critiquing the use of HBM and TRA-TPB in HIV research in SSA as discussed in section 2.1, Joffe & Bettega (2003) instead advocate for a SRT approach to conducting research, as it focuses on and captures locally-held conceptualizations of HIV and health better than TRA-TPB theoretical interventions and research. Building further on the role of health systems as barriers to care, Campbell, et al. (2011a) explore the role of a "good hospital" in facilitating good quality care as highly relevant to health users, which correlates here with findings in Chapters 6 & 8.

Campbell has also done extensive research on health-enabling and limiting community environments in relation to HIV treatment support and adherence in SSA, in particular South Africa (2003; Campbell, et al., 2007), and Zimbabwe (Campbell, et al., 2012a, 2013a, 2013b), which will be considered in the discussion of study findings in Chapter 9. The building of HIV-supportive community contexts and social environments is also seen by Skovdal & Daniel (2012) as essential to the uptake of pediatric HIV services across SSA contexts. Building orphan competent

community contexts to support children who are HIV orphans or adversely affected by HIV has been studied by Skovdal & Campbell (2010), and additional structural supports such as cash transfers to such communities have been explored by Skovdal, et al. (2010). Such contexts are relevant to findings in Chapters 5-7, as the SRs held by HCWs, adult carers, and children reflect the impact of both community and structural support in improving HIV care access and adherence for children.

And finally, the broader community social contexts impacting on access and adherence at the family and individual levels has been extensively researched in Zimbabwe by Skovdal, et al., in regards to their impact on gendered family and social roles (2011b), and intergenerational family dynamics and HIV care (2011a). Recognizing that wider sociocultural norms and internal family dynamics influence children's and caregivers' HIV care access and adherence, these studies are relevant for Chapters 6 & 7, which examine the SRs, identities, and social contexts of adult carers and children.

2.3: Theoretical research perspectives underlying work with children

As discussed in section 2.2.2, children are a population with a unique but also potentially disadvantaged position in society, in that they are actively developing their own social identity through the socialization process, in contrast to adults, who have already passed through this process and occupy a more privileged social position as a result (James, et al., 1998). In contrast to adults, less research is done with children, often due to adult ethical concerns or social constraints limiting research on childhood and children (Graue & Walsh, 1998). However, child health, in particular health issues related to children and HIV/AIDS, is a growing field not only for applied research as noted in Chapter 1, but also for theoretical perspectives and thought (Grieg & Taylor, 1999). As children are key participants in this research study, which focuses on their access and adherence to HIV services in the community, there is a need to review relevant theoretical views on children and childhood to inform and situate this research further.

2.3.1: Historical theoretical perspectives on children & childhood

The modern study of childhood as a phenomenon is often traced back to Aries (1962), who conducted an "archaeology of childhood" leading to the theoretical

assertion that it is not fixed, but a dynamic state with significant cultural and symbolic changes across time, place and context (in James, et al., 1998, p. 4). Such theoretical constructions of childhood and children in the past have included that of children being "Dionysian"- evil and needing to be controlled and socialized; "Apollonian" children who are innocent and not responsible for their actions, and who are later seen as the idealized, "immanent child" of Rousseau and Locke; and the "naturally developing" child of developmental psychology of the early 20th century (Jenks, 2005, p. 62-70; James, et al., 1998). It is important to note that these conceptualizations and theoretical perspectives are Western-oriented in their positioning of the child in society. However, as will be seen in Chapters 4-7, although the study setting is a culture previously colonized by a Western power, some of the historical and current SRs held in regards to children in this reflect both "Western" and indigenous power dynamics and perceptions of children, particularly those of children needing to be controlled by adults, and of children being "innocent," in regards to HIV infection (Taylor, 1998; Kyaddondo, et al., 2013).

In terms of psychology, theorists historically working in the area of child development, in particular Piaget and his stages of child cognitive development, have been derided by modern sociocultural theorists as being overly reductionist in their concepts of childhood and children (see James, et al., 1998; Graue & Walsh, 1998). This criticism can be largely justified for historical theorists such as Freud, Pavlov, and even Erickson, whose work is still taught in developmental psychology, and their findings are not relevant to the theoretical perspective taken by this thesis (Grieg & Taylor, 1999; James & James, 2004). Piaget's work, however, did advance the concept of children learning by "schemas" and that knowledge develops through the assimilation and accommodation of these schemas into a world view, which is both relevant and complementary to the SRT theoretical perspective taken in this study, in that SRs are seen as being socially created and malleable to facilitate orientation within a social world and communication within a society (Jenks, 2005; Moscovici in Duveen & Lloyd, 1990).

Another child psychology researcher who has been far less divisive to modern social psychologists, in terms of his theoretical contributions is Vygotsky, whose "Sociocultural Theory" focuses on the dynamic interactions between individuals and

society, including the active engagement and participation of children in their own socialization (1978, in James, et al., 1998). A contemporary of Piaget but working in the Soviet Union in the 1930s, his research only became available on publication in the West in the 1970s (Grieg & Taylor, 1999), but continues to resonate with psychologists to date. His work is relevant to this study in both his theoretical conceptualization of how children internalize the socialization process, which can be seen in Chapter 7, through the SRs produced by the child participants in the draw-and-write exercise, and through the exercise itself, a social activity method similar to those for which Vygotsky advocated when doing research with children, which later contributed to his concept of "Activity Theory" (Grieg & Taylor, 1999; Graue & Walsh, 1998). Considering people's social interactions within culturally defined contexts is also at the heart of SRT, however, the SRs used in these situations is of primary interest to SRT, as opposed to the motives or intentions being of primary interest to activist theorists (Moscovici, 2008; Graue & Walsh, 1998). This research will focus mainly on SRs and SRT, but acknowledges the historical research contributions of Vygotsky and Piaget to this field of psychology.

2.3.2: Current theoretical perspectives on children & childhood

In contrast to the historical perspectives on children, more recent theoretical work on childhood and children suggests there are four current sociology-influenced discourses, that of the socially structured child, which positions children as social actors with the same needs and rights of other citizens in a society; the tribal child, where children comprise their own autonomous community within a larger social context; the minority group child, where children are positioned within the context of their power relationship with adults; and the socially constructed child, which sees childhood as a social construction, with children inhabiting "a world of meaning created by themselves and through their interaction with adults" (James, et al., 1998, p. 28).

This thesis will utilize the notion of the socially constructed child, as its conceptual framework blends well with that of SRT, being a social constructivist position. Here, childhood and children are seen as a product of the immediate social context, in which there may be multiple competing ideas of children co-existing in a society, which are divergent and open to contestation and challenge (James, et al., 1998;

Jenks 1982; James & Prout, 1997). In this thesis, examining the SRs held of children by the key stakeholder groups, as seen in Chapters 5-7, and which includes the views of children themselves, allows for exploration of these SRs, the comparison of which will provide a fuller picture of the role and function of children within the local study setting. The historical review undertaken in Chapter 4 adds further background information on the development of the SRs of children currently in use in the district.

In addition, there is a growing literature on African theoretical contributions to perspectives on childhood and children which is relevant to this study, and to which this study will contribute. Ensor (2012) and Honwana & DeBoeck (2005) call for the development of new, African-centered theories and constructs about African children and childhoods, by reflecting on how Western-based research has often constructed them as victims of war, famine, or HIV/AIDS, with their resilience and competency in such situations ignored. Skovdal (2009) has also found this to be the dominant Western norm in discourse about African youth, as has Park (2010), who support the call for the development of new discourses and SRs of African children.

Further, Super & Harkness (2008) argue for African contexts and considerations to be taken more seriously by global theory and research into childhood and children, and voice concern over how foreign theoretical concepts may not translate well into African contexts. SRT is advocated as one theoretical perspective which translates well into the African setting, given its focus on local knowledge and understandings. Super, et al. (2011) further contribute to this field by providing a review of past and current African-centered child development research, and advocate for researchers and theorists to consider the "developmental niche," or the local settings, cultural customs, and "ethnotheories" or indigenous knowledge systems in which children learn to interact with society. In this regard, SRT is a useful and appropriate theory to be used for this research, fitting their theoretical and research requirements well.

Finally, the anthropological work of Cheney (2007, 2010a, 2010b) is also relevant to this study setting, particularly Chapter 7, as the theoretical and social context for her work is the experience and constructs of childhood and schooling in northern and eastern Uganda. Her research is the first to examine the sociological impacts of the

Ugandan primary education curriculum on participating children, in terms of socializing and indoctrinating them into the official "ideals" of Ugandan society as espoused by the state, and includes an examination of the effects of the national HIV/AIDS curriculum on school-going children through ethnographic research. As little research has been done on this national HIV/AIDS curriculum, her findings will be considered in this study to help inform and situate the SRs discussed here by the participating children in Chapter 7, for although the ethnic groups in the northern and eastern regions of Uganda are different than those in the western region, local social contexts and challenges are similar.

2.3.3: Putting theory into practice: Limitations

As discussed above, there is a need to broaden the theoretical discourse on childhood and children to include cross-cultural and non-Western/Eurocentric views (Jenks, 2005), as more work needs to be done to further develop and incorporate these theoretical views into global research. Although Western theoretical concepts of children now tend to position them as social actors within their communities, it is important to consider that they may in fact be constrained or limited by the broader pre-existing social contexts of their society, by larger structural barriers to action such as poverty (Skovdal, et al., 2010; Campbell, et al., 2012c), or by local social issues such as gender roles and norms, cultural practices, or legal restrictions (Skovdal, et al., 2010; Cheney, 2007).

Although Western-based theorists may hold that children are active social participants, which may be reflected in Western cultures (James, et al., 1998), this cannot be assumed in all cultural contexts, as some participants in this research study see children's social agency as a threatening and divisive topic, as will be discussed further in Chapters 6 & 7. In the local social context of this study, the SR of children as needing to be controlled by adults is still held by many adult participants, and is not yet consigned to "the dustbin of history" (ibid, p. 9). In such situations, children's agency may be externally constrained, with them unable to overcome the social power differentials which shape their capacity to be active participants in society and in their own health care (see also Skovdal, 2009). Research needs to consider that social spaces and contexts often reflect the needs and wants of the more powerful majority, which in this case are adults not children.

Examining the social setting in which health services are provided, as will be seen in Chapter 8, will capture and explore the nuances of this local social context.

2.3.4: Relevance for children's HIV access & adherence

In terms of this thesis, and its focus on children's access and adherence to HIV services in western Uganda, reviewing the relevant theoretical viewpoints on children and childhood illustrates how there is a need to include children's voices in research about and with children, and that doing so provides a social space for their views to be expressed, heard, and reflected upon. This study will attempt to do so through direct research activities with children, as will be further discussed in Chapters 3 (methods) & 7 (findings). The socially-mediated process of socializing children will also be considered, with the historical social context given in Chapter 4 to provide further insight regarding this process.

However, children are one social group in a larger society, and may in fact be a disadvantaged one compared with adult social groups (James, et al., 1998). This may result in HIV access and adherence for children being mediated by several social groups, all of which may have competing or contradicting SRs of children & HIV. Using SRT allows for an examination of the SRs held by the key stakeholder groups, to gain a fuller picture of what they perceive hinders or helps children to access HIV services. This will be seen in Chapters 4-7, the historical social context and stakeholder data chapters of this study.

2.4: Using SRT to study children's HIV access & adherence

How SRT will be used to conduct the research in this study will be briefly reviewed here, with the specific research methods detailed further in Chapter 3. SRT will be used as the main theoretical model of this thesis, to examine the SRs of children, HIV and health services from the past and present against the broader social context and the health care setting, namely the local health clinic where care takes place, in Chapters 4-8. This will show how SRs are reflected in people's actions, and consider the impact on children's access and adherence to HIV services in this community. These findings will then be used in Chapter 9 to explore the potential future trends for this community's SRs, and what broader social changes could help to improve children's HIV care access and adherence locally.

2.4.1: Using SRT to reflect on past SRs against historical social context

As social context plays a significant role in SRs and in SRT, this thesis will examine not only the present day SRs currently in use by the key stakeholder groups of HCWs, adult carers, and children, but will also attempt to use a literature review to extrapolate the SRs of prior eras regarding children, HIV/AIDS, and health services. This will be done in Chapter 4, through a historical social context review centering on Kabarole district, the setting for this research study. Although prior SRT studies do not exist for Uganda, source material will include historical and recent scholarship from the fields of anthropology and health services research as its document source, and will be outlined further in Chapter 4.

The starting point for this SR reconstruction attempt is theoretical work done by Bauer & Gaskell (1999, 2008), who propose adding a time component to the study of SRs, as they posit that SRs should not be viewed as static concepts, but as long-term social projects, where SRs can evolve or be reinforced in a society over time, as influenced by social conditions and occurrences, and goals. This has come to be referred to in SRT as the "Toblerone model", after the triangular-shaped, three-dimensional Swiss chocolate bar (Gaskell in Deaux & Philogene, 2001, p. 235). By adding a time dimension or component to SRT research, this would allow the researcher to examine both the content and the communicative social functions served by the SRs, within a given society over a given time period (Bauer & Gaskell, 1999; 2008). In doing so, the SRs and social projects of the present can be seen in connection to past, and may also be able to be extrapolated into the future, much like the multiple segments of a Toblerone chocolate bar make up one cohesive whole.

Examining SRs by including a time dimension would not only allow the researcher to trace the social progression or regression of SRs over time, but may better capture the wider social environment itself (Bauer & Gaskell, 1999; 2008). Research findings could then be well positioned to explore the need and potential for social change within a society, by using its SRs from the past and the present, to speculate as to the general trend or direction of the SRs within its own context (Foster, 2011). This level of SRT analysis could also be further applied to

communities negotiating social change, by using SRs to explore which interventions would "fit" best with their own SRs and social context needs. To my knowledge, this has not been attempted before in the SRT research community, and this thesis will be the first application test of this theoretical construct.

2.4.2: Using SRT to map out present SRs of key stakeholder groups

As SRT is the theoretical perspective chosen for this thesis, the present SRs held by the key stakeholder groups in this study will be elicited, in effect, to tell us where this community is, in regards to children's HIV care access and adherence locally. These SRs will be explored in turn in Chapter 5 (HCWs), Chapter 6 (adult carers of children), and Chapter 7 (children) by discussing their content and conducting further assessment influenced by Attride-Stirling's (2001) Thematic Network Analysis (TNA) to reveal common or contradictory themes, both within and across the groups. Whilst the specific research methods will be discussed in Chapter 3, as the goal of the thesis is ultimately to explore how SRs, social identity and social context in this community impact on children's HIV access and adherence, qualitative inquiry best lends itself to this research goal. The findings will then be further discussed in Chapter 9, in relation to what social changes would be possible within the community context to facilitate improved HIV care access and adherence for children.

2.4.3: Using SRT to examine the clinic practice setting against SRs held by participants

In addition, as discussed in sections 2.1 and 2.2, as actual health behaviours are an important outcome for improving children's HIV care access and adherence, Chapter 8 will consist of a focused clinic ethnography, which centers on observed practices via participant observation, at the local health clinic in this community. These observations will be used in comparison with the SRs generated in Chapters 5-7, to explore what participants *say* happens in the clinical setting, versus observations of what *actually* happens in the clinical setting. As SRT lends itself easily to exploring local lived realities through a more active, ethnographic approach, by capturing actual behavior in complex social settings, it is a better choice for this research than TRA/TPB from section 2.1. Findings from Chapter 8 will also be included in Chapter 9, to consider what aspects of social change may or

may not be possible within this community, to improve HIV care access and adherence for children.

2.4.4: Implications of using SRT

For this research study, I have chosen to use the social psychological theoretical framework of SRT, as it allows for a fuller exploration of the interplay between the individual and society regarding children's HIV services access barriers. By reviewing the SRs, social identities, and social contexts experienced by the three stakeholder groups of HCWs, adult carers of children, and children, psychological and social barriers to children's HIV service access can be discovered and explored. However, the implications of choosing SRT over the other theoretical disciplines previously discussed must be considered in closing.

SRT is a social constructivist position, and positions society as having power and prominence over the individual, in that society "shapes" or influences individuals into pre-determined ways of being and expressing themselves which are considered acceptable to those in power, frequently to reinforce a status quo which keeps social elites in power (Duveen, 2001). Although alternative SRs for resistance and social change are possible, to develop they often need a powerful minority to foment and advance these SRs in society at large (Jovchelovitch, 2007). Much SRT research has traditionally sought to determine "what is" in society, but not necessarily to challenge the status quo or to actively work to create new SRs that "will be" within a research study (Howarth, 2006).

Although SRT is more a framework for social exploration rather than experimentation, exploration is a necessary first step in the critical examination of social interactions and communications, so that future intervention work can use these SRs as starting points for social change. The applied use of Bauer & Gaskell's (1999) Toblerone model in this study will help to advance this critical potential of SRT, in that the present SRs will be connected to the historical past to shed light on their development, and to potentially extrapolate where they may progress in the future, and where interventions to help shape future SRs may be possible, as discussed in Chapter 9. In this way, studying a society's present SRs can illuminate the social changes needed to achieve future goals, and further shed

light on how to facilitate these changes in ways which will fit within the particular social context or setting. This can be achieved by exploring the SRs used by key stakeholder social groups, to determine if there are areas of differences, convergences, and tensions between the SRs they hold, which could be harnessed to challenge the status quo by changing or creating new SRs in support of social change.

Conclusion

For this research study, the SRs of children, HIV, and health services held by HCWs, adult carers, and children, are explored and analysed for areas of differences, convergences, and tensions. As will be explored in subsequent chapters, the main points of difference in the SRs are related to the impact and role of HIV within the community, and the capacity of health services to manage HIV, as seen by the HCWs versus the adults and children. Areas where the stakeholder SRs converge include the role and social position of children as dependent on adults within society, as all stakeholder groups used this SR, as well as the limited capacity of health services to gain access to children for HIV services, due to this social positioning. An area of tension concerns the SRs of HIV, and those of children who are HIV-positive, which was disconcerting for all groups involved, with adults not wanting to acknowledge it as being a problem, but HCWs and children openly expressing their fears and concerns on the topic.

Exploring the SRs held by stakeholder groups in this way allows for a better understanding of where their society is, which must take place before social transformation can begin. As will be discussed in Chapter 9, these areas of difference, convergence, and tension suggest how future interventions can build on opportunities to develop the social cohesion, which would help to decrease psychosocial barriers and increase access to children's HIV services. They also point to ways of avoiding the risks of social fracture and division, which could undermine efforts to decrease barriers and increase access, and thereby help in future community-oriented health intervention planning. As Uganda is considered a country with "low social cohesion and low wealth" (Barnett & Whiteside, 2006, p. 96), its social challenges are numerous, and using SRT as the theoretical framework for this study will help in identifying areas of potential social change for

future work to increase children's access to HIV services (Howarth, et al., 2004; Campbell, et al., 2007). As the goal of this study is to explore the potential psychosocial barriers to children's HIV service access, and to determine what is needed for people to circumvent these barriers on a personal and on a social level, SRT has shown itself to be the better approach for this research study, the methodology of which will now be explored.

Chapter 3: Methodology & Research Design

Introduction

In this chapter, the methodology of this study will be discussed, in terms of the theoretical rationale and approach to the research design, the actual data collection for the research project, and the process of data analysis and its broader social implications in conducting this study. Section 3.1 will briefly review the research team, the theoretical background of Social Representations Theory (SRT) as outlined in Chapter 2, and will explore the qualitative methodological approach of this thesis and related issues of generalizability. In section 3.2, the methods chosen to be used in this study will be discussed, as will participant demographics and the process of collecting data in the field location. Further details about the field location social context will be discussed in Chapter 4, with particular attention given to tracing historical social representations (SRs) as relevant to this study. Section 3.3 details the data analysis process influenced by Attride-Stirling's (2001) Thematic Network Analysis (TNA) and the preparation of the raw data, with the data findings discussed in depth in Chapters 5-9. Ethical and broader social considerations which emerged from the research process will be discussed in Section 3.4, and reflect the challenges in conducting an ethical, culturally sensitive, and informed and informative research study. Section 3.5 will consider the research process overall, including issues of positionality and limitations faced in using this approach.

3.1: Research team, theoretical rationale & methodological approach

This section provides an introduction to the research team, a brief review of the theoretical rationale underlying this research, and discusses the methodological approach taken for this research using qualitative methods. Criticisms related to the generalizability of qualitative research are also discussed, and alternate approaches to ensuring research rigor and reliability are presented in response to these criticisms.

3.1.1: Background of researcher & research team

My interest in conducting this PhD research developed from working in Kabarole district, Uganda, in 2009-10, on a large, biomedically-oriented research project as part of the requirements for a Master's degree in Canada. My research at that time

was focused more on quantitative aspects of children's HIV service provision, and was conducted primarily through standardized survey questionnaires and interviews, using statistical computer software and modelling for analysis. However, I felt that this work was not really capturing the underlying factors which impact on how people choose to use health services for themselves and their children. Having previously completed a nursing degree and working as a Registered Nurse in the Canadian system, my practice experiences led me to believe that a more holistic approach to health research was needed here, including more attention on the personal and social factors underlying health choices. When I received funding to continue on to undertake a PhD, I decided to return to explore the psychological and social factors underlying children's HIV service access. As this district was facing a situation where people were not accessing HIV care for children *despite* the availability of services and medication, I felt a more qualitative exploration of the psychological and social factors as to why this was occurring, could be a better approach and hopefully would provide further insights.

Returning to Kabarole district, I chose to use prior connections with local contacts who had worked on various research projects conducted in the district in the past, to see if they would be available for further work. I was able to connect via email with one local contact, TR, prior to going to Uganda, who had good connections with local gatekeepers in various government positions, as well as with some of the research assistants (RAs) I had worked with in 2009-10. Upon arrival in Fort Portal, I was able to reconnect with two ladies I had worked with previously, LB and RT, who were available for contract work and were interested in the project. Outside of this research, they mainly work with local or foreign research projects, typically through the district government and non-governmental organizations (NGOs), with which they have long-standing connections. I had developed a good working relationship with them previously, and knew from working directly with them in the past, that they had positive rapport with local research participants, including good interviewing skills and a good sense of when to probe deeper with questioning, in a way that encouraged a positive, safe experience for participants. They were contracted to be the primary, full-time RAs for interviews, focus groups, and the clinical ethnography, as well as some of the transcription and translation work. In addition, I hired a third RA part-time, a young man, JR, who had worked with them

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on previous research projects, to assist with the focus groups and transcription and translation work. Details of the day-to-day data collection are discussed in section 3.2.3.

3.1.2: Theoretical rationale: SRT

As seen in the review of current HIV/AIDS research conducted in Chapter 1, there is a need for further research into the lived experiences of children, families, and health care workers (HCWs) in regards to children's HIV testing and treatment access and adherence. Whilst quantitative clinical and structural aspects of HIV infection are well-known, the qualitative psychological and social impacts of HIV infection on children, families, and society are deserving of further research, to explore their potential impacts on service uptake and provision. Exploring these views or SRs of these stakeholder groups could help to improve our understanding of their lived experiences, and the underlying personal and social dynamics which may influence their HIV care choices and access to clinical services. Using qualitative methodological approaches could capture the rich depth and breadth of SRs, and the daily, lived experiences of participants in ways which are not as well captured by quantitative methods.

As discussed in Chapter 2, for this research, SRT is the preferred theoretical perspective, as it uses a social constructivist philosophical position to examine how societies cope with new information and challenges to their daily life, by acts of "sense making," by finding ways of integrating the information into their lives, modifying it to fit, or rejecting it altogether (Moscovici, 2008). In Kabarole district, the pandemic of HIV/AIDS has had, and continues to have, significant social and personal impacts beyond the clinical and structural aspects of care and service access. Given this continued sense-making, often in the light of clinical, social, or technological changes, SRT as a theoretical background in combination with qualitative research methods, was used to capture the current lived experiences of participants, to situate them within the historical social context of HIV in Uganda and the current clinical context of service provision, and to consider future actions and next steps, to improve children's HIV service access and adherence locally.

Although there is no specific set of research methods required or suggested for SRT, with researchers in the theoretical field using both quantitative and qualitative methods, given the goals of this research, qualitative-based methods were chosen to use in this thesis. This choice echoes back to the original SRT research of Moscovici, in terms of using a qualitative-based approach to examine the SRs held by key social groups within a society, as a change agent enters their realm (Moscovici, 2008, 2000), in this case, the SRs of children and HIV in regards to treatment access and adherence. Prior work by Joffe (1993, 1996) on the SRs of HIV/AIDS, as well as work by Campbell (2003) on the impact and uptake of HIV programming by affected communities, also influences this research in terms of study orientation, design, and methods chosen.

3.1.3: Methodological approach & generalizability of findings

Based on previous quantitative research experience conducted in the area in 2009-10, I was interested in using qualitative-based research, as it was felt that qualitative methods would lend themselves better to capturing the lived experience of the participants, particularly in terms of SRs, social context, and identity (Campbell, 2003; Jovchelovitch, 2007; Braun & Clarke, 2006). Limitations inherent in the nature of traditional quantitative methods, in particular the use of structured surveys were seen as hindering rapport, with the structure and format of the survey also limiting the capacity of the participants to respond, thereby limiting the information generated by the research, as has been noted across sub-Saharan African (SSA) settings (Randall, et al., 2013).

In particular, for this study I wanted to focus on qualitative aspects of research using SRT to capture perceptions of HIV and health services held by participants which may not be reflected in quantitative surveying (Randall, et al., 2013), as it was felt that this was key information missing and needed to better understand people's health choices. Given the research questions, theoretical perspective, and goals of this study, capturing the why through thick, qualitative descriptions (Bauer & Gaskell, 2007) of SRs, social context, and social identities provides better insight into the psychological and social barriers and facilitators of children's HIV access and adherence within this community.

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Although qualitative research is often criticized for procedural risks, such as response bias and "validity," these are risks which are in fact inherent in any research project, qualitative or quantitative, perhaps as an effect of the research process itself (Randall, et al., 2013; Bauer & Gaskell, 2007). Despite this, questions of "generalizability" of qualitative research findings persist in the broader scholarly world, particularly in research areas dominated by physical or biomedical science (Bauer & Gaskell, 2007; Lincoln & Guba, 1985). However, Cornish (2004) suggests that there are three ways in which smaller-scale qualitative research studies can be evaluated for "generalizability," which are more appropriate to the nature of the inquiry and the goals of the research, than merely co-opting technical terms and concepts from quantitative research and trying to make them fit.

First, the role of human judgment is crucial (Cornish, 2004), in concert with "thick description" of the research (Bauer & Gaskell, 2007; Lincoln & Guba, 1985), so that informed judgments can be made by the reader about how general the findings presented are. Key in this is the triangulation of data findings with work by other researchers in similar settings (Bauer & Gaskell, 2007), which in this thesis, has been referred to throughout the chapters, as well as through an analysis of the historical social context in which the study setting exists in Chapter 4. Second is an examination of the how representative a particular case or situation is, to determine how transferable the findings are, from one situation to another of a similar cultural context (Cornish, 2004). For HIV/AIDS research, this is highly relevant and a much better assessment indicator than is often used for quantitative research, given that many countries hardest hit by HIV have similar cultural contexts, histories, or influences, and face similar challenges in managing the pandemic. Finally, how qualitative research contributes to the development or refinement of theoretical frameworks should be considered, either in supporting or critiquing and challenging them (ibid). In this thesis, the data findings generated here do both, by supporting SRT as a valid and useful theoretical framework for HIV research, and by capturing data findings and "whys" which not only challenge other theoretical frameworks currently in use as discussed in Chapter 2, but which also suggest that significant aspects of the lived experience of children and HIV care are not being captured by these competing theories at all.

3.2: Study design, demographics & collecting data

In section 3.2, an outline of the study design focuses on qualitative methods chosen to conduct the research in the field setting, which are discussed in detail here. A brief introduction to the research setting in the form of the data collection settings is given, and participant demographics are outlined in section 3.2.2. Limitations on the study design resulting from the study setting are also discussed, with the process for setting up the research project and collecting the data in the field outlined in section 3.2.4.

3.2.1: Study design: Methods chosen

This study was based in Kabarole district, Uganda, where field data collection was conducted out of the Amooti Health Centre III clinical catchment area, and occurred during May to August 2011. Data analysis and write-up was begun upon return to London, UK in September 2011, through to the PhD thesis submission in July 2014.

Influenced by SRT, this research used a data-driven, multi-method approach (Bauer & Gaskell, 2007) to investigate the SRs, social contexts and identities held by participants concerning children and HIV service access and adherence in their community. The construction and reconstruction of these SRs in specific social contexts as facilitated by the research methods chosen were also examined, with consideration given to the existence of contradictory representations between stakeholder groups, which can open up the possibility for debate, dialogue and change within a social context (Campbell, et al., 2007).

In terms of choosing qualitative methods for adults, personal interviews and focus group discussions were used as they were considered effective, low-cost, and low-tech interventions appropriate to a developing country setting (Bauer & Gaskell, 2007). Whereas with personal interviews, privacy and confidentiality concerns about sensitive topics such as children and HIV can be addressed through the effective use of private spaces for interviewing, focus group discussions allow for an examination of more "public" discourse, as a mixed group of strangers or people who are not-well acquainted with each other may express different ideas and concepts when together than when alone (Campbell, et al., 2007). Using both

methods together would allow both social modes to be examined, and could help to facilitate the widest range of SRs to emerge through the research process.

For children, however, a more child-friendly way of conducting research was sought, as the nature of inquiry and experience using verbal methods is more adult-oriented and may be less interesting to children (James, et al., 1998; Punch, 2002). Instead, to capture children's interest and their SRs of children and HIV, a draw-and-write exercise was chosen as the primary research method for this stakeholder group. It was chosen as it is, again, a low-cost, low-tech method that has been used successfully in many settings in SSA to produce interesting results which reflect the lives of the children and the societies in which they live (Campbell, et al., 2010; Skovdal & Ogutu, 2009). In addition, it is a very child-friendly method, as creating art is an enjoyable activity for children (Campbell, et al., 2010; Skovdal & Ogutu, 2009; Vygotsky in Grieg & Taylor, 1999). Although advanced technological methods exist for conducting visual research, such as Photovoice (Wang & Burris, 1997) or other digital ethnography methods (Lahlou, 2008), logistical and technological limitations on their use in the field included unreliable power sources, risk of breakage and/or theft due to harsh travel conditions, and negative local sensitivities to the use of cameras which are seen as exploitative and trust-eroding, as per discussions with local stakeholders.

Content was therefore sourced and triangulated via semi-structured, individual in-depth interviews (IDIs) and focus groups (FGs) for adult participants, and draw-and-write exercises for participating children. In addition, a focused, clinical ethnography with corresponding field notes was conducted to examine the day-to-day service setting and service provision dynamics (Bauer & Gaskell, 2007). These data sources are outlined in the table below and discussed in further depth following the table. For both IDIs and FGs, one topic guide was developed by the researcher, which used open-ended questions to elicit participant SRs on a variety of topics concerning health and illness, health services, and children and HIV (ibid), and is found in Appendix 5.

Table 3.1: Study data sources

	HCWs	Adult Carers	Children	Researcher
Interviews	N=15	n=30		
Focus Groups		n=3 groups x 5 participants for 15 participants		
Draw-and-Write			N=82	
Clinical Ethnography				N=5 hours x 8 sessions for 40 hours
Field Notes				N=40 hours
Total Participants	N=15	N=45	N=82	N=40 hours

In-depth interviews

IDIs were undertaken with adult members of the targeted stakeholder groups, selected through purposive sampling as discussed in section 3.2.2, participant demographics. The IDIs lasted from 25 to 60 minutes, with an average length of 40 minutes. They were conducted with HCWs (n=15), adult carers of children under the age of 18 who regularly used Amooti clinic services for their children (n=17), and adult carers who did not use Amooti clinic services (n=13), for a total of 45 adults participating in these interviews. For corpus construction (Bauer & Gaskell, 2007), as the focus was on looking at the SRs generated by the stakeholder groups themselves, both for within and cross-group comparisons, the data findings from the HCWs were analyzed as one stakeholder group, with findings discussed in Chapter 5. Accordingly, the carer findings resulting from the IDIs were combined with the information generated from the FG data, to create its own corpus which is analyzed in Chapter 6.

Focus groups

FG discussions were used with adult carers in order to evaluate the effect of inter-group dynamics and differences of experience on the dialogue and SRs produced

by the research experience (Campbell, et al., 2007). Participant demographics were the same as those for the IDIs, with 3 groups of 5 participants for a total of 15 adult carers in total taking part. Groups were mixed in terms of usage of the clinic, with all groups composed of participants who both used the clinic and those who did not. FGs lasting from 60 to 90 minutes each, with an average length of 85 minutes, and the 3 groups consisted of a men's group (n=5), a women's group (n=5), and a mixed gender group (n=5). This was done to better facilitate the discussion of potentially socially sensitive material around the topics of children, HIV, and health service provision (ibid). Using an all-male group, an all-female group, and a mixed group also helped in the observation of in-group dynamics, particularly gender norms and social rules, and helped the researcher to reflect on the social context of the wider paternal hierarchical social structure as discussed in Chapter 4. The data generated were collated with IDI findings to construct the data corpus for the adult carer stakeholder group as explored further in Chapter 6.

Draw-and-write exercises

For the draw-and-write exercise, the two government-run primary schools which were within the catchment area of Amooti clinic health services were chosen as settings for this research. This was done not only to ensure the widest sample of child participants, but also to account for potential local variations within the school setting, such as teacher perspectives and interpretations of the standard national HIV/AIDS curriculum used (Cheney, 2007), as these could in turn influence the SRs being developed by pupils in attendance in differing ways. In addition, as the schools were in 2 different physical locations in relation to the clinic, with one being more "rural" and isolated, and the other being located in a more urbanized part of town, local geographical effects and contextual influences could also potentially result in differing SRs held by pupils. Conducting research in both these locations was seen as the most appropriate way to control for these potential variables, and to capture the widest possible variety of lived experiences and the resulting SRs which pupils may hold. Primary schools were also the preferred location for this research due to safety issues for researchers and participants, as will be discussed further in section 3.2.2.

From the two primary schools in the Amooti clinic catchment area, randomly selected 12 year old pupils were selected to participate in the exercise (n=41 children per school). Children aged 12 years old were given on average 45 minutes to draw a picture and write a brief story reflecting on the exercise, "draw a picture and write a short accompanying story about a child who has been affected by HIV/AIDS in any way." This method has been successfully used in SSA to generate the SRs of HIV, health settings, and children, as held by children (Campbell, et al., 2010; Skovdal & Ogutu, 2009). The age of 12 years was chosen as the target participant age, as cognitive and physical abilities are typically developed enough to allow for rich content generated in picture and text, yet children at this age have not yet taken on fully adult SRs, identities and perceptions (Campbell, et al., 2010; Skovdal & Ogutu, 2009; Howarth, 2002a). The exercise provided rich data from this stakeholder group, discussed in detail in Chapter 7.

Clinical ethnography & field notes

A focused, clinical ethnography with corresponding field notes was undertaken by the researcher and RAs, in order to conduct participant observation of day-to-day clinic practices and experiences (Bauer & Gaskell, 2007). Eight sessions of 5 hours each for a total of 40 hours (N=40) were spent at Amooti health centre to observe the clinical processes and interactions between HCWs and health service users. Days were chosen at random and scattered across the work week of Monday to Friday during operational hours from 10am to 5pm. Observations were written down as field notes in a diary which was kept by me during the data collection period, frequently after discussion with the RAs to clarify interpretations and to translate conversations overheard. This was both a reflective process and a data source to triangulate information gathered during IDIs and FGs, and the draw-and-write exercise with the children (ibid). It allowed me to look critically at clinical processes, and to draw on a background in clinical quality improvement research in observing the clinical processes, in order to explore the implications for children's HIV service delivery and uptake, as seen in Chapters 8 & 9.

3.2.2: Research settings, participant demographics & considerations

The Amooti clinic catchment area was used for purposive sampling of the stakeholder groups, both of adult participants who were aged 18 and over, and child

participants for the draw-and-write data, who were the targeted age of 12 years old (Campbell, et al., 2010; Skovdal & Ogutu, 2009), as outlined below. Further information on the area can be found in Chapter 4 as part of the historical social context examined as background scaffolding for the SRs currently in use in this society. The Amooti town area was the main base for conducting interviews with adult carers, and was chosen after consulting local stakeholders, as it best reflected the general demographic and geographic characteristics of the district.

Whilst IDIs were held in a private household location off the main road, due to space limitations, FGs were held in a larger private building near the health clinic and town council office. In addition, two primary schools were selected as the schools where the children's research was conducted, as they are the two government-run schools serving the area. The more urban primary school has 735 pupils and 14 teachers, and the more rural primary school has 498 pupils and 8 teachers. Smaller private or religious schools were purposefully not chosen due to the potential impact of independent or religious curriculum on HIV/AIDS messaging presented, as exposure to the national HIV education curriculum could not be fully guaranteed (Cheney, 2007). This could also have resulted in participating children having little exposure to SRs about HIV and children, which could have impacted on the data generated in a negative way. For HCWs, Amooti clinic and the district capital Fort Portal were the locations for conducting their IDIs.

Participant demographics

Participants in this research study totaled 15 HCWs and health officials, 45 adult carers of children, and 82 children attending local primary schools, for a total of 142 participants (N=142). See Table 3.2 for relevant participant demographics, with participant inclusion and exclusion criteria discussed below. Adults who fit multiple inclusion criteria were asked to self-identify with one selected stakeholder group of their choosing for study purposes.

	HCWs	Adults	Children
Number of Participants	15	45	82
Male	8	22	44
Female	7	23	38
Education: N/A		1	
Education: None		2	
Highest Education: Primary	1	28	82
Highest Education: Secondary	7	12	
Highest Education: Tertiary	7	2	
Age: N/A	1	1	
Age: under 18			82
Age: 18-25	1	13	
Age: 26-35	8	10	
Age: 36-45	2	14	
Age: 46-55	2	4	
Age: 56+	1	3	

Inclusion & exclusion criteria for participation

Inclusion criteria for adults were as follows:

- a parent or primary caregiver aged 18 years or older, of a child under 15 years as per the UNAIDS definition of "child" (UNAIDS, 2010), living in Kabarole district at the time of the study; or,

- a currently employed health care worker aged 18 years or older, living in Kabarole district at the time of the study.

Exclusion criteria for adult participants were the following:

- not being aged 18 or older; and
- not residing in Kabarole district at the time of the study.

Inclusion criteria for children were:

- a child having attained the age of 12 years, living in Kabarole district at the time of the study, and attending either of the two selected primary schools.

Exclusion criteria for child participants were:

- not being aged 12 years at the time of the study; and
- not residing in Kabarole district at the time of the study; and
- not attending either of the two primary schools on the day of the research exercise.

Study limitations

In terms of limitations on participants, for children, using a school-based setting limited access to participants to only school-going children and excluded those not currently in education or attending school on the day of the exercise. Given the local sensitivities involved in accessing children at the time of the research, using a school-based approach was the more appropriate option in terms of working with children, despite excluding out-of-school children. Local sensitivities were heightened due to several stressful and upsetting incidents involving children being kidnapped, killed, and dismembered for use in ritual "medicine" or "magic," most notably in attempts to ensure financial or business success (Rogers, 2011; Vernaschi, 2010). These incidents have taken place on several occasions and in several locations across Uganda during the period of 2010-11, prior to the researcher returning to Kabarole district to conduct this research study, and parents and local officials were understandably on alert for unusual goings-on involving children at this time. As a result, after consultation with local stakeholders, obtaining official permissions and using a school-based approach was seen as being the most respectful and appropriate way of engaging with the children of this community to conduct research.

In addition, as Uganda has a school-based national HIV curriculum (Government of Uganda, 2002), which would effectively guarantee at least some exposure to HIV SRs and related issues for participants, this was another positive aspect of working with school-going children. Given the use of an HIV curriculum in schools, it allowed the researcher to also reflect on the role of SRs in socializing children through the education system (D'Alessio, 1990; Corsaro, 1990), and to contrast between the official curriculum "version" of HIV and children in Uganda with the lived experience of pupils who participated, as seen in Chapter 7. This further illustrated how there are significant discrepancies and tensions between the "official" SRs of HIV in Uganda and the real-life SRs which many children chose to describe in their stories and pictures.

In considering the role and impact of HIV on participants personally, whilst participants did not have to disclose HIV status to participate, they were asked questions about HIV, children, and health services in order to examine the SRs they held of those topics. HIV status was not asked as it could have unintentionally put participants at risk for social stigma, which could also have impacted negatively on participation in the research. In addition, without a blood test to unequivocally confirm their status, which was well beyond the scope and budget of this research, it would not have been possible to confirm the self-reported HIV status of participants. Regardless, given that the SRs of children and HIV on children's access to HIV and health services were the main focus of this study, the methods outlined in section 3.2.1 allowed the research team to obtain this information with the least amount of personal or social risk to themselves and participants.

Although it was anticipated that participants would not experience distress during their participation in this study, given the nature of the inquiry and methods used, in the event that distress occurred, participants would have been referred to local health services for assistance and intervention, and their participation would have been discontinued without penalty. Also, I am a licensed Registered Nurse with experience in Emergency and Mental Health clinical situations, including patient counselling experience in HIV and life-threatening illnesses and emergencies. The research team's local contact information was provided to them at the start of their participation, as part of the informed consent process, and in case of emergencies

or problems. Longer-term contact information was also provided, and informal, post-research follow up meetings with available local stakeholders were conducted by me and the research team shortly before departure. No emergency situations or crises occurred during the research study, nor immediately after whilst I was still in country, and post-study, no problems have been reported by local RAs, with whom I remain in contact via email.

3.2.3: Setting up the research project & collecting data

In addition to the ethics reviews conducted in the United Kingdom and Uganda prior to starting data collection, there were numerous local permissions involved in order to gain access to potential research participants. These are detailed in section 3.4.1, along with the ethics process, and included local permissions to access Amooti health centre, the two government-run primary schools, and to work in the town. Local permissions obtained were crucial in being able to access potential research participants, as well as to secure safe and private locations in which the data collection could be conducted as discussed in section 3.2.2. My prior history in Kabarole district, helped in establishing rapport and trust with local officials and stakeholders, as the prior work had provided a network of contacts which were drawn upon in setting up this research study.

Upon arrival in the district, meetings were arranged with local officials to obtain local permissions to conduct research in the field. As discussed in section 3.1.1, three RAs (LB, RT, and JR) were hired to conduct the field data collection, and translation and transcription work in support of the research project. In addition, the office of a Fort Portal-based community organization was also available to me to use occasionally, and to assist with paperwork and logistical needs such as forms being printed and secure internet access. Working for the organization was an administrative assistant (RA) who occasionally provided additional translation and transcription services when needed. This resulted in a research team composed of me, three RAs and one additional assistant. The RAs and the administrative assistant signed contracts and were remunerated based on local rates and in accordance with the nature of the work, such as conducting IDIs versus transcribing or translating documents.

To introduce the project and its orientation, two days of training were held, where I met with the RAs and all aspects of project logistics were discussed. The topic guide and trial IDIs and FGs were also practiced, to better acquaint the RAs with the study methodology and goals. As the lead RAs, LB and RT, had several years of experience in conducting research on health matters, I felt confident that they would do well in the field. In the field, I accompanied the RAs for all data collection, but let them take the lead in conducting the IDIs, FGs and draw-and-writes, due to my lack of fluency in the main local language, Rutooro. In conducting the clinical ethnography, one RA would accompany me to the clinic, and we jointly sat and observed, discussing events that occurred with real-time translation of non-English conversations. In organizing the data collection and transcriptions, we decided the RAs should take turns, so that one would be in the field with me, whilst the other was working on the transcriptions, once we started to conduct the research. In the IDIs where English was the language used, I conducted the interview with the RA assisting, and did the transcription myself. All team members were also briefed in terms of confidentiality and asked to sign consent forms in support of keeping participant information confidential during and after the research project.

As the research progressed, we held 3 separate meetings to act as a sort of "check in," where we could discuss and give feedback on the research process, as well as discuss some of the ideas and themes initially emerging from the research. The RAs were interested in this, and the discussion often turned to Ugandan society and the lived experiences of the research participants. Although the RAs were generally better-off economically than most of the study participants as they were employed, with LB and RT also married to husbands with full-time jobs, they sympathized with the participants, as poverty and a lack of opportunity were seen as having negative impacts on adults and children generally. The impact of the costs of living were also felt to have a negative influence as well, particularly as the Ugandan shilling had devalued by roughly 25% between my prior visit in 2009-10 and my time there in 2011, with basic costs for food and fuel rising nonetheless. In addition, the impact of traditional beliefs versus modern Ugandan society, including religion, was also discussed, with the RAs concerned that more conservative religious and social ideas were emerging and threatening to cause problems for people living with HIV, or those doing HIV-related research, including themselves. Given that

discriminatory legislation against homosexuals and women has been enacted in Uganda since this field research, as will be discussed in Chapter 4, their concerns are not only valid but now enshrined in law.

Whilst the RAs were generally sympathetic to the research participants, they did feel that a lack of education about health and HIV was a main concern, similar to the biomedical research studies they have previously worked on and as discussed in Chapters 1 & 2. However, despite this perspective being held by them, the data findings in this study do capture psychosocial factors underlying children's HIV care access and adherence, suggesting that they kept the focus on the topic guide questions, and were able to focus on these areas of research whilst conducting the IDIs, FGs, and draw-and-writes. Regardless of philosophical and theoretical differences, throughout the project experiences in the field and at the "check-in" meetings, we were able to build on previous rapport, which made for positive team dynamics and enhanced trust amongst team members, and resulted in a generally positive experience for those involved.

Collecting data

Prior to beginning data collection, the topic guide for both the IDIs and FGs had been developed by the researcher, and was then vetted and discussed with the help of the RAs, which included translation and back-translation by 2 different RAs to assess accuracy and for cultural considerations. Initially, 5 IDIs were conducted as pilot interviews to determine the appropriateness of the topic guide and to determine the themes arising from the guide. After review, the research team discussed the content, and was satisfied with both the process and the results, so that no further changes were needed to either the topic guide or the IDI facilitation techniques developed through the training, and the initial IDIs were included in the corpus for analysis.

In starting the data collection, a local contact was recruited in Amooti town who assisted the team in finding a suitable location to conduct the IDIs and who occasionally assisted the RAs in finding research participants. Participant sampling for adults was done via convenience and snowball sampling, due to the nature of day-to-day life locally, where residents were reluctant to schedule appointments in

advance due to work or family situations (Bauer & Gaskell, 2007; Campbell, 2003; Campbell, et al., 2005). Despite this challenge, the research team was able to find participants for the IDIs on the days they were conducted locally. For the FGs, as they were to be held at a nearby location due to space requirements, arrangements were made in advance with participants sampled via convenience and snowball methods (Bauer & Gaskell, 2007), to show up to the location on a set day and time. Although there was often a bit of waiting involved for participants to show up, all who agreed to participate were able to attend. For HCWs and children, convenience sampling for the IDIs and draw-and-write exercise was done at their place of work or study on a pre-arranged date and time, as this was deemed most appropriate after consultation with local stakeholders and potential HCW participants.

3.3: Data analysis & interpretation

This section focuses on the analysis and interpretation of the data through thematic content analysis influenced by Attride-Stirling's (2001) Thematic Network Analysis. First, an overview of how the data were prepared for analysis is given, followed by an explanation of how TNA was an influence in conducting the analysis. The actual data findings are discussed in Chapters 5-9, with stakeholder group findings in Chapters 5-7.

3.3.1: Preparing the data

To capture verbal data, IDIs and FGs were recorded using a digital voice recorder and anonymized files were uploaded onto my laptop for password-protected storage. The languages used in the IDIs and FGs were either English or Rutooro/Runyankole, the local languages of the area, which were chosen by the participant. Although there are minor historical linguistic differences between Rutooro and Runyankole, they are mutually intelligible by local stakeholders, RAs and participants, and so were treated as such during the data collection period. For the English language participants, I conducted the exercise with assistance from an RA. For the Rutooro/Runyankole language participants, an RA conducted the interviews with assistance from me. I was present for all data collection events.

Content in English was transcribed by me, with content not in English translated and transcribed into English by one of the RAs, with random checks for quality and

accuracy carried out by another RA. No major discrepancies or problems were found during these checks. The use of multiple checks between translators, and checks for inter-coder reliability of translations is recommended to ensure objective and accurate analysis (Liakopoulos in Bauer & Gaskell, 2007). This has been done previously in SSA, in settings where there may are multiple languages spoken by the participants, or where the primary researcher does not speak the local language (see Campbell, et al., 2010, 2005; Skovdal, et al., 2010). All transcriptions were typed in Word document or Rich Text file format, which became primary source documents for data analysis. A total of 45 IDIs and 3 FGs were conducted for 48 primary documents of 255 pages. In addition, the hand-written field notes from the clinical ethnography observations were typed out as Word or Rich Text documents for inclusion in data analysis, resulting in 8 primary documents of 36 pages in total.

The visual data, in the form of the draw-and-write pictures and stories, were scanned and uploaded as computer files onto a password-protected laptop, with the original hard copies kept in safe storage. The picture and story comprised one total unit for analysis, and of a total of 82 potential units, 6 were excluded for analysis due to no related HIV content, resulting in 76 primary documents. Children were given the opportunity to write the story in either English or Rutooro/Runyankole, and as for IDIs and FGs, translation, transcription, and random checks for accuracy were used when the works were not in English. In preparing these primary documents for analysis, both components were used to determine overall meanings, SRs and themes, by comparing the visual information provided by the picture with the written content provided, as per the instructions given, "draw a picture and write an accompanying story about a child who has been affected by HIV/AIDS in any way," as discussed in section 3.2.1 above. As will be explored in Chapter 7, the SRs produced in these works, and the themes resulting from them were very straightforward and clearly expressed by the children. All content was uploaded into NVivo 9 for organization and coding purposes (QSR International, 2014), and examples can be found in Appendices 8-11.

3.3.2: Conducting the data analysis

For the analysis of the data, Attride-Stirling's (2001) work was an influence on the thematic content analysis undertaken. As the research sought to capture the SRs,

social context, and identities held and used by participants, using thematic analysis allowed for the evaluation of the data in terms of themes which reflect the interconnectedness of these components, and nuanced similarities and differences across stakeholder groups (ibid). It also provided an analysis process which is clear, concise, and supported by theory, which is important in terms of being able to replicate the study for validity and reliability concerns (Attride-Stirling, 2001; Braun & Clarke, 2006).

Attride-Stirling (2001) outlines six steps for data analysis, in order to discover the social meanings and SRs inherent in the data. Whilst the first three steps outline how the data should be managed, the final three suggest how to interpret the data findings. First, exploratory data analysis occurred by reading through the transcripts and draw-and-write exercises, to determine core themes which emerged from the primary documents, which were written down as rough notes. This led to an initial coding framework totaling 202 codes, which were then used to begin to work with the primary documents in NVivo 9, in order to code text segments and pictures which contained these initial codes.

Second, the initial codes and text segments were re-read and re-analyzed further to develop 66 "basic" theme clusters based on the initial codes. An example of a basic theme is seen in section 5.1, 1A1, where "traditional medicine versus modern medicine" was constructed from the codes "traditional herbal medicine," "modern medicine," and "Western/clinic medicine." Third, basic themes were further examined and re-analyzed to group them into 37 "organizing" themes, which are networks of related content which reflect shared issues. From section 6.1, organizing theme 2C of "jealousy and 'treatment envy' from increased HIV resources and attention on the disease" results from the basic themes of "more resources for HIV than for other illnesses," and "HIV-positive people doing better than HIV-negative ones due to more clinical support and resources."

From these, 12 broader global themes emerge, which capture the over-arching concerns and issues which emerge from the data. In Chapter 7, the global theme of section 7.2, "HIV/AIDS continues to have terrible impacts on our society" is developed from the organizing themes of 2A "HIV maims and kills people," 2B "HIV

and poverty are inextricably linked in our society," and 2C "social contradictions about women, girls, and HIV." In general, the process builds up key findings from a detailed examination of numerous, highly specific smaller codes, to larger, more universal shared concepts and issues, which contain the SRs used by participants and reveal their content and meaning to participants. This allows for an examination of how SRs work in creating a social worldview from which people operate.

The fourth step is to describe and explore the thematic networks generated by this process, which can be found correspondingly in Chapters 5-7. Fifth, summaries of the findings are provided and discussed in Chapters 5-7, with Attride-Stirling's (2001) sixth step, where the findings and interpretations are related back to the broader research questions posed by this research, occurring throughout Chapters 5-9. This process allowed for ease of comparison within and across stakeholder groups, particularly where themes may have overlapped or been complimentary to each other. The use of thematic content analysis also blended well with the examination of the historical social context of the setting (Chapter 4) and the current clinical social context (Chapter 8), as a form of triangulation against the stakeholder group data findings (Chapters 5-7).

During data analysis, no significant gender differences in SRs held by participants were observed, as males and females who participated expressed a variety of socially-held and mediated SRs with no statistical or qualitative difference observed when considered by gender or age. Although this finding could also be a function of statistical power and the small sample for this study, it could also reflect the theoretical positioning of SRT, that SRs are created and shared both within and between groups, in order to mediate and facilitate communication and knowledge production between the individual and the wider social group (D'Alessio, 1990; Jovchelovitch, 2007). As such, individual group members may choose to use certain SRs for certain purposes, and other SRs for other purposes, which may not necessarily be linked to gender or age, but more to communication and context (ibid). Although work has been done by theorists on the links between SRs and gender in terms of semiotics and the constructions of gender identities, this is beyond the scope of this thesis and its research goals (Lloyd & Duveen, 1990).

Whilst it is acknowledged that for many social sciences disciplines, delineating the impacts of gender and age on research findings is an important consideration, in a smaller-scale SRT-based research study this may not always be possible, as seen here. As the research questions for this study focus on exploring the overall SRs held and used by participants as they related to children and HIV on an aggregate level, gender- and age-specific analyses were not explicit goals for this study. The main focus of this research was to map out the SRs in use on a general level, and to explore if and how they captured and reflected the barriers to HIV service access for children in this community. Although the impact of gender on HIV service access, and on some of the SRs in use in the community was discussed by some participants in Chapters 6 & 7, a detailed analysis and delineation of SRs by gender or age is beyond the scope of this thesis, but could be an area for further research.

3.4: Ethics & social considerations

In this section, the ethics process will be outlined, including in-country and local permissions obtained to conduct this study in Kabarole district, with underlying ethical principles noted. Special considerations for working with vulnerable populations include potential risks to participants and the impact of remuneration for participating in this research study, given the significant levels of poverty in this region. Issues concerning informed consent and confidentiality are also discussed, with best attempts to ensure these safeguards taken by the research team.

3.4.1: Ethics approval

Ethical approval and fieldwork permission for this study was granted in London, United Kingdom, by the London School of Economics and Political Science, through the Research Degrees Office and the Research Ethics Committee of the Institute of Social Psychology (now Department of Social Psychology). In Kampala, Uganda, ethical approval was granted by UNCST, the Ugandan National Committee for Science and Technology. All approvals were granted in advance of conducting research in Kabarole district. See Appendices 1-4 for copies of the approvals granted by these governing bodies.

Upon arrival in Kabarole district, meetings were held with local research contacts and officials, to obtain local permissions to conduct the data collection in the area.

Local governance structures and officials in Kabarole district who gave their approval to conduct this research, included:

- the District Health Officer for Kabarole District and the In-Charge Clinical Officer of Amooti Health Centre III for aspects related to HCWs and health services;
- the Amooti Local Chairman for support and approval of research conducted in town with health service users; and
- the District Education Officer for Kabarole District and the Head Teachers for the research with local children in the two government-run primary schools within the Amooti clinic catchment area.

All research was conducted in line with the principles for good ethical research outlined by the British Psychological Society (BPS), as well as those of conducting research with vulnerable groups outlined by the Canadian Institutes of Health Research (CIHR), which funded this research study (BPS, 2010, 2009; CIHR, et al., 2010). Key principles from these professional and research bodies in conducting safe and ethical research include: maintaining a respect for the individual autonomy and dignity of research participants, maximizing social benefit and minimizing risk and harm to participants, obtaining and documenting consent from participants and ensuring the confidentiality of data collected, and being accountable to research participants throughout the process (ibid). In addition, as I am a licensed Registered Nurse, the good conduct and research principles of my licensure body, the Code of Ethics of the Canadian Nurses Association (2008) were upheld during this research. These focus on providing safe and competent care, in this case conducting the research project, ensuring informed decision making of participants, maintaining dignity, privacy and confidentiality of participants, being accountable, and promoting social justice and human rights through this research (ibid).

3.4.2: Special considerations: Vulnerable populations & remuneration
In working with populations which can be considered "vulnerable," such as children or those adversely affected by power imbalances in society, consideration should be given to the purpose and impact of research on their day-to-day lives, as well as during the research experience. Although children are traditionally considered a

"vulnerable population," it can also be argued that adult participants could also be considered "at risk," given the stigmatizing potential of HIV research (Punch, 2002; CIHR, et al., 2010; BPS, 2010). For this research, ethics approval was sought prior to fieldwork, and ethical guidelines followed at all times, with all reasonable attempts made to try and limit the risks of participating in the study. As there is a demonstrated need for further research with children in regards to improving access and adherence to HIV services, as seen in Chapter 1, it was felt that the potential benefits of conducting this research to capture children's voices and experiences outweighed the small risks posed by participation (Punch, 2002; BPS, 2010). In addition, as outlined in section 3.2.2, the research was carried out in ways considered socially and culturally acceptable by local informants and stakeholders, to the best of the abilities of the research team.

Regarding the adult participants, they are also not immune to vulnerabilities, as adult carers could be concerned that their participation might lead to their being excluded from health services. Given this, participants were reminded of the independence and neutrality of the research team from health services, as well as of the confidentiality and anonymous nature of all data generated from the IDIs and FGs. HCWs also faced vulnerabilities in participating, given their position within the system and its own power dynamics between coworkers. As all cadres of HCWs acted as participants, and as there were multiple participants sharing the same job description (e.g. "nurse," "community health worker," "official"), it is hoped this would convey further anonymity and confidentiality for individual responses and quotes used in this thesis. Regardless of stakeholder group membership, for this study, all participants were considered to be vulnerable from the outset, and best attempts were made to ensure participant safety through study design, and informed consent and confidentiality as discussed below.

Remuneration for participation in the research study was used here and as such, is an aspect of conducting research with vulnerable populations which must be considered. Although research project remuneration occurs in richer countries as well as in poorer ones, researchers are split as to the ethics and appropriateness of this practice (Grady, 2001). For this study, token remuneration was given to those who chose to participate, as a small "thank you" for having spent their time

participating in the study. Prior research studies in Kabarole district, as well as elsewhere in Uganda, have remunerated participants, and in doing so, have established this as a common local practice prior to this study taking place (Kaler, et al., 2010; McCreesh, et al., 2013).

In order to try to prevent or limit influence over the information given by the participant, or the duration of the research activity, remuneration was offered at the end of the session and was not mentioned before the participant agreed to take part. Appropriate levels of remuneration were determined with the help of RAs and local informants who had better knowledge of local costs and salaries, to ensure the value was minor enough to serve as an acknowledgement of participation, but not so high as to overly influence participation or research outcomes. Whilst it is acknowledged that remuneration could still influence the data generated by the research activities, I felt it was appropriate to compensate people for their time and effort, given the socioeconomic status of most participants, where over 70% of individuals live below the international poverty line of less than $1.25 USD per person per day (African Agency for Integrated Development, 2010).

For adults participating in the IDIs in their local village, a token gift of laundry soap worth approximately $0.50 USD (1,250 UGX) was given for their participation. Adults who attended FGs, had their transport costs reimbursed, which ranged from approximately $0.50 to $2.00 USD (1,250 to 5,000 UGX) round-trip dependent on location, and a small snack worth approximately $0.60 USD (1,500 UGX) was provided on conclusion of the FG, given its extended duration and distance from the village. HCWs who participated in IDIs were provided with a small snack worth $0.60 USD and an honorarium of $2.00 USD (5,000 UGX) for their participation, which typically occurred during a lunch break. For participating children and schools, the schools were remunerated with supplies totaling approximately $8.00 USD (20,000 UGX), including exercise notebooks, art supplies, and geometry sets for future use by attending children. Remuneration for children who participated consisted of a pencil and an exercise notebook totaling $0.20 USD (500 UGX) per child. Where possible, items in kind were given as remuneration, with money only given to HCWs in lieu of their giving up a break, and to FG participants for transport costs borne by them in attending.

3.4.3: Informed consent

Informed consent has become a major concern for researchers given its often dubious history, not only resulting from World War II's Nuremberg trials (World Medical Association, 2014), but also in the light of much psychological research from the 1960s and 1970s, where the safety and rights of participants were often secondary to the research study aims and goals (Burger, 2011; O'Toole, 1997). Given my background in medical sciences, where informed consent is of paramount importance given the severity and permanence of medical interventions, best attempts were made to ensure all participants were aware of the risks and benefits of participating in the research conducted for this study, and in line with the ethical principles as outlined in section 3.4.1.

For adults, consent was obtained through written and verbal formats, by providing written information about the study and by obtaining signed consent forms in the main local language used by participants, as well as by explaining the research study verbally (BPS, 2010). Information sheets about the study were provided in English or the local language, which also contained contact information for the research team, and participants could take them with them if they wished. This two-pronged approach combining written and verbal consent was used given the potential for illiteracy or low literacy levels amongst participants, who may not have felt comfortable in disclosing this to me out of embarrassment. This approach was used with all participants, including HCWs, to ensure fair treatment, and in recognition that people may process information differently, such as preferring written information over spoken, or vice versa.

The purpose of the research study was explained, as well as confidentiality measures to be taken in the use of the data, and participants were encouraged to ask questions at any time during the research exercise. Adult participants were given the opportunity to drop out of the study at any time, and contact information for the researcher, both locally and in the UK was also provided. Although it is acknowledged that it may be difficult for participants to contact me in the long-term, arrangements were made with the RAs so that I could be contacted when out of the country, in case a participant did not want to have their data included in the research after the fieldwork had finished. This was the best arrangement that could

be made given the resources, timing, and distances involved. In addition, as discussed above, the research team made several follow-up visits to the village after the data collection had finished, so that if participants had any final questions or concerns, they could be addressed directly. Again, no concerns or requests to be excluded resulted from these final visits.

For children, the researcher team visited the schools one week prior to conducting the exercise to discuss the research with the children and teachers at the schools and to provide the children with information to take home to their carers. This delay in conducting the research gave the children time to discuss participation with their carers and teachers, to facilitate decision-making over the child's participation in the research. The research team then returned to the schools approximately one week later, where the research activity and study was again discussed with the children, and where verbal and written consent was obtained from both the participating children, and the teachers in charge of the classrooms where the exercises took place.

Obtaining consent from school children and teachers for in-school research has been used in previous settings successfully, when the nature of the research has been in connection with school curriculum or matters (Howarth, 2002a, 2002b). As HIV is taught in Ugandan primary schools as part of the curriculum (Government of Uganda, 2002), and after extensive discussions with local stakeholders and researchers at the LSE, this was felt to be the most appropriate process for obtaining consent for the research. A draw-and-write exercise had been approved by the Ethics boards of both LSE and UNCST, and the targeted age of 12 years was felt to be appropriate for the children's capacity to understand the research goals and express them to their parents or guardians. As the town in which the schools were situated was also participating in the research, it was felt this was an acceptable process given the continual presence of the research team, and the prior transparency with local adult participants and officials.

The purpose of the research and the role of confidentiality were discussed with the children, and they were given the opportunity to ask questions of the research team at any time during the exercise. Children were given the opportunity to not

participate or to drop out at any time, with the research team's contact information provided to them, as well as to the teachers in case longer-term follow-up or contact was needed. The research team also visited the schools approximately two weeks later to conduct follow-up with the teachers and to meet briefly with the students to see if there were any further questions or issues to be discussed. This led to an informal question and answer session at both schools, about both the study and HIV in general, in which both the research team and the teachers participated to answer pupils' questions. No problems or concerns emerged during this visit or after.

3.4.4: Confidentiality

Regarding confidentiality, in line with informed consent, the security of documents and research material is of the utmost importance (BPS, 2010; CIHR, et al., 2010). To safeguard personal information, access to the information was strictly controlled, and was limited to the RAs directly involved with the research study and myself. This included not using online databases or data bank such as Google documents or Dropbox, as their security and confidentiality is to date unknown; all sensitive information and raw data have been kept offline as much as possible. Locations and times to collect data were varied so that there were no predictable patterns as to what data were being collected when and from whom, with types of data and locations being varied across the time allotted for data collection.

Data collected were anonymized to the fullest extent possible, with any information which would reveal the participant's status or social circumstances blinded or redacted from transcriptions and text. I created a master list of participant names linked to codes for transcripts, which was kept on a password-protected computer to which only I had access, which was kept in secure, locked storage when not in use. No names or any other identifying information such as gender were included in any transcripts, and were removed before transcribing and replaced with only an identification code.

Where participants could be singled out based on job description, such as in Chapter 5 with the HCWs, these details have been kept to a minimum, and anonymized and blinded as much as possible to obfuscate the individuals behind

the data. For example, all nurses are described as simply "nurses" so that individual quotes are reflective not of individuals but of their relative position within health services. Although there is still the possibility that some individuals will be identifiable despite these safeguards, a balance has had to be struck between protecting participant confidentiality and including content which is vital to understanding the issues surrounding children's HIV service access and uptake. In addition, it is hoped that the time component, in terms of the normal operational delay from data collection to thesis publication, here roughly 3 years, will also provide an amount of confidentiality to participants.

Section 3.5: Reflection on the research process

In order to better situate the subsequent data findings, it is important to reflect on the research process. The implications of using a case study approach, and the limitations in using SRT will be discussed, and the positionality of the researcher and the potential impact on research outcomes, will be considered here.

3.5.1: Implications of using a case study approach

For this thesis, a case study approach was been used to explore the SRs held and used by the 3 key stakeholder groups who are most directly involved with issues concerning children's HIV service access, namely HCWs, adult carers, and children. Using a case study approach has its benefits and limitations, which are explored here in relation to this research.

In terms of the data generated by the case study approach, it allows for the investigation of an issue within a real-life setting, which here provides a rich and thick description of the lived experiences surrounding children and HIV (Bauer & Gaskell, 2007). However, case studies, as in other types of research, may not always capture all the experiences encountered by the participants within the social setting, depending on the focus, breadth, and depth of the methods chosen. For this study, whilst it is recognized that there are additional social groups who may have held differing SRs than those expressed here, the use of SRT tries to circumvent this, as participants discuss general representations, which are used across as well as within social groups. As research suggests that there is a core range of representations in use, as part of their communicative function within a society is

that they are used to communicate across social groups, once repetitions of SRs start to appear within sampling, the risk of "missing" SRs lessens accordingly (Moscovici, 2008; Bauer & Gaskell, 2007).

In addition, using a case study approach to explore a non-normative situation, here that of a clinic where there was a surplus of HIV medication and services, as opposed to the more normative shortages of HIV medications and services, is often the better type of situation to study in that it may provide unusual or unique insights which can then be considered in light of more "usual" situations (Eisenhardt, 1989). For this research, exploring why services are not taken up even under the "best" of conditions, can inform situations where services are not taken up under the more usual "worse" conditions of HIV service and medication shortages.

Regarding the conclusions drawn from using a case study approach, although it may be limited in terms of replicability and generalizability, as discussed in section 3.1.3, it must also be acknowledged that all research is imperfect, and contains the potential for misrepresentations, misinterpretations, and biases, both from the researcher and from the research participants. However, in considering the research process for this study, I feel that the main stakeholder groups provided SRs which reflected their lived experience of children and HIV, and that both the personal, psychological experiences and the external, social contexts were captured and explored in this study. As case studies are traditionally used within the discipline of psychology to explore a particular problem or facet of personal or social life, or the interaction between the two, this work reflects that tradition by focusing in on both the psychological and the social aspects of the barriers to children's HIV services within this community, in a way which resonates with other HIV-affected settings in Uganda and internationally (Cornish, 2004).

3.5.2: Positionality of the researcher

Research studies, particularly those conducted in cross-cultural or multicultural environments, are increasingly called upon to be more reflexive about their internal processes, and to consider the impact of researcher positionality on the research process (Caretta, 2014). Although the impact of bias on research participants has been a frequent topic for discussion over the years, it has been only more recently

through feminist and critical theory, that the underlying potential biases of the research team has been called into question (Sultana, 2007). Considering one's positionality and being reflective on the research process is a key ethical task for researchers, and exploring this issue can also help to provide a greater context for the research conducted, given that neither the research nor the researcher is ever truly neutral or value-free (Thomas, 1993).

For me, as a white, female, foreign research student with a background in clinical health services, I found myself having to negotiate multiple worlds and positions throughout the research study, depending on the social context and people involved. Although at times I was an "outsider," as I could not speak the local language and was not from Uganda, I also found myself to be more of an "insider" for many aspects of the research (Merriam, et al., 2001; Srivastava, 2006). Being a health care provider gave me insight into the world of the health clinic, and the challenges faced by the staff members there in terms of bureaucracy and clients. Having had numerous family members ill with chronic diseases over the years connected me with the challenges faced by families in trying to access health care, including the frustrations experienced when a system doesn't meet your needs. Having worked as a research assistant gave me pause to reflect on how things were going for my research assistants, and I tried to balance out my role as their employer with my role of a student who also has a supervisor and funders, to whom I report and to which I am responsible for the work done. And being a student helped me to try to see the world through the eyes of the children participating, as many of them were facing uncertainties related to future study, work, and income, to which I could also relate and appreciate. And despite all of these "insider" moments, I acknowledge it was possible that I may have misinterpreted some of the data and research experiences I had in the community. At times my positionality had positive impacts on the research, in terms of connecting with people and having background knowledge on the subject matter, and at other times the impact was more negative, in that I had to consciously work to limit my own biases, and to try to ensure the voices of the participants were captured and presented as accurately as possible.

In terms of my positionality influencing the research study topic of children and HIV, I often felt myself caught between two worlds whilst conducting research: that of the

HCWs, as my own immediate work background was in the area of clinical service provision, but also that of the adults and children, as I was a relative of several family members, including children, who had lived with chronic and life-threatening illnesses such as cancer, to which stigma and fear are still linked. However, I felt that this was in fact a strength which gave me insight into both sides of the issue of health service provision, and allowed me to take a more balanced view and give voice to both perspectives in a fair and equal way. In addition, the topic of children and HIV was an issue that was related to my own experiences, in terms of difficult chronic conditions in young people, yet was different enough that I could be less emotionally involved as I would be if it were a disease which had personally impacted me. Although researchers are ideally meant to be as objective as possible, post-modernist theory suggests that objectivity is impossible, as all knowledge is subjectively created (Thomas, 1993). It may be better to think of research as being "subjectively objective," in that researchers always approach the research topic and methods with their own experiences, preferences, and biases, but that the best researchers acknowledge this, and try to limit this influence on the findings as much as possible.

My positionality also can be seen in the approaches to the research study taken. For this research, my previous experience working in this part of Uganda on a quantitative, biomedical research study directly influenced me to do a qualitative study, as discussed in section 3.1.1. Although the prior study confirmed the need for further research into the barriers preventing children from accessing HIV services and medication, I felt that the quantitative approach taken did not do justice to the nature and scope of the problem faced by both HCWs and service users in this community. From my own background, having been both a HCW and a relative of people living with serious chronic illnesses, I wanted to capture these lived experiences from both sides, and to explore the inner and outer aspects of service provision and service uptake jointly. I wanted to capture the multiple viewpoints of children's HIV service provision and explore them together, which is not always done in medical-based, quantitative studies. In addition, I didn't want to lose the person in the data, but also wanted to ensure that the results couldn't be dismissed simply as a token anecdote. This led me to choose qualitative-based methods which would capture multiple stakeholder voices and find the unity in diversity which

would give strength to the discussion of their shared experiences. Based on my previous work and on discussions with more experienced researchers, I also chose to use different data collection approaches for adults versus child participants, recognizing that the varied age and life experiences of the different stakeholder groups would result in different needs and capacities to participate. As I wanted to capture the lived experiences of participants "as is," I chose methods which I felt would accommodate their needs and capacities to participate.

The analysis of the data findings and the conclusions I have drawn in this study are also influenced by my positionality. As I chose to use a qualitative approach with multiple methods, this lent itself more to qualitative-influenced analysis than quantitative-based methods. SRT-based research can be analysed in several ways, with two common choices being text mining from media or database sources, which uses a word frequency approach, and narrative-based interview methods, which trace out the life trajectories of participants and explore how SRs and stories form self-identity (Lahlou, 2001; Jovchelovitch, 2007). For my research, I was drawn to qualitative thematic analysis, as it seemed to be the best "fit" with the study goals of mapping out the SRs in use regarding children, HIV, and health services, and allowed for the opportunity to explore the similarities and differences in the SRs used by the stakeholder groups. This allowed for an examination of the psychosocial barriers to children's HIV service access, and when combined with Bauer & Gaskell's (1999) Toblerone model, pointed to future directions for work to address and reduce these barriers, by building on shared SRs and using conflicting SRs as entry points for broader social dialogue and discussion on children and HIV.

The challenge for me was to ensure there was a balance in the viewpoints of the stakeholder groups, and to ensure the data sets were analysed with equal weight and voice given to them. This was difficult at times, for while the HCWs were the most fluent and expressive about the barriers to children's HIV services as they saw them, the pictures and stories produced by children had the most emotional impact for me, as I am a more visually-oriented person, and the content was very visceral and "raw." As a result, at times I found it difficult to balance out the voices of the stakeholder groups, particularly that of the adult carers, and so chose to give each stakeholder group their own chapter as "space" for analysis, with the final chapter

being a communal "space" to consider the findings as a whole, and to explore what broader social possibilities exist to address the barriers faced by participants in accessing and providing children's HIV services. Including my own voice and the voices of the research assistants was also difficult, and limited in retrospect, as at the time I felt the focus of the study should be on the participants. Although there is reflection on the research process here and in Chapter 8, in future work I would include more information from the research assistants and myself as data for analysis and not just as a reflexive process. Ultimately, no research study is perfect, and by acknowledging the potential influence my positionality had on the research topic, approach, analyses, and conclusions, I hope to situate the knowledge produced by this study back into its greater overall context (Rose, 1997).

3.5.3: Limitations of SRT and the thesis approach

A thesis has limitations, and this work is no exception. Choices have been made in terms of theory, methodology, and analysis, which have both shaped and been shaped by the research experience and data collection. The implications of these limitations, and how they impact on the topic of children's HIV service access, are considered here in closing.

Regarding the limitations of using SRT as my theoretical perspective, I recognize that alternative theoretical perspectives will be disregarded, as previously discussed in Chapter 2. By choosing to use a social constructivist position, this positions society as having the ultimate supremacy over the individual, and can assume that there is limited individual capacity for action and resistance to the social status quo, as opposed to more individualistic perspectives such as behaviourism, where the individual is positioned as having ultimate control over his or her life (Abraham, et al., 1998; Trafimow, 2009). However, given the broader social context of this setting and topic, choosing SRT is justified, as it gives me the perspective to examine the interplay between the individual and society, in a setting where there are serious social power inequalities related to "low social cohesion and low wealth" (Barnett & Whiteside, 2006, p. 96). In addition, using SRT also provides a modicum of mental safety for participants, as it allows them to speak more generally and abstractly about a potentially disturbing and highly emotional topic, without having to disclose their own HIV status or stories, if they choose not to do so. Given the findings of

stigma and its impacts discussed in subsequent chapters, this is a "safer" option than other theories may provide, and I am glad I chose it.

SRT has also been criticized for its appearance of reinforcing the social status quo through social determinism, by portraying research participants as passive and unable to challenge or break free from the SRs in use in their society (Voelklein & Howarth, 2005; Howarth, 2004). Instead, my research findings suggest SRT acknowledges that, whilst individuals can always make their own choices, a larger social collective and social cohesion on a particular topic is needed to scale up any major changes to the social status quo, as is discussed in Chapter 9. Although SRT can be seen as lacking an overtly critical agenda, as SRs may not critically engage with the social status quo but reflect it and the underlying social hegemony (Howarth, 2006; Voelklein & Howarth, 2005), my experience suggests this may be more about the researcher and the scope of the research project, as this work questions many practices and SRs seen by stakeholders as barriers to children's HIV service access. Instead, this is a valid question for all research studies: should researchers only observe and report social happenings, or should researchers use their knowledge to challenge and change the social settings in which they work? For this research, I feel the former must happen before the latter can occur, and so position this research study as the former, and a beginning.

As for methodological limitations, in choosing qualitative-based methods, I limit my ability to draw quantitative or numerical conclusions on children's HIV access from this research. However, accurate quantitative statistics are not possible without conducting a large-scale, population-based study including HIV testing, which is beyond the scope of this research (Lowenthal, et al., 2014). I also recognize there are other stakeholder groups and voices which were not a part of this study, including church groups and the clergy, teenagers, children of other age groups, and children not attending school. Although there is the possibility that their inclusion may have led to alternate SRs being generated, reflecting upon the findings discussed here in the following chapters, I feel confident that the SRs generated here are relevant to these groups as well, and reflect the broader SRs used to frame the lived experiences shared across stakeholder groups, all of whom share the current health system and social context concerning children and HIV.

Finally, in terms of the analytical limitations of this thesis approach, using SRT does exclude other analytical choices which link theory, methods, and analysis together, such as participatory action research or grounded theory (Thomas, 1993; Glaser & Strauss, 1967). Although these approaches have their benefits, such as keeping the focus of research on the participants, and providing participants with the opportunity to create and drive the research agenda (ibid), I felt that this would not work, due to previous failed attempts by other researchers working in this setting. As for the limitations of the analysis of the data generated, it is possible that alternate interpretations of the SRs presented here may not have been captured by this study. In addition, despite best efforts to ensure the findings were data-driven and captured the voices of the participants accurately, I acknowledge there may have been inadvertent mistranslations or misinterpretations during the analysis process, which may have impacted on coding, theme generation, and final interpretation. Ideally, a large-scale, well-staffed and well-funded multi-year research study would use the SRT approach and thematic analysis to ensure the highest amount of accuracy and community involvement possible. However, given the limited budget and scope of this PhD research, all efforts were made to ensure a high-quality study which captures and reflects the voices of the participants, and also considers the impacts of the research process and researcher on the study itself.

Conclusion

Despite the potential for difficulties in conducting this study, given the multiple stakeholder groups and multiple methods for collecting data, the research project ran well and I was able to construct a good corpus which could then be used for analysis. Risks to participants were kept to a minimum, and the research team worked well together with no major incidents or problems in conducting the work, and none reported to me since the in-field data collection was concluded. As much preparation had been undertaken before the study was conducted, and as I had prior experience working on research studies in the area, the in-field research progressed smoothly and was successfully completed within the projected time frame of four months, thanks to careful thought, planning, and implementation.

Chapter 4: Historical social context of Kabarole district

Introduction

The country of Uganda has an interesting trajectory on the "leading edge" of the global HIV/AIDS pandemic experience, as the pandemic hit in the 1970s, well ahead of other countries in sub-Saharan Africa (SSA) which would be affected in the 1980s (Barnett & Whiteside, 2006, p. 127-131; Parkhurst, 2005; Mugyenyi, 2008). Its turbulent social history from that era further complicates many of the social effects of HIV, including negative impacts on families, communities, and health service provision (ibid). In addition, many of the social contexts and social representations (SRs) which are currently in use in Uganda in relation to HIV and health services, have historical roots which can be traced back to this era or earlier. An overview of the historical SRs and social contexts, relevant to Kabarole district and the area of research, namely children and their access to HIV services, will be explored here. As the social and political history of Uganda has both had an impact on, and been impacted by, the emergence and spread of HIV within the country, it is important to examine this information to help situate the data findings presented in Chapters 5 through 8 more fully. In addition, more recent HIV/AIDS-related policy directions in Uganda will be considered in terms of potential social impacts, in the light of these historical trends.

Although records for Kabarole district in the pre-colonial and colonial eras are scant, it is possible to trace back social and political conditions, with sources compared for triangulation of data as much as possible, given the limited scholarship available, and the fact that the British colonial administration of the era may have been less than objective in its reporting (Winter, 1959; Ingham, 1975; Taylor, 1998). However, these works do provide an insight on Ugandan society and social structures leading up to the post-colonial independence era, after which indigenous Ugandan social scholarship becomes more available (see Kyemba, 1977; Mutibwa, 1992). The sources used here will be examined using a Social Representations Theory (SRT)-influenced historical approach, through a longitudinal examination of the background context of social and historical conditions in Ugandan society, which may influence the current SRs and study findings of the present as detailed in Chapters 5 through 8.

The rationale for examining this social history is from work done by Bauer & Gaskell (1999, 2008), as discussed more in-depth in Chapter 2, who make the case for examining SRs not as static, single-point entities, but rather as long-term, evolving social projects, with representations changing or being reinforced by a society over time, as influenced by broader social conditions, occurrences, and goals. They have proposed a "Toblerone model" for SRs, where a time element should be considered when researching SRs, in that the social projects of SRs are continuous, and that, like the multiple segments of a Toblerone chocolate bar, the SR projects of the present can also be extended into the past and potentially extrapolated into the future (ibid). Examining SRs in this way not only allows the researcher to better see the social progression or regression of SRs over time, by illustrating how the past has impacted on the present, but would also capture the wider social context or *milieu* in which the SR is situated. Such research findings would be a useful way of examining the need and potential for social change within a society, by triangulating current data against historical events, and allowing for cautious speculation as to where the SRs could be potentially trending to occur (Foster, 2011). Such an analysis could then be used to help communities in negotiating social change, by determining which SRs help or hinder them in achieving their social goals, which will be done in Chapter 9.

4.1: Pre-colonial era (pre-1830s)

4.1.1: Social conditions in pre-colonial western Uganda

Although there is limited recorded scholarship in the history of western Uganda, oral histories have recorded the political and social structures of the kingdoms and ethnic groups residing in what is now called Kabarole district (Ingham, 1975). This tradition recounts kings and events going back tens of generations, and is regarded by scholars as being the only way of tracing back this part of Uganda's past (Ingham, 1975; Taylor, 1998). A generalized sociopolitical pattern which emerges is that of kings assuming control of an area typically through inheritance or warfare, often by infighting within the royal family, and ruling until death or being deposed by another family member or court member (ibid). Whilst such political changes affected the elites of society, life for the non-royal peasantry remained fairly consistent, with clan-based subsistence agriculture, itinerant pastoralism of livestock, or a mixture of both (ibid). Social organization was very much a rigid, top-

down hierarchy, with royals over commoners, men over women, and the elderly over the adults and the young, and deference to those of a higher social standing than you being obligatory and unquestioned within the confines of a highly stratified, patrilineal clan system (ibid). Economic trading and contacts with outsiders was limited and regional, as the area was self-sustaining in terms of crops, water, and metals (Ingham, 1975).

Figure 4.1: Map of Toro during British Protectorate era
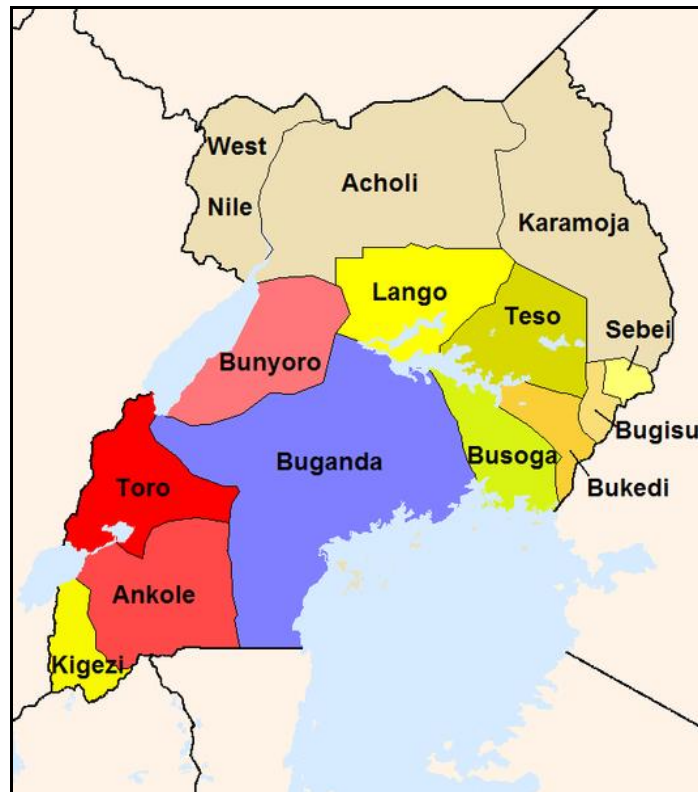
(Wikimedia Commons, 2013)

The wider region (see Figure 4.1) has traditionally been a multiethnic entity, and three ethnic groups are predominant to date: the Batooro (Batoro), who remain the majority in the district and give name to the Toro (also spelled Tooro) kingdom; the Bunyankole (Banyankole, Banyankore) with historical links to the Nkore/Ankole state to the south; and the Bakonjo (Konjo) in the Rwenzori mountains with links to what is now the Democratic Republic of the Congo (Ingham, 1975; Taylor, 1998; Government of Uganda, 2011). The creation of the Toro kingdom in the 1830s, which encompasses Kabarole district today, saw increased connections between

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these ethnic groups, as a result of the monarchy's impetus to gain and retain social control, with many customs blending due to the similar social, economic and geographic day-to-day living conditions across the ethnic groups in general (Ingham, 1975; Taylor, 1998).

4.1.2: Pre-colonial representations of children and family structures

Whilst it is difficult to reconstruct the representations of children, the anthropological studies from the colonial era do offer insight into rural family dynamics not yet affected by the major social changes which take place at end of that era in the 1940s (Taylor, 1998; Winter, 1959). Traditional family structures in the pre-colonial era were highly patrilineal, age-hierarchical, and frequently polygynous; the family unit consisted of a man and his wife or wives, with senior wives typically having more familial power than junior wives, living in a family compound with their children and frequently his parents, if they were still alive (ibid). This social pattern continues in Uganda today, as 28% of married women report being in a polygynous marriage, with their experiences ranging from degrees of acceptance, to uneasy partnership, to conflict and strife (Seeley, 2012). Historically, if the man was well-off, he would have multiple wives, and the family compound was typically a collection of huts with one being built for each wife and shared by her and the children she had with the man, with the man sleeping at alternate huts over time (Taylor, 1998; Winter, 1959). If the man was less well-off, he would either have only one wife, or a few smaller huts could be shared jointly between multiple wives and their children (ibid). Jockeying for power was not infrequent between wives, who did the majority of the farming on the family's plot of land and ran the household (ibid). The man would also engage in a variety of duties, ranging from very little, to active farming, hunting, or more rarely trading in local markets (Winter, 1959). Women could exercise limited agency in negotiating the choice of husband, but often faced major family or social consequences in doing so (ibid). Such difficult family dynamics continue today, as seen in Chapters 5 & 6 concerning HIV disclosure and marriage.

For children, "childhood" was focused on socialization into the clan and the indoctrination into strictly divided gender roles, and children of both sexes were seen primarily as workers for the family, typically helping the wives in subsistence agriculture and livestock rearing (Taylor, 1998; Cheney, 2007). Education of

children was informal and focused on the life skills needed to survive as a subsistence farmer of the time (Taylor, 1998). The gender bias and preference was toward males, as boys stayed with the father's clan and also acted as a de facto insurance policy for old age: the more sons a man had, the more virile and masculine he was considered socially, and the more likely he would be well-provided for in his old age (Taylor, 1998; Winter, 1959). Girls were seen as less valuable to the family, as they would go to live in the family clan of the husband once married, and so not be there to work or provide for their parents (ibid). However, they still had economic value in that they were sold for a bride price once of marriageable age, typically at puberty, or could be promised for marriage at any time in their childhood or "traded" for a wife for a son (ibid).

4.1.3: Pre-colonial representations of health, illness & health services

Although pre-colonial representations of health and illness are difficult to source, anthropological studies in Kabarole district suggest a conceptualization of health as the absence of disease, similar to many other cultures and eras (Taylor, 1998; Winter, 1959). Local SRs of illness were often portrayed in magico-religious terms, as the result of "witchcraft" or sorcery, typically from a malevolent person wishing ill on the afflicted person, and either performing a curse themselves or obtaining the services of a "doctor-diviner" to curse the targeted person (Taylor, 1998). Incidents such as a miscarriage or the illness and/or death of a child were also interpreted as witchcraft, possibly arising from jealous co-wives (Winter, 1959). Historical illnesses appear to include epidemic outbreaks, malaria, malnutrition, parasites, gastrointestinal and respiratory infections, illnesses related to pregnancies, and injuries, particularly burns from cooking fires, which still occur in Kabarole district and Uganda (Kuhanen, 2005).

Health services in the pre-colonial era were centered on local herbal knowledge, home-based remedies, and spiritual belief practices, and sometimes involved magico-religious work, which was handed down within families, or accessed through the services of a "doctor-diviner" (Taylor, 1998; Winter, 1959). Most health service provision was home-based or village-based, from the practitioners who either offered their services for free if a relative, or for payment if not related, mainly using livestock or foodstuffs, or in the later colonial years, money (ibid). Witchcraft

was also a convenient insult and accusation used in interpersonal conflict on a regular basis (Winter, 1959). Given the mysterious and often malevolent SRs of misfortune and illness, these health service providers were often viewed with suspicion and mistrust, as the person curing the illness may well have been contracted to cause it in the first place (Taylor, 1998). The power to heal held by these individuals was also viewed with fear and unease, as the "cure" often didn't work, in which case the patients or the family were often blamed for the failure instead (ibid). Echoes of such fear, suspicion, and blame have been resurrected in the representations of HIV, as will be discussed in section 4.4, and are also seen in Chapters 5-7.

4.1.4: Relevance for current representations of children, HIV, access & adherence
Representations linked to social and family hierarchical structure from the pre-colonial era appear to still influence present day SRs discussed in subsequent chapters. As will be discussed in more detail in Chapters 5-8, the general social organization in the district still tends to be top-down hierarchical, both in the health care system and in the home, with men having greater privilege and power over women in all aspects of social and familial life. Women still have limited life and social choices, and continue to be economically marginalized and socially stigmatized, particularly with HIV stigma, as noted by adult and child participants in Chapters 6 & 7. Male privilege is still the norm in society and in relationships, with health service users themselves noting that modified forms of polygyny continue into the present, as will be discussed in Chapters 6 & 7.

Adults continue to have greater power over children, as will be seen in Chapters 5 & 7, with children still being represented as sources of labour, income to a farming family, and as old age insurance. In Chapter 6, adult participants remark on how school-going children are becoming more assertive and "misbehave" more frequently than in previous years, and feel threatened by this change in social positioning. Despite this, however, many participants (see Chapters 5-7) feel that girls still face familial and economic pressure to give up schooling before reaching the secondary level, which often results in their dropping out and working on the family farm, getting married when still a teenager, or engaging in transactional sex relationships to be able to afford to continue schooling (Samara, 2010). In addition,

a latent mistrust in health service providers still exists for some service users, as noted in Chapters 5-7. As will be explored further in Chapter 8, the impact of HIV stigma and a lack of social and familial trust, combined with a top-down social hierarchy replicated in the clinic, all impact negatively on children's likelihood of access and adherence to HIV services.

4.2: Colonial era (1830s to late 1950s)

4.2.1: Social conditions in colonial western Uganda

The colonial era in Uganda, from roughly the 1830s up to independence in 1962, sees the increasing use of written records and scholarship, which aids in reconstructing the political and social dynamics of the time, albeit predominantly from the British point of view (Kuhanen, 2005). Although British influence in the area was ongoing from the early 1800s, Uganda was taken over as a protectorate of Great Britain under the Imperial British East Africa Company in 1888 at the height of the "Scramble for Africa" by European nations (Ingham, 1975). The period of the late 1880s through to the early 1920s was the peak of the British colonial era in Uganda, in which British influence and political power was at its height, and during when the historical kingdoms were used as vassal states enforcing local law and order under the "supervision" of a colonial administrator (ibid). The kingdom of Toro in western Uganda was one such kingdom, which had been engineered into being by a son of the then-king of the larger Bunyoro-Kitara empire, by partitioning off part of the empire and turning it into his own kingdom, with the help of the British in exchange for his support of their drive to open the area up to trade and transport into central Africa from the Swahili coast (ibid). The kingdom of Toro was therefore a sort of kingdom of convenience for the British, allowing them to keep control of the area, without having to actually be in control of it themselves (ibid).

Unlike similar ventures in southern Africa, however, the British East Africa Company did not fare well in Uganda, in terms of its mandate to increase trade and make money for the crown, and within three years, in 1891, it pulled out of the western region, with the British colonial administration left to manage and monitor the kingdom and its rulers, to varying degrees of success from both the British and Batooro perspectives (Ingham, 1975). Over the next several decades, an often antagonistic relationship pattern emerged, where the British sought to impose rules

on the region and its rulers, which did not take into account or reflect local conditions or realities, and which were then patently ignored by Toro rulers, who found them to be ineffective and undermining of their local authority (ibid). Interestingly, this pattern can still be seen today, in terms of tensions and contradictions between international and Ugandan national government policies, versus the variety of local interpretations and implementations, or even the outright lack thereof (Ingham, 1975; Taylor, 1998). Section 4.4 will discuss the current impacts on HIV funding and programming in terms of global versus local scale.

For the general population, however, the political machinations of these elites had little effect on them, as the traditional lifestyles, in terms of socioeconomic conditions and social kinship practices, lasted through the era (Taylor, 1998; Ingham, 1975; Winter, 1959). Britain's socioeconomic needs in support of the Second World War impacted on colonial-era Uganda by opening the area up to foreign trade and economic influences, including exposure to European-influenced lifestyles, through the beginning of wide-scale wage employment and migrant labour into towns for wage paying jobs (Ingham, 1975; Winter, 1959). In addition, the late colonial era of the 1920s to 1940s saw the establishment of government dispensaries, later to become Ugandan government health centres, throughout smaller regional towns in Uganda, and the building of hospitals in larger, regional administrative towns (Winter, 1959; Taylor, 1998; Ingham, 1975). Whilst Christian missionaries had been providing formal education to selected children in the kingdom since the mid-1800s, by the late colonial era, secondary schools and technical colleges had also been created, in line with British hopes of devolving their presence in Uganda, and leaving it in the hands of local civil servants in a form of home-rule (Ingham, 1975; Taylor, 1998).

4.2.2: Colonial era representations of children & family structures

By the colonial era, the advent of the missionary schools and churches in Kabarole district was starting to influence the representations of families and childhood, with a corresponding effect on family dynamics (Taylor, 1998). Although the numbers of children attending missionary elementary schools was low, the establishment of religious institutions and the uptake of Christianity and its social messages had a wider impact on family structures, with traditional polygyny conflicting with the

foreign concepts of Christian monogamy as the basis for marriage (Taylor, 1998; Winter, 1959). Over time, an urban-rural split emerged, with Christian concepts of monogamy becoming more accepted in urban areas, and isolated rural areas which were out of reach of the missionaries, maintaining their traditional practices (ibid). By the end of the colonial era, however, the concept of monogamous marriage became more normative, and became the legally accepted form of marriage prior to independence in 1962 (Taylor, 1998).

In terms of the changing notion of "childhood," the colonial era mission schools were the first establishment of a formal education system, and contained colonial and Western representations of children and childhood, which influenced the families of children who attended them, through changing concepts of work and society (Cheney, 2007; Taylor, 1998). The children who attended these schools at first were the ones who were being prepared for paid employment of some kind, where literacy and numeracy skills were required for wage labour (ibid). The larger social shift towards paid employment in the 1940s changed family dynamics, as migrant labour and the beginnings of a colonial, indigenous middle-class of civil servants being groomed to take over from the British, saw some leave farming for towns and cities to capitalize on this opportunity, often adopting Westernized lifestyles along with it (ibid). The majority of the population, however, remained rural and fairly traditional in lifestyle (Winter, 1959).

4.2.3: Colonial era representations of health, illness & health services
With the colonial era in Kabarole district, Western ideas about health and illness only slowly came into use in the district, due to the lack of direct Western influence, infrastructure, and development in the area (Taylor, 1998; Winter, 1959). Missionaries at first had only rudimentary medical skills and supplies, but later mission societies sent medical personnel, who often became very knowledgeable about local diseases and remedies (Taylor, 1998; Kuhanen, 2005). Whilst larger towns had hospitals built primarily to serve foreign staff and local townspeople living there, local dispensaries which served the wider population were only opened up in smaller and rural towns from about 1920 on (Winter, 1959; Taylor, 1998; Ingham, 1975). The late colonial period of the 1920s to 1940s also saw an increase of

mission-based health services, often operating in a coordinated effort with government services (Kuhanen, 2005).

The increasing use of dispensaries, and the Western medication provided from them, slowly started to influence representations of illness, as many newly developed Western medicines and treatments for local ailments and diseases were more effective than traditional methods had been (Taylor, 1998; Winter, 1959). As a result, Western concepts of health and illness became increasingly accepted across the population, often alongside traditional beliefs and representations through medical syncretism, particularly in the remote and rural areas, where Western health service access was often linked to missionaries moving through the area (ibid).

The end of the colonial era saw a further increase in the uptake of Westernized health representations, as the success of Western medicine in effectively treating local diseases was combined with more hospitals and health centres being built for the local population (Winter, 1959; Taylor, 1998; Ingham, 1975). For most of the colonial era, there had been only 13 hospitals in Uganda, with just one in the district at Fort Portal (Kuhanen, 2005). By the 1950s, a Western-style medical system and medical education system had been created in Uganda, including a nursing college in the Fort Portal area and additional hospitals outside of town (ibid). Despite this "foreign" system being imposed on local populations across the country, there was a general acceptance of it, as it was seen to be not only effective for many illnesses, but also relatively value free, as it was not connected to the traditional health methods and their link to witchcraft and sorcery (Taylor, 1998; Ingham, 1975). As Christianity became more adopted by the local population, so too was the Western model of medical services, as the two became linked through outreach work by the Christian churches throughout Kabarole district and elsewhere in Uganda (Taylor, 1998; Kuhanen, 2005). However, despite the positive response by the local population, health services were generally poorly funded, poorly staffed in terms of numbers and qualifications, and plagued by poor record keeping and reporting, characteristics which remain to date (Kuhanen, 2005). These problems will be further explored in Chapters 5, 6, 8 & 9.

4.2.4: Relevance for current representations of children, HIV, access & adherence

One major representation emerges from this review which is relevant to current HIV service issues, as will be detailed further in Chapters 5, 8 & 9. Kabarole district was established essentially as a "kingdom of convenience," as opposed to a state emerging from a prior ethnic or politically unified entity, which could be linked to a lack of social cohesion within the area, as will be discussed in Chapters 5-8. Many of the research participants feel they do not work or live in a supportive social environment, with children feeling particularly vulnerable to a community riddled with HIV risk. Although social cohesion can come through wider ethnic group or cultural ties, as seen in eastern Uganda with the Baganda cultural group (Seeley, 2012; Cheney, 2007; Kuhanen, 2005), here there appears to be a lack of social cohesion in the district, with little social capital or trust, as an underlying social context. This is further influenced by a historical reliance on individual family clans for social support and assistance (Winter, 1959; Taylor, 1998). For participants in this study, the main source of help and support remains the extended family first, and then, possibly, immediate neighbours if circumstances are dire (see Chapter 6). This suggests there may be a continuing lack of social capital and trust since independence, which may have roots in the pre-independence eras, but which has intensified in the anarchic post-independence eras, as seen in sections 4.3 & 4.4.

Putnam (2000) defines social capital as the networks between people which have value by bringing life enrichment and mutual support to those who engage in them. This also suggests that broad social connections are needed to develop social capital, which in some countries has come through engagement in civic or leisure activities, such as community or church groups, shared activities, and discussions (ibid). Engaging in these activities can help to build a sense of trust in other people and shared community, which allows for even stronger social ties and networks to then be developed (ibid). In this regard, social capital is seen not as a function of simply "getting by," or basic survival, but rather that of "getting ahead," where more aspirational needs can be met through a supportive social setting (ibid, p. 23).

In Kabarole district, it appears that people are unable to move from getting by to getting ahead due to this lack of social capital, trust, and social cohesion (Putnam, 2000), and that the community resources which are in the district, whether

government-run, private, or religious institution-based, are either not available to, or are not resonating with, service users, exacerbating social tension. This occurs despite reports which suggest that there are between 150 and 400 different non-governmental organizations (NGOs) and community-based organizations (CBOs) in the district, of which the majority are purportedly poorly funded, poorly staffed, and do not offer much assistance beyond a limited network of people or communities, as corroborated by participants in Chapter 6 (Kajubu, 2010; Mbayahi, 2012).

These social tensions and a lack of institutional social capital are also seen in the health service system, through the continued frustrations between local-level health service "elites" and national or international representatives, as seen in grievances over HIV services and health clinic staffing between health care workers (HCWs) and officials, in Chapters 5 & 8. This unsupportive relationship is further complicated by a health service system that was born of colonial era needs, but has not been modernized to keep up with current demand or service provision modalities resulting from HIV (see Chapter 8). When coupled with a habitually poor material supply and an excluding social environment as discussed in 4.1.4 and Chapter 8, and continued low social capital, cohesion and trust as seen here, prospects for increased uptake of clinic services by children and families do not appear promising, as will be discussed in Chapter 9.

4.3: Post-colonial era (1960s to late 1970s)

4.3.1: Social conditions in post-colonial western Uganda

After a series of political wrangles in the late 1950s, Milton Obote and the Uganda People's Congress party joined with a Buganda loyalist party to bring about Ugandan independence from Britain in 1962, with Obote becoming Uganda's first Prime Minister (Mutibwa, 1992). It is important to note, though, that this push for independence and self-governance was not from the wider population themselves, but was engineered by local political elites for their own benefit, a pattern that haunts Ugandan politics to the present day (ibid). The early 1960s saw an increased adoption of Westernized ideas about education, work, and health, and there was a relatively smooth transition to independent statehood (Kuhanen, 2010a). However, in 1966, accusations of smuggling and profiteering against his regime led Obote to suspend the constitution and establish a state of emergency,

giving him unlimited powers where he declared himself President of Uganda, consolidated his power base over the country through the use of the military and cronyism, and in 1967, abolished the traditional kingdoms which helped him gain power (Mutibwa, 1992; Kyemba, 1977). An assassination attempt on Obote's life in 1969 started a reign of terror, marked by human rights abuses of perceived enemies by the military and secret police, including forced disappearances and murders (ibid).

Uganda would fare no better in the 1970s, when all hell truly broke loose. In 1971, Obote was deposed in a coup d'etat by a Ugandan army commander named Idi Amin, whose own reign of terror would be characterized by political capriciousness, economic ineptitude, and the sociopathic slaughter of anywhere from 80,000-500,000 people, often on the flimsiest of whims (Keatley, 2003; Kyemba, 1977; Mugyenyi, 2008; White, 2012a). Amin's homicidal pillage and plunder of Uganda would finally end in 1979, when, in a failed attempt to invade Tanzania, he fled into exile, eventually settling in Saudi Arabia and dying there in 2003 (Keatley, 2003; Mugyenyi, 2008). The latter years of Amin's regime can only be described as social anarchy, and the chaos it produced was to become the prime breeding ground for Uganda's next disasters: civil war and the disease of HIV/AIDS (Kyemba, 1977; Mutibwa, 1992; Mugyenyi, 2008).

The anarchy of Amin's rule in the 1970s provided ideal conditions for HIV/AIDS, and the emergence of the disease can be traced back to a key area in Uganda: the Rakai district (Kuhanen, 2010a, 2010b). An important border area on Lake Victoria between Uganda and Tanzania, Rakai was the key black market centre which provided anyone not in Amin's elite circle with goods smuggled in from Tanzania (Barnett & Whiteside, 2006; Kuhanen, 2010c). It was also a major farming and fishing area, and when combined with the smuggling of trade goods, became the only real economy people could have access to, for a price (Seeley & Allison, 2005; Kuhanen, 2010a, 2010b). For men, that price was often engaging in smuggling, and for women, prostitution became the major activity used to earn income or goods (Kuhanen, 2010a; Larson, 1989; Mugyenyi, 2008). Across Uganda, people did whatever they could to survive, regardless of whether they thought it might be illegal or immoral; it was simply survival (Kuhanen 2010a, 2010b). The lifestyle based on

this illegal trade was called *magendo*, and referred to living for today, as no one thought they were going to see tomorrow, and were often right (Kuhanan, 2010a; Barnett & Whiteside, 2006). A risky lifestyle was the only option, as those "caught" engaging in illegal activities by police or soldiers, who were often the customers of said activities, could be let off, fined, incarcerated, attacked, raped, or outright murdered with impunity, as Amin had dissolved the justice system along with the constitution upon taking power in 1971 (Kuhanen, 2010a; Barnett & Whiteside, 2006; Mugyenyi, 2008). Echoes of this can be seen in Chapter 7, in present-day children's SRs about the inevitability of HIV infection and social risk in their community.

4.3.2: Post-colonial era representations of children & families

The social chaos of the post-colonial era makes it difficult to piece together the representations of children, as society and families were under great stress and often highly fractured at the time (Mugyenyi, 2008). Some scholars suggest that the era of 1966-86 was that of a lost generation in Uganda, as schools and jobs were virtually non-existent, and children grew up very quickly in order to survive, with many doing whatever it took to survive the chaos (Mutibwa, 1992). As formal education and social opportunity was denied them, and as they were often surrounded by fear and death, this lost generation also in a sense had lost childhoods, further impacted by the beginnings of HIV/AIDS, where whole families were again destroyed, with many children experiencing orphanhood or being moved from extended family to extended family (Mugyenyi, 2008; Cheney, 2007; Kipp, et al., 2007). The psychosocial impacts of repeated destruction, death, and deprivation are almost unfathomable, yet children and their families managed to survive this era nonetheless.

4.3.3: Post-colonial representations of health, illness & health services

With independence in 1962, the government had increased health services, continuing to work with Christian religious institutions to provide the bulk of health services and training, particularly nursing schools, outside of Kampala (Kyemba, 1977; Kuhanen, 2005). As the colonial era health system was still feasible to run immediately post-independence, there was no pressure on it to modify the original centralized feeder system design into a network of regional referral centres outside

Kampala, supported by increased funding and staffing levels, as was happening in other countries globally (Kuhanen, 2005). Instead, the high-level, intensive health work remained based in the large teaching hospitals in Kampala, with smaller hospitals and health centres in minor towns outside of Kampala referring in major cases in to be seen, having themselves been referred the cases from the more rural dispensaries which were neither equipped nor staffed to handle them (Kyemba, 1977; Mugyenyi, 2008; Kuhanen, 2005). Although this system may have worked at the time, the social chaos of the 1970s quickly overwhelmed the system, with those not in Kampala left underserved and cut off from higher-level and higher-quality health services, until total system collapse in the late 1970s destroyed health services across the country (Kyemba, 1977; Mugyenyi, 2008).

Although Westernized notions of health and illness had become the norm in Kabarole district, medical syncretism was still in use, with many people using both Westernized medical services and traditional, indigenous herbs as a sort of hedge against each other, particularly in the still underserved rural areas (Taylor, 1998). Medical syncretism also became a way for people to cope with poor health service provision during the late Obote, Amin and early "bush war" years from 1966-1986, when the health service system barely functioned across Uganda, and many HCWs had either "disappeared," been killed, or fled outside of Uganda to safety and paying jobs, in order to send remittances back to their families to keep them alive, as this was often the only source of income available to them, the economy having collapsed under Amin (Kyemba, 1977).

4.3.4: Relevance for current representations of children, HIV, access & adherence
The civil strife of the later Obote and Amin years had a disastrous effect on population health across Uganda, and decimated health services and staff, with the population often going back to using traditional medicines where they could, or coping via medical syncretism, as most Western-style medical supplies were either unattainable or had to be smuggled in at great cost and risk (Kyemba, 1977; Mugyenyi, 2008). Matters of health and illness became secondary to sheer survival, given the effects of the social chaos and warfare (Mugyenyi, 2008). The effects of this system destruction can still be seen today, as the SRs discussed in Chapters 5-8 reflect how the Ugandan health system does not have enough supplies, staffing,

or capacity to be fully functional or to provide high quality services, and that no health service providers in Uganda, public or private, offer services which truly resonate with potential clients. This appears to be limiting health service usage generally, as is discussed in detail in Chapter 8.

The social chaos of the era reinforced the perspective that politicians and leaders did not have the best interests of the people in mind, but rather took power by any means necessary for their own profit and benefit. This suspicion and mistrust of those in authority can still be seen in Chapters 5, 6 & 8, where both HCWs and adult carers discuss the SRs surrounding HCWs and allegations of profiteering on their part. As discussed in section 4.2.4, although there appears to have been little social cohesion, trust and social capital, not just in Kabarole district, but in many parts of Uganda prior to independence, the post-colonial era of Obote and Amin ensured the destruction of any social cohesion, as the state became oppressive and murderous, civil authority broke down, and it became every one for himself under the *magendo* system of live for today (Kuhanan, 2010a).

During this civil strife, children grew up in uncertain and unstable times, often without education or social support (Cheney, 2007). If these children survived this era, they then had to face a new threat as they themselves became adults and parents: HIV/AIDS (Mugyenyi, 2008). Although the impact of experiencing such widespread social trauma in situations such as war or genocide is well-researched, the psychological impact of growing up facing both the effects of widespread social anarchy and war, and the emergence of a major epidemic leading to significant amounts of death and suffering, deserves further research, as is occurring in the field of "complex emergencies" (Keen, 2008). Whilst the impact of these experiences may depend on individual and context-specific factors, the potential impact on the lives of survivors should be considered and acknowledged when doing research in Uganda (Mugyenyi, 2008; Mutibwa, 1992). This relates to Chapters 6 & 7, where the SRs held by adult carers and children offer insight into how the era of HIV/AIDS has impacted negatively on family experiences and dynamics, making it difficult both to be a parent and to be a child in Ugandan society.

4.4: Modern era: The era of AIDS (1980 to present)

4.4.1: Social conditions in modern western Uganda

The end of Amin in 1979 saw Uganda governed briefly by a Presidential Commission which saw 3 short presidencies in less than a year, followed by a questionable election and the return to power of exiled former President Milton Obote in 1980, which culminated in a so-called "bush war" for control of the country between Obote's government forces and a coalition rebel army called the National Resistance Army (NRA) led by Yoweri Museveni (Mutibwa, 1992; Mugyenyi, 2008). As the de facto civil war fueled continued socioeconomic chaos, the death toll of anywhere from 100,000-500,000 people was starting to be challenged by another killer: HIV/AIDS (White, 2012b; Mugyenyi, 2008). By the time Obote was deposed by coup d'etat and exiled for a second and final time in 1985, HIV/AIDS was running rampant across a broken and war-weary country, further adding to insult, injury, and misery (Mutibwa, 1992; Mugyenyi, 2008). After brief military rule, Yoweri Museveni and the NRA gained control of the country in 1986, and have remained in power to date (Mutibwa, 1992; AVERT, 2014a). His leadership, although at times democratically questionable, has given Uganda a relatively stable political environment in which to start to rebuild and advance on social and economic fronts, after so many years of chaos and blatant kleptocracy (Mutibwa, 1992). However, despite Museveni's efforts to stabilize and improve social conditions in Uganda, his time in office may well come to be defined as the era of AIDS.

As the Amin years drew to a close, as early as 1976, reports of a wasting disease colloquially called *silimu* ("slim") began to emerge out of Rakai, with cases of it spreading to the capital, Kampala, a few years later (Kuhanen, 2010c; Seeley & Allison, 2005; Putzel, 2004). Unlike the typical infectious disease pattern which affects mostly children and the elderly, silimu was affecting otherwise healthy adults in the prime of their life, and turning them into wasted skeletons before peoples' eyes (Mugyenyi, 2008). By the mid-1980s, case numbers in Kampala's major hospitals were mounting, with fear and accusations of plague and witchcraft spreading throughout the country, hearkening back to pre- and colonial-era SRs of illness, as in sections 4.1.3 & 4.2.3 (Kuhanen, 2010b; Mugyenyi, 2008). The beginning of the bush war, with large numbers of internally displaced people fleeing the fighting, seemed to accelerate the spread of the disease along transport

corridors into all areas of Uganda, with no district spared and no one unaffected (Mugyenyi, 2008; Kuhanen 2010a; Allen & Heald, 2004).

By the mid-1980s, HIV/AIDS had gone global, as official reports of a "gay plague" which surfaced in the United States in 1982, looked remarkably similar to Uganda's *silimu* (Barnett & Whiteside, 2006, p. 30-32; Joffe, 1993). Soon international clinicians linked the two, with further research into the new disease of "Acquired Immune Deficiency Syndrome" leading to the isolation of the Human Immunodeficiency Virus (HIV) which causes AIDS in 1986 (AVERT, 2014b). But the name mattered little to Ugandans, as the death toll was still mounting and there was no cure or effective treatment (Barnett & Whiteside, 2006). In 1987, Museveni's government acted by creating a frank educational communication strategy about HIV/AIDS within the public space, including how it was spread, which came to be known as the "ABC Method" of sexual abstinence, being faithful to one sexual partner, and using condoms, which is still used in HIV prevention campaigns globally (AVERT, 2014a; Barnett & Whiteside, 2006, p. 345; Parkhurst, 2011).

The 1980s also saw the emergence of home-grown Ugandan NGOs and CBOs, including national organizations such as The AIDS Support Organization (TASO), which have tried to meet the social support needs of people living with HIV, with medical programming such as antiretroviral treatment (ART) provision added more recently as it has become available in the country (TASO, 2014a; Putzel, 2004). TASO has been cited by many as an example of best practices in the field of community mobilization, and a significant force in the early efforts to fight HIV stigma, through low-tech, local community engagement and communication about HIV (Stoneburner & Low-Beer, 2004; Allen, 2006). TASO was also one of the first organizations to challenge stigma and the negative SRs of HIV-positive people through "living positively" campaigns, where life with HIV infection was openly discussed and HIV education provided (TASO, 2014a; Stoneburner & Low-Beer, 2004; Allen, 2006). Such campaigns remain a major part of HIV programming globally (Barnett & Whiteside, 2006).

However, coverage from such organizations has not been universal throughout Uganda, as participants in this study have stated TASO is not active in their region,

as reflected in TASO's coverage map (TASO, 2014b). Also, in regions where NGOs and CBOs do exist, there is no guarantee of access, or quality of services. As noted in section 4.2.4, despite a large number of small NGOs and CBOs operating in Kabarole district, they appear to have little local impact (Kajubu, 2010; Mbayahi, 2012), and have not helped the participants in this research in terms of social services or HIV support. In addition, retrospective accounts suggest that other factors may have influenced the outcomes of these early years of HIV. Sheer resilience may have mitigated the effects of HIV more than previously thought, particularly when external assistance was not available (Seeley, et al., 2010). The role of the "ABC Method" in reducing HIV infections has also been questioned, with some suggesting that the fear of death, and social behavior controls preached by churches or enforced by civic authorities may have influenced many to modify their sexual behavior so as not to contract HIV (Parkhurst, 2011; Allen & Heald, 2004; Putzel, 2004). To date, the role of the ABC Method and governmental intervention in the early years of AIDS is still being debated by scholars (Parkhurst, 2012, 2005).

By the 1990s, however, the international AIDS reponse had begun, with HIV/AIDS becoming a global cause, through mounting political activism in Western countries, linked into the gay and lesbian civil rights movement, in whose community HIV/AIDS had also hit hard (AVERT, 2014c, 2014d). This increased global awareness translated into international fundraising and political pressure on governments and international agencies, to provide funding and technical support to the SSA countries hardest hit by the illness, with Uganda becoming a major recipient of such funding (Mugyenyi, 2008). However, since the 1990s, this international support for HIV programming and treatment has increasingly come with strings attached, and had been criticized by local service providers as neglecting local Ugandan needs in order to achieve donor country targets, many of which focus more on political or social ideology than science or support, and which often do not fit the reality of local life in Uganda (Human Rights Watch, 2005; Allen, 2006; Mugyenyi, 2008; Parkhurst, 2012).

Although the Ugandan government established the Joint Clinical Research Centre (JCRC) in 1990, to try to control and coordinate the HIV clinical response and research work being done in the country, including ART coordination and provision,

JCRC and most Ugandan HIV programming and services remain highly dependent on foreign funding (Mugyenyi, 2008; AVERT, 2014a). The majority of this funding has come from two major funding bodies created to support HIV programming globally, which are under de facto American control due to sheer scale of financing (AVERT, 2014e, 2014f; Oomman, et al., 2007; Seckinelgin, 2012). The first, the Global Fund, is based in Switzerland but is controlled by an American funding majority, with the US being the single biggest donor country at 33% of total funding (AVERT, 2014e; Oomman, et al., 2007). The second funding source, the US President's Emergency Plan for AIDS Relief (PEPFAR), is a wholly American-controlled initiative which disperses HIV programme funding and technical aid to countries in SSA, but has been increasingly criticized in recent years for supporting programmes which reflect only right wing, neo-conservative Christian "values" as opposed to culturally or scientifically appropriate interventions (AVERT, 2014f; Human Rights Watch, 2005; Oomman, et al., 2007; Parkhurst, 2012).

The relationship between Museveni and former US President G.W. Bush has also been criticized, with suggestions of undue influence being used to push an American neo-conservative agenda onto Uganda, as has been reflected recently in the passing of legislation which curtails the civil rights of homosexuals in Uganda, through the "Bahati Bill," which criminalizes homosexuality (AVERT, 2014a). Other bills which could reinforce extant social stigma and discrimination, particularly against women and girls, have also been signed into law, in a worrying trend of increasing human rights suppression (New Vision, 2014). Given the low levels of social capital, trust, and social cohesion as discussed in section 4.2.4, the potential future effects of such legislation on Ugandan society, as well as on HIV service provision are worrying, as they may act to increase stigma, and decrease HIV service access further. As a result of this legislation, many donor countries, including the United States, have reduced or halted aid programmes to Uganda as a result, the health impacts of which are yet to be seen (IRIN, 2014a; BBC, 2014a). Recently, the global-local donor relationship between international funders and Uganda has been strained, due to corruption and misuse of Global Fund financing, with payments to Uganda suspended during 2005 as a result (AVERT, 2014a).

4.4.2: Modern era: Growing up with HIV as the lived reality for children & families

After coming to power in 1986, Museveni led a nation-wide push to rebuild schools, with "free" primary education, in the form of school fees being abolished, becoming a policy priority for the government (Mugyenyi, 2008; Cheney, 2007). It was also a useful way to reinforce power and socialize the youth of Uganda into adopting pro-government sentiments and values, given the government's need to stabilize the country and ensure political control after the end of the recent bush war (Human Rights Watch, 2005; Cheney, 2007; Parkhurst, 2005). With the era of AIDS, schools became a prime battle ground in the fight against HIV/AIDS, and in 2002, began to teach children about it using the PIASCY curriculum (President's Initiative on AIDS Strategy for Communication to Youth), which is still taught from the Primary 3 (Grade 3) level up, at roughly age 8 or older (USAID & Population Council, 2009). This curriculum teaches primarily abstinence-based HIV prevention messages, focusing on how children should avoid sexual behaviours, and thereby avoid HIV, linking the two together without additional discussion about the social factors or conditions which may impact on HIV transmission, nor the development of ART as HIV treatment (Government of Uganda, 2002; Human Rights Watch, 2005; USAID & Population Council, 2009). However, as will be seen in Chapter 7, this does not reflect the wider social realities seen by children participating in this study. Although hailed as revolutionary at the time, PIASCY has since been criticized for its overreliance on abstinence as a means of "controlling" HIV, given the complex social realities surrounding HIV infection in Uganda (Human Rights Watch, 2005).

In Chapter 7, findings suggest that children are growing up with a certain fatalism about HIV/AIDS, almost expecting to get it, in that they are realistic in knowing how great their odds of being infected are, given the sexual patterns in society and the lack of personal safety in society for all children. Girls and women are portrayed as being particularly vulnerable to HIV, with research suggesting they have little economic power and are at risk for gender-based violence (see Samara, 2010; Cheney, 2007). Further Ugandan research suggests that girls from poor families who wish to continue schooling often have to engage in transactional sex with older men, to finance the unfunded school costs of uniforms, school supplies, and feminine hygiene products needed to attend post-puberty (Samara, 2010; Human Rights Watch, 2005). Also, given recent research concerning the incidence of non-

consensual sex and HIV infection amongst women in Uganda, further investigation by researchers is needed and warranted (Birdthistle, et al., 2013).

Although Ugandan adults in this study are reluctant to discuss sexuality and children, children are willing to do so, as seen in Chapters 6 & 7. The works of the children who participated in this research also reflect both social and school hypocrisy, suggesting the HIV curriculum is not reflective of their social reality for HIV infection, as it should be, if they are to effectively negotiate the inherent social risk of living in a society with such HIV prevalence as Uganda. Whilst schools are supposed to be the places for socializing children into a society through the use of the SRs extant in a society, Chapter 7 will discuss how the national HIV curriculum may in fact be reflecting an idealized society, rather than the real society into which the children need to be socialized in order to live and later effectively transition into adulthood (see also Jacob, et al., 2007; Mutonyi, et al., 2010; Norton & Mutonyi, 2010; Human Rights Watch, 2005).

4.4.3: Representations of health, illness & health services in the HIV era
By 1986, the era of HIV was in full swing, with HIV threatening the country's very existence (Mugyenyi, 2008). HCWs in Uganda, having seen so much death and destruction around them for so many years, and being so helpless to stop it on all fronts, resigned themselves to also being unable to treat this disease which was now killing so many of their patients and coworkers (Kyemba, 1977; Mugyenyi, 2008). As the hospitals and health centres had been so devoid of supplies, equipment and staff for decades due to the continued anarchy in the country, they feared for the worst (ibid). The public reacted with fear, shame, and worry, with HIV stigma and denial reactions becoming coping strategies from which they managed their emotions about a disease they could do nothing to stop, yet which was killing their loved ones en masse (Mugyenyi, 2008; Ssengonzi, 2009; BBC, 2000).

Further, the implications of the chaos of the 1970s were to be especially disastrous on health services during the era of AIDS in the 1980s, as the levels of financing, staffing, supply, and service provision never had a chance to get to the levels they should be at, to be effective in the face of such an epidemic (Kyemba, 1977; Mugyenyi, 2008). HIV hit Uganda when its health system was in tatters, and then

proceeded to rip through not only the population at large, but also the health care professions, as they worked with infectious, sick and dying patients with a chronic lack of protective gear and supplies, such as gowns and gloves (ibid). Under these conditions, many staff themselves were infected and died, causing not only a further loss of critical health care staff, but also a massive psychosocial trauma and blow to their surviving coworkers (Mugyenyi, 2008; Harrowing & Mill, 2009). Reports from that era, and as HCWs discuss in Chapter 5, capture the destruction of professional identities, and the impact of burnout on staff, which became almost a coping strategy, given the massive losses experienced on a daily basis (Fournier, et al., 2007; Harrowing & Mill, 2009). SRs of hospitals and health centres changed to those of places of death, where people went to die, where HIV/AIDS reigned, and where staff were helpless and useless to patients, echoes of which are still seen in Chapters 6 & 7 (Kapiriri, et al., 2003; Mbonye, et al., 2010).

Capitalizing on the poor state of the health service sector, medical syncretism in the 1990s was exploited by charlatans touting herbal "HIV cures" which did nothing at best, and harmed or killed people at worst, often in connection with Christian-based revivalist or fundamentalist "faith healers," espousing that Christian belief and being a "born again" Christian could cure HIV, when in fact, the only result was death (Mugyenyi, 2008, p. 85-94; Human Rights Watch, 2005). Many still have a following to date, and have been cited as a cause of death in cases where people have defaulted from HIV drug treatment and died soon after (ibid). This occurs despite positive work done by many religious institutions across Uganda. However, as ART became more available in Kabarole district since the early 2000s, this fraud has lessened, and as will be further explored in Chapters 5 & 6, ART is very slowly starting to change the negative SRs of the health system still held by many in the district. ART has also brought a new optimism to HCWs in the clinics which have access to them, as will be seen in Chapter 5, and the potential to increase and improve HIV treatment uptake and outcomes is a positive future trend, despite the shadow of questionable international funding support trailing behind it (Stein, et al., 2006; Kyakuwa, 2009; Holzemer, et al., 2009).

4.4.4: Relevance for current representations of children, HIV, access & adherence

The era of AIDS has resulted in new representations of health and illness, with HIV status now playing a major defining role in what is healthy versus what is ill in the societies most impacted by it (Kitzinger in Markova & Farr, 1995; Joffe, 1993). In the community of this study, health status has been reclassified to refer to HIV status, with good health seen as being HIV-negative or HIV-free, and illness now being represented by HIV-positive status, as HIV has become the dominant health narrative as discussed in Chapters 5-7 (ibid). In Uganda, this has happened partly due to the severity and reach of the disease, but also due to the influence of the power and political agenda of the international organizations which finance Ugandan health services, and who have chosen to earmark funding for HIV instead of other local illnesses which often have greater day-to-day impacts, such as malaria, or gastrointestinal illnesses, as discussed in Chapters 6 & 8 (Oomman, et al., 2007; Vassall, et al., 2012; Kabarole District Local Government, 2010).

As will be discussed further in Chapters 5 & 6, there is a growing public resentment on the over-emphasis of HIV, as it is seen to be favoured at the expense of other illnesses. In one donor report, HIV/AIDS and STDs received over 205 million US dollars out of the 362 million US dollars earmarked for health for 57% of the budget (Action for Global Health, 2010). Given the massive, long-term shortages across the Ugandan health system, which will be examined in Chapter 8, this complaint is an accurate representation of the current global attention, funding and politics which focuses on HIV, as opposed to addressing local needs which are not covered by the strictly siloed funding systems currently in place to allocate HIV funding (Action for Global Health, 2010; Campbell, et al., 2012b; Skovdal, et. al., 2011a). As Uganda's government is highly dependent on foreign donor funding to run their health service system, with up to 40% of the health budget coming from foreign aid, it is a case of "whoever has the gold makes the rules," with international funders possessing a significant amount of power and political influence in dictating how their money will be spent, not unlike the British colonial administrators of the past in section 4.2.3 (Action for Global Health, 2010).

However, as research has demonstrated, health programming that does not resonate with local users is generally unsuccessful in the long run, regardless of

how well funded it is (Campbell & Cornish, 2010; Skovdal, et al., 2011a). Although at first glance, current international efforts appear to advocate for a reorientation of HIV services to the needs of service users, such as with the current UNAIDS (2010a, 2010b) policy campaign of "Getting to Zero," which calls for a massive reduction in HIV infections, accompanied by increased ART access to an 80% global coverage rate. A more careful reading suggests that the majority of programming funding will be allocated to biomedical and ART services, as opposed to supporting community-based services which seek to change behavior and prevent HIV infection in the first place (Action for Global Health, 2010; AVERT, 2014a, 2014e, 2014f). Unfortunately, this may be a step backwards in terms of creating an improved and sustainable local HIV service response.

Conclusion

It can be said that the recent history of Uganda is also, at least in part, the history of HIV/AIDS. The way in which HIV/AIDS would come to affect countries in SSA in the late 1990s, was seen in Uganda in the early 1990s, when HIV/AIDS hit its transmission and prevalence peak (Mugyenyi, 2008; Barnett & Whiteside, 2006). The historical context regarding the social and cultural aspects of HIV transmission in Uganda has been well documented by Kuhanen (2010a, 2010b, 2010c), but has focused on the initial epicenter of the illness, the Rakai district of Uganda, as opposed to other localities, including Kabarole district. However, tracing this wider social trajectory does allow the researcher to find relevant patterns which fit local study conditions, and that has been the case in this chapter. By combining the few available recorded sources for local social history, with studies which reflect more generalized Ugandan HIV social transmission patterns and experiences, the subsequent thesis chapters become better situated within the historical and sociocultural contexts relevant to their setting. Clusters of representations emerge which, as will be discussed in subsequent chapters, do have a connection to the current SRs in use by participants, regarding HIV service access for children.

Although it is impossible to fully recreate the past for research purposes, examining the representations emerging from the historical social context of the study location provides a sort of background scaffolding, onto which the current representations can be mapped to reflect on their own history. In this regard, Bauer & Gaskell's

(1999, 2008) "Toblerone model" of SRs has added value by providing a deeper understanding of the representational projects carried out by study participants in their social environment. Establishing this social milieu is helpful in understanding the SRs that emerge in the data chapters of this thesis, namely Chapters 5-8. Given what is seen here in the "past," the current SRs which will be discussed in Chapters 5-8 "make sense" and are understandable, in terms of the social challenges which people in this community must navigate. Reviewing the background social context of this study setting has been a useful exercise to understand where many of the SRs which will be discussed in the following chapters are coming from- literally.

Chapter 5: Social representations held by Health Care Workers

Introduction

This is the first of four empirical chapters, where I examine the findings from the in-depth interviews (N=15) with health care workers (HCWs), and focus on children's access to HIV services at Amooti health centre. The positions within the health care system represented here range from the District Health Officer and government officials, through to clinical health professionals such as Registered Nurses and Clinical Officers (a bachelor's degree-level position used as an alternative to Medical Doctors in Uganda, typically in underserved areas), as well as unlicensed Community Health Workers and Support Staff members. The findings discussed here provide the HCW perspective as to why children's HIV service access is low, despite testing and treatment resources available at their clinic.

In examining this data, it is vital to build a picture of how HCWs see their work environment, their clients, themselves and how they negotiate the health care system as providers, as it relates to the facilitation or hindrance of children's HIV service access. In line with the theoretical perspective which underpins this study, that of social representations theory (SRT), the findings discussed here reflect the interplay between social representations (SRs), social identity, and social context, in the lived experiences of participants. SRT reveals here how the most prevalent representations of children and HIV in use in society impact on children's access in a negative way. Social identity is relevant here as professional identity plays a key role in how HCWs function as care providers within the health care system. Social context is important as people always function within a particular context, with their representations and identity situated in, influenced by, and influencing this context.

In conducting a data analysis influenced by Attride-Stirling's (2001) Thematic Network Analysis (TNA), the 3 global themes which emerged are discussed here, and focus on how the interplay of social context, representations and the role of professional identity underlie service provision and impact on children's access to HIV services. These global themes are:

1. <u>Supply side opportunities & constraints as seen by HCWs</u>, which reflect how ART has become the "bright light" in an otherwise gloomy health care system full of constraints.

2. <u>Demand side opportunities & constraints</u>, which according to HCWs, reflect a social climate for children with HIV which is stigmatizing and excluding.

3. <u>Implications of these demand and supply constraints for professional identities</u>, in that being a HCW is a positive and rewarding experience despite work difficulties.

The data explored in this chapter elaborates on my research questions by:

- Mapping out what the SRs of HIV, children, and health services are, as seen by participating HCWs.

- Reflecting on how these representations in use in society have a negative influence on health service access for HIV-affected children.

- Examining the areas of tension created by competing SRs of children, HIV and health services, and how HCWs use professional identity to mediate this tension.

- Exploring how HCWs have recreated their self-identity to that of a "heroic worker" battling to provide HIV services in the face of resource shortages and public reluctance to use services.

- Outlining how increasing and improving service provision for children with HIV will require "tapping in" to the improving professional identity of HCWs and harnessing it for further public engagement and outreach.

5.1: Supply side opportunities & constraints as seen by HCWs

The findings in this section discuss how, despite serious supply side constraints and difficulties, most notably a lack of consistent supplies, funding and adequate staffing at the clinic, ART has become a positive force for health and healing and a significant opportunity for positive clinical interventions. Missed opportunities include a lack of media attention being paid to educating the public about children with HIV, as well as the need for increased public outreach campaigns and family counselling.

Table 5.1: Global theme: Supply side opportunities & constraints

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
1A Tensions in health care system confuse children's carers and are working against one another (discussed in 5.1.1)	1A1 Traditional medicine vs modern medicine	-traditional herbal medicine -modern medicine -Western/clinic medicine	-patients choose which medical system to use -legitimate beliefs vs fraudulent practices	-competing providers makes service provision/choice difficult -choice based on access/cost not quality
	1A2 Tensions between local, government and NGO priorities & provisions	-lack of government leadership -lack of government accountability -unmet need for interventions -NGO assistance vital	-lack of government leadership & accountability leads to negative impact on health system	-poor support impacts negatively on care options provided -parents may be dissuaded from using clinic for children
1B Health care system resources limit what can be done for patients & children (5.1.2)	1B1 Challenges of service delivery & staffing	-short staffing -pediatric services lacking -over-reliance on volunteers	-permanently understaffed -unlicensed workers may impact poorly on patient safety	-poor staffing levels prevent better HIV care
	1B2 Lack of financial & materiel resources	-funding shortfall -lack of essential supplies	-funding & priorities inappropriate or unsustainable	-resigned to the reality of poor funding & its negative impact on care
	1B3 Lack of institutional outreach- services reactive, not proactive	-sensitizing adults to children's needs -need improved outreach services	-sensitizing adult public to use health care services -opportunities for outreach -solutions to long-term problems	-adults not aware of children's health needs -no support to provide outreach services
1C	1C1 Current	-media HIV	-reorient	-need for public

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Shortcomings of wider HIV educational responses (5.1.3)	media campaigns exclude children either as topics or audiences	coverage excludes children -HIV seen as adult disease	media to include children and pediatric HIV	engagement & dialogue over children & HIV
	1C2 Not enough counseling services for families	-opportunities to do counseling -need for child-focused interventions	-counseling skills help families	-need for improved HIV counselling skills for children & families
1D Miracle of ART availability vs previous work without ART (5.1.4)	1D1 ART has greatly improved clinical practice outcomes	-death less frequent -confidence -drugs make patient physical appearance better -pre-ART clinical practice -ART saves lives	-people used to die & it was horrible -ART a positive force which helps their work -increased confidence in providing care	-ART has improved practice & confidence -ART helping those who access it

5.1.1: Tensions in health care system confuse children's carers & are working against one another

This organizing theme reflects the conflicts between traditional and modern medicine as seen by HCWs, which are founded on legitimate fears over safety for patients. Whilst many HCWs recognized that traditional herbal medication may work, the lack of standards and reliability cause them to fear for their patients. The ability of HCWs to provide high quality, consistent services, which would contribute to increased service uptake by the public, is hampered by a fragmented logistical milieu, where supply provision is divided between an international NGO and the government. As there is little cohesion or uniformity between these supply systems, HCWs perceive the overall impact to be that of confusing the public and making them reluctant to use the clinic services, which are seen as being unreliable.

1A1 Traditional medicine vs modern medicine

HCWs acknowledge that most of the public tend to take a blended or syncretic

approach to health services access, due to the fact that neither the traditional healers nor the Westernized medical system fully and effectively meets their needs. However, some HCWs see traditional healers and medicine as a form of "deception", with practitioners only out to make money off of patients, as they operate on a for-profit basis. This view is influenced by a real history of HIV treatment politics in Uganda as seen in Chapter 4, where fraudulent HIV cures and charlatan healers were a part of the historical response to HIV, before ART became available (Mugyenyi, 2008). In addition, "faith healing" in charismatic Christian churches still occurs and has a large following, but has caused serious health problems for HIV patients, as they are often told to stop taking their ART drugs, which has resulted in serious illness and death (IRIN, 2010).

> R: [Patients] like modern drugs. Eh, now they were, they were sensitized, they are now, trained. But before, they used to like using traditional medicine [and] people would deceive them: "herbal, you will get cured." You will get cured of HIV/AIDS, such things. They use herbs, but in the end, things go wrong, they again do what? Come to the health unit for treatment.
> I: Are there [those] who use traditional herbs, then come to the health unit for treatment, in the villages?
> R: They are there.
> I: They are there? How do they know that traditional herbs work better than modern medicine?
> R: We don't know, they are just being deceived. (HCW #22, Nurse, female, 31)

A further example of the confusion and competition between systems, is seen in the use of herbal medicine, as for some illnesses such as malaria, local herbs have historically helped. HCWs openly acknowledge this, but are concerned due to a lack of research on safe dosages or other contraindications which could result in injury to patients (Food and Agriculture Organization, 1993). This "hit and miss" nature of herbal medicine is what concerns them the most: that a lack of product standardization puts patients at risk for drug overdose or misuse.

> I: How do [clients] know that modern medicine helps?
> R: There are some diseases which need to use herbal medicine- but for malaria you need to take tablets and someone must go the hospital. Even when they don't go to government hospital but they still go to a private clinic.
> I: Are there people who use both medicines- herbal and modern?
> R: Mmm [yes].
> I: How do they know that using both medicines may help them- both

herbal and modern medicine?
R: There are some herbal medicines like trees- there are some trees they brought claiming that they cure malaria, and when you use them and you are not cured, you end up going to the hospital. And sometimes they use herbal medicine and you find someone getting cured [laughs]. (HCW #3, Official, male, 57)

HCWs reason that patients tend to use traditional medicine due to pragmatic reasons more than beliefs, as it is often cheaper and easier to access than using the clinic, and that erratic drug supply and shortages of medication likely influences traditional medicine use as well. Findings from adult carers in Chapter 6 corroborate this view.

1A2 Tensions between local, government and NGO priorities & provisions

The lack of alignment between local, government and international HIV service provision has a negative impact on service provision by HCWs, as local service is dependent on 2 supply chains, as discussed in Chapters 4 & 8, with ART coming from an international non-governmental organization (NGO), and all other medical supplies, including HIV testing kits and some adult drugs, coming from the Ugandan National Medical Stores, the governmental supply chain system. Although the NGO ensures drugs are there for children and caregivers, the Ugandan government is frequently unable to provide other essential supplies, such as HIV test kits, on a regular, reliable basis.

"There's times… when we don't get… testing kits, they're not in time. We examine many mothers, [run out of kits and] they go-- were not examined. You see we're missing those [mothers], only a few will come back. If the mothers are not tested they ask me-- I tell her, "go for [a HIV] checkup, you've not [been] checked when you're pregnant." Yes and they go, but those who deliver in the village, what can we do for them? [For] at least two months, mothers are not examined." (HCW #28, Nurse, female, 49)

HCWs feel "stuck" and unsure of how to proceed in terms of negotiating this situation. Although the chain of command protocol is to go to the government first, they are unlikely to get the supplies they need from National Medical Stores, due to a lack of both capacity to respond, and accountability for response within the system. In addition, the mandate of the international NGO limits what they provide to the clinic to ART for children and adults. This lack of coordination in connecting local service provider needs to government and international resources results in

haphazard supply chains, which negatively impact on HCWs by fragmenting the materiel they are able to provide as part of their service, and is ultimately beyond their control.

5.1.2: Health care system resources limit what can be done for patients & children

In this organizing theme, HCWs further address the shortages which they believe impact on their capacity to provide high quality, comprehensive care and services for clients.

1B1 Challenges of service delivery & staffing

For HCWs, staff shortages are seen as a huge challenge, as clinic staffing is at less than 50% capacity, which makes full service delivery physically impossible. Positions are open and recruited for but never filled, with the explanation by senior management given as a lack of available qualified staff in the area, as well as a reluctance of HCWs outside the District to relocate, exacerbated by government funding for a full staffing complement simply not being there. The aptly named "Kampala Declaration" has addressed a chronic lack of skilled HCWs across the African continent, in combination with "brain drain" of skilled African professionals to countries both in sub-Saharan Africa (SSA) and abroad, where the pay and working conditions are better (WHO, 2008). This neglected aspect of HIV care in international policy is a huge barrier to achieving the UNAIDS policy of scale up, and is still not adequately addressed nor funded by international donors, as little to no funding is set aside to address staffing issues (UNAIDS, 2010b).

> R: Umm, the difficulties? Yeah, the first thing is that we are understaffed. And we are few, we are supposed to be nineteen.
> I: Nineteen?
> R: Yeah. But we are nine.
> I: Nine!
> R: So, we are sometimes overworked and people don't understand. [The public] think[s] we just don't want to work well. (HCW #8, Clinical Officer, female, age not given)

In addition, it was noted that a reliance on "inherited" workflow practices is an additional service delivery problem, as will be addressed in Chapter 8. Older, colonial-style ways of providing clinic services are used, such as processing patients in groups, and holding illness-specific days where the clinic focuses on a

single health problem, which are not as effective as an integrated care model, particularly in light of a less than 50% staffing rate (Wells, et al., 2011).

> "Then, we sometimes get a challenge with the staffing. As I told you we are few compared to the expected number. So, if you came here on a Wednesday [*a day designated specifically for HIV*], you will find like 100 people here waiting for two health workers. Because I work here with another nurse. And sometimes we have two expert clients who come and help us... But you really see there is a gap. It is like a clinic on its own, then we have to do other activities in other departments. Here, there's a lot of recording here. We have very, very many recordings and… there are other things we have to do apart from that. Procuring drugs, then making reports, such things." (HCW #8, Clinical Officer, female, age not given)

HCWs see the need to innovate and tailor their clinical practice to the current realities of their workload, workflow and patient flow, yet given the low staffing levels, they may not have the time or capacity to redesign their practice. HCWs feel that they are doing everything they can to simply try and keep things running at all, let alone efficiently or effectively.

1B2 Lack of financial & materiel resources

HCWs feel frustration at systemic limitations which result in poor quality care, and have feelings of helplessness and powerlessness over their predicament and its impact on themselves and their patients.

> "Sometimes there are no drugs and we have to wait for… the government to send drugs. We can't intervene when there are no drugs." (HCW #8, Clinical Officer, female, age not given)

This potential identity threat to themselves as competent practitioners is averted psychologically by resigning themselves to the problem being out of their hands, and rationalizing that it was up to those higher up the chain of command to fix the problem.

1B3 Lack of institutional outreach- services reactive, not proactive

There is recognition that the current service model is not working as well as it could be, and is unsustainable in the long term, with some HCWs suggesting how they could improve services for their clients.

> "[People] stay at home, they don't want to go [to the clinic]… They need counseling and maybe organizing seminars in the villages so that they are sensitized about HIV/AIDS and they become aware that this disease exists and they should also be encouraged to go for testing." (HCW #1, Community Health Worker, male, 34)

For HCWs, the problem remains the lack of staffing capacity and financing to increase outreach programming, which is seen to be the main barrier to this model of service delivery. Whilst staff members express a willingness to go out to more remote villages to do HIV testing and educational outreach, they would need additional financial support and personnel to be able to do it without compromising the already overburdened day-to-day clinic operations, and express doubt that the Ugandan government or donors would provide the resources to facilitate this programming.

5.1.3: Shortcomings of wider HIV educational responses

HCWs also reflect on the challenges of discussing HIV and children, both in their own counselling practice and in the wider Ugandan media.

1C1 Current media campaigns exclude children either as topics or audiences

According to HCWs, HIV information and education programming in the Ugandan media is overly adult-focused, and mentions young children only in 2 ways. Firstly, by focusing on the prevention of mother-to-child transmission of HIV (PMTCT), where pregnant women are advised to be tested for HIV when going for a prenatal health check, and to take ART medication around the time of delivery, if the test was positive. Secondly, by focusing on abstinence-only messages, which linked into the government's national HIV curriculum, which is taught in primary schools in Uganda and which is criticized for its non-acknowledgement or outright denial of the realities of youth sexuality, including child sexual abuse and transactional sex for school fees (Government of Uganda, 2002; Cheney, 2007; Samara, 2010).

> "We have a population now that is in the media world. [Children] can access this information...on radios [where people] talk about HIV. How a child can get HIV. So, we are on [the] radio. Children are also listening–we can't say, 'this message is only meant for adults.' So, children I think, at any level, they pick up this information." (HCW #45, Official, male, 32)

Although the general media discusses HIV/AIDS quite frequently across a variety of formats (radio, newspapers, etc.), there is no specific messaging for young children at their level of understanding, unlike in South Africa, where an HIV-positive Sesame Street Muppet is a recurring character on the children's television show (Sesame Workshop, no date). One newspaper supplement for teenagers, "Straight Talk," is government-run and heavily linked to the school curriculum, but is produced in English as opposed to local languages (Government of Uganda, 2002). Overall, the media messaging in Uganda retains its target audiences as adults, and focuses on adult-focused HIV issues, such as PMTCT testing. The government HIV curriculum will be discussed further in Chapter 7, including its criticisms (Cheney, 2007; Samara, 2010).

1C2 Not enough counseling services for families

HCWs discuss how they do basic HIV counselling for adults and children as part of their VCT training programme, and most feel they were capable of doing the job well.

> "When children get older, we advise the mothers to bring the children with them so we [can] counsel them. There's a way we counsel them, now [that] the child [has] become infected… there's a way we counsel them smoothly, so they accept and they know that, 'every day [I] am supposed to take drugs.'" (HCW #26, Nurse, female, 35)

However, there are limitations in their work due to poor staffing, where there are not enough people to be able to do a high quality job, in terms of time allotted to clients and the scope of support they can offer. This is compounded by limited social support services in this community, for although more major towns in district have links to HIV support organizations such as Uganda's The AIDS Support Organization (TASO, 2014a), this town is not served by their programming. In this part of the District, there are no services available for additional support other than the clinic, church or mosque-linked volunteers or extended family members. Mental health services across Uganda are in very short supply, with psychiatric services extremely limited and centered in Kampala, about 5 hours' drive away.

5.1.4: Miracle of ART availability vs previous work without ART

HCWs see ART as playing a major role in restoring their clinical capacity and hope

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for their patients, but this positive outlook is tempered by fears of the potential for drug resistance by poor treatment adherence and patients engaging in risky behaviours after starting treatment.

1D1 ART has greatly improved clinical practice outcomes

Repeated stories were told about the so-called "Lazarus effect" on HIV patients who start on ART, which also gives HCWs a major boost to their clinical practice outcomes and a resulting sense of professional accomplishment (Castro & Farmer, 2005). ART is seen as a "game changer" in the clinical case management of HIV.

> R: Nowadays there is a big difference, because now the ARVs drugs are available to help those people who have [HIV]. We now have testing facilities and when someone goes and tests and finds that he has it, they start the drugs there and then and they get a good life…
> I: How was it in the past?
> R: It was too much. Because during those days, there were no drugs, there wasn't even- no sensitization campaigns, to sensitize people so that they know how to prevent… [HIV] and how to get treatment. But nowadays, at least it is okay… because of those drugs they are receiving and even the sensitization they are receiving from the health workers.
> I: It's not like in the past when people were dying-
> R: [interjects] Eh! During those days people used to get diarrhea and a terrible loss of weight, someone would look exactly like a skeleton- but these days, no. (HCW #1, Community Health Worker, male, 34)

However, fears of a "dark side" to increasing ART use are discussed, where there is a risk of the public becoming complacent in HIV prevention, due to the increasing availability and profile of HIV drugs in Uganda. HCWs fear that the public may assume that HIV is "curable" instead of "treatable," or that the drugs are "easy" to get and use, when they are actually quite complex to manage clinically for HCWs and patients alike.

> "I think now these days, it's no longer like those days when [the public] used to fear [HIV]. These days it seems like malaria… So, drugs- it's really made a difference in how they react." (HCW #7, Outreach Worker, male, 29).

There is a debate over the role of "therapeutic citizenship" occurring at the clinic, which stems from concerns that adult HIV patients may take risks when their physical health begins to improve after starting on ART treatment, and that this may fuel the spread of HIV again, as people think HIV is "curable" as opposed to being a

chronic illness (Ngyuen et al., 2007). This can be seen as both a stigmatizing representation, and a legitimate concern, coming from memories of the time before ART, where so many patients died from HIV and the HCWs were unable to save them.

> "If this patient gets treatment and adheres to it and doesn't affect or infect others, then that patient, he remains normal and good for the community. But those people who are infected and they don't get treatment, they die soon- and those who get treatment [but] they continue infecting others… that's a big problem… You know when these people [are] "cured"- let me say [cured], but they become better- [patients get] these habits of going to take beers, whatever. They lose control and they start infecting each other… it's very common." (HCW #26, Nurse, female, 35)

For the HCWs who lived through the "bad old days," there was a distinct concern that they do not want to be back at "square one" due to drug resistance. This is compounded by the fact that ART programming services in Uganda are reliant on lower cost first and second level drugs, with the third level very expensive and not available through donors at present. There is no fourth level of ART drugs.

5.2: Demand side opportunities and constraints as seen by HCWs

The current social climate for children with HIV is seen by HCWs as still being stigmatizing and excluding, with negative SRs of HIV and children in wide use in society. Stigma, AIDS denial and a general social disempowerment of children all constrain children's HIV care access in negative ways, if children with HIV are even talked about by the public at all.

Table 5.2: Global theme: Demand side opportunities & constraints

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A Stigmatization of HIV/AIDS makes it difficult for children to access treatment (in 5.2.1)	2A1 Parents can't cope with the potential stigma & blame for their child's HIV	-blame parents -caregivers "give up" on children -HIV-positive children "hidden" away	-parental fear of blame leads to clinical absence of children from HIV treatment	-parents don't bring children in due to fear

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	2A2 AIDS denial may be presenting as "ignorance" in the face of social stigma	-denial of children's HIV as coping -misbeliefs about children & HIV	-denial as coping strategy against potential social stigma & blame	-"ignorance" of children's HIV is the safer social option
2B Genuine ignorance of HIV risk for children possible (5.2.2)	2B1 "Ignorance" of HIV & children may be genuine in the community	-HIV education adult-focused	-general lack of education about children & HIV	-need for dialogue about HIV & children
2C Representations of children negatively influence access to HIV services (5.2.3)	2C1 Community status of children: Competing roles & values may limit health care access	-sociocultural role of children -adult ambivalence towards caring for children -children dependent on adults for health care	-community roles & norms for children: children lack agency -children dependent on adults for health care access	-traditional social roles for children limit HIV service access
	2C2 Moral status of children: Seen as "good" and "innocent" related to HIV	-children are "good" -children are "innocent" -denial of child sexuality	-being "good" and "innocent" socially incompatible with being HIV-positive	-parents not children seen as to blame for HIV status
	2C3 Legal status of children: Should help facilitate health access but does not	-children's rights -traditional social status of children	-clash between "traditional" status of child & modern rights frameworks	-legal status of children precarious, rights not supported
	2C4 Socioeconomic status of children: Opportunity costs often too high to commit	-SES impact on families -costs of child rearing -costs of HIV treatment	-SES stressors can trigger child abuse and/or neglect -financial difficulties in	-poor SES appears to prevent children's HIV service access

	to a child's HIV treatment		treating children for HIV	

5.2.1: Stigmatization of HIV/AIDS makes it difficult to access treatment for children

2A1 Parents can't cope with the potential stigma & blame for their child's HIV

HCWs see the social "blame" for HIV as being placed on the parent due to the main route of infection being vertical transmission from mother to child. Mothers are particularly stigmatized and under serious social pressure to hide a positive HIV status for themselves as well as their children (see Campbell, et al., 2005). The child is then positioned socially as the "blameless victim" of not only the parents' HIV-inducing behavior, but also of the parents' failure to access life-saving treatment for the child (Hejoaka, 2009).

> "[The public] talk about [HIV positive children], but they say that if [the child] is still young, they say that the problem is about the what? The parents. Because the kid, [doesn't] have anything to tell, [there's no] talk about him or her, because he's still young. The blame is all about what? The parents' [actions]." (HCW #34, Nurse, female, 37)

The public is seen as being aware of PMTCT programming due to strong media dialogue and education, so parents, and particularly mothers, who are not accessing this programme, are seen as being irresponsible parents if they end up being "outed" as HIV-positive. In this sense, parents are "damned if they do or if they don't," with HIV status being a no-win situation for them, as their preferred method of coping is to avoid diagnosis altogether, either through hiding their test results or "ignoring" HIV, as seen in Chapter 6.

2A2 AIDS denial may be presenting as "ignorance" in the face of social stigma

As parents are unable to negotiate the social stigma discussed above, one coping method they may be using is to deny their HIV risk or positive status altogether, particularly given the risk for gossip which reportedly takes place in the community. HCWs perceive that, although people "know" that HIV-positive children exist, they don't want to acknowledge them, and so parents at risk take an "out of sight, out of mind" approach, until their hand is forced and the child becomes sick and in need of HIV services at the clinic.

> "It seems [people] don't recognize HIV-positive children… They say [the children] are sick, but they talk about them when knowing that maybe their parents are the ones who infected them with HIV/AIDS. Now, you might find a parent of the child, maybe dies when suffering from HIV/AIDS. So, after… [people] say that: "isn't this child HIV positive, really?" If the child starts to… get fevers every now and then. So, we hear some people saying, "eh, isn't this child HIV positive?" (HCW #22, Nurse, female, 31)

This "ignorance" is the more socially acceptable option, and allows for parents with HIV-positive children to preserve a more positive social identity, in the face of continued stigmatizing SRs of HIV, which frame it as being an adult disease acquired through immoral sexual activity such as pre- or extra-marital sex, including transactional sex. This representation does not allow for the nuances of daily life with HIV, nor the social circumstances under which it may have been acquired, reflecting a continued essentialist approach to Ugandan HIV education which does not capture the multiple lived realities of being HIV positive in Uganda (Joffe, 1993; Cheney, 2007).

5.2.2: Genuine ignorance of HIV risk for children
2B1 "Ignorance" of HIV & children may be genuine in the community
HCWs also acknowledge that there is at least a small segment of the population that truly does not know about children's risk for HIV, and that this legitimate ignorance most likely comes from a lack of HIV education in more rural and remote areas served by the clinic, further fuelled by poverty and poor education levels.

> "Some people believe that young children can't get HIV… Such people are not educated or sensitized… Even now some people still don't know." (HCW #33, Community Health Worker, male, 33)

As HIV is also represented overwhelmingly as a stigmatized adult disease in the popular media, there is a lack of overt, inclusive social dialogue about children and HIV which would engage these hard-to-reach populations on this topic. In addition, the lack of current outreach services, as discussed in 5.1.2, further adds to the continued potential for real ignorance about children's HIV.

5.2.3: Representations of children

2C1 Community status of children: Competing roles & values may limit health care access

As discussed in Chapter 4, the traditional sociocultural status and role of children in Uganda was two-fold. First, children were valued as they increased the family clan numbers, and carried on the family lineage. Also, they were seen as "assets" for the parents, in terms of being a source of labour and therefore having production value, through the dowry income from girls, or as a type of "old age insurance" from the eldest boy who would take over the family land and look after the parents in their old age (Taylor, 1998). For HCWs, this historical social context still operates to an extent today, as children are often seen as valuable in terms of the farm work they can do, to help increase the family income.

> "Although we encourage [people] to come for family planning they don't hear that, maybe it's their culture- they have to produce [children]. They say children are good, but although the children are many and they are making even the parent to suffer… in their minds [having lots of] children [is] good." (HCW # 26, Nurse, female, 35)

Traditionally, more children means more workers for the land, which means more income potential, despite the push for children's schooling which takes them away from farming. HCWs feel that, for local parents, traditional ideas about the social role and function of children clash with modern values, in terms of children's schooling and the difficult economic reality of daily life in the area.

> "People around [here], they believe in child marriage, early marriages, so they tell us it's better to get a partner other than going to school generally. They don't know the benefit of education… They treat [their children] well, except the majorities are poor, so they have a belief if children can also concentrate on [farming], they can earn an income to the family. So they have a tendency of working together, children and the parent." (HCW #27, Clinical Officer, male, 48)

This is underscored by the fact that the vast majority of clinic users work in subsistence agriculture, and that most are impoverished, with little money for the opportunity costs of sending their children to school, such as uniforms and school supplies (African Agency for Integrated Development, 2010). As paid employment is also difficult to come by in the local area, continuing schooling may not make economic sense to many parents, who may not support their children continuing

their education beyond a certain level. One story of an HIV-positive child seen at the clinic reflects the difficult economic and social circumstances families are often in, where HIV is yet another problem to try to address, but ends up becoming the "breaking point."

> "[Most children we see are] okay, they're healthy… some are at school [and] they are doing well. [But] yesterday… there came a small girl- we have made that girl grow, the mother and father died because of HIV, she is 15 years or maybe 14 years. I asked her, 'why are you not at school?" She said to me, "[I] am sick from time to time… so the one who is taking care of me told me to stop schooling..." She's now at home… with someone taking care [of her]- not a mother or a father- and she's currently sick. [Such] children are suffering." (HCW # 28, Nurse, female, 49)

Difficult family circumstances and stressed relationships also put HIV-infected children at risk for treatment default or poor adherence, as seen in another example. Although the father values treatment for his son, interpersonal conflict results in him giving up.

> R: There's a boy, [he's] HIV positive and has TB. That boy, he came here, [we] opened the file for him, then started him on TB treatment first. But that boy, he takes drugs when he likes or when he doesn't like. Then the father said, "if you don't want to be here, okay, you go to where?"
> I: [Where] you feel you are comfortable.
> R: Then [we] called him to go to take his blood for CD4. He refused to come, then the father got money and he took him to Buhinga [a hospital several towns away] for the CD4 checkup. When reaching there, when [their staff] went to bleed him, he just said, "no, no, no, leave me, I will come back tomorrow." … What the father has done, he has just removed that boy from the village, he has just brought him here in the [town] center. And put him in a small room, just alone.
> I: And he is not taking the treatments?
> R: Umm. [Yes.] So now the parent has what?
> I: [Interjects.] Has given up.
> R: He has given up because he was tired of him. (HCW #34, Nurse, female, 37)

HCWs feel they are unable to intervene due not only to being overworked, but also as they are unwilling and unable to override parental authority, as there are no real social services or child protective services in Uganda to whom they could turn for help or enforcement. Although there is a legal framework for children's rights in Uganda, there is neither enforcement nor funding to support children (Cheney,

2007), who would most likely end up at a relative's house if unable to stay with their parents. Although there are two faith-based NGOs in the next major town which work with orphans, they have no real capacity to deal with children who are vulnerable to parental neglect or abuse, leaving children dependent on their immediate families for support.

> "A child depends on the adults. Eh, most children who are HIV-positive… some of them are receiving care. So, I don't know about those who aren't coming, but I suspect they are there. So, their life is actually dependent on the adults, their adult caretakers." (HCW #8, Clinical Officer, female, age not given)

HCWs feel families are generally stuck in such situations, and see the parent having difficulties coping with the child's HIV illness, often in addition to their own HIV-positive status as well. What limited counselling they can offer is not seen as being enough, as some sort of social services would be needed to better address such issues.

2C2 Moral status of children: Seen as "good" and "innocent" related to HIV

HCWs generally see children as being "good" and "innocent" in terms of their moral relationship to HIV, in that the most common mode of transmission remains vertical, from mother to child. As well, children are seen as being intrinsically valuable as human beings in their own right, and deserving of the same rights as adults in terms of health care access.

> "You just see the life of the child as being good." (HCW #1, Community Health Worker, male, 34)

> "Parents or guardians…are the ones who bring their children here, and most of them, if the child is having HIV, the mother is also down with HIV." (HCW #7, Outreach Worker, male, 29)

HCWs did not stigmatize or pass blame onto the children, regardless of the circumstances surrounding infection, but wanted carers to take responsibility for their children and look after them, including securing appropriate health care access for them when needed.

2C3 Legal status of children: Should help facilitate health access but does not

As the enforcement of laws to protect children in Uganda is poor to nonexistent on the local level, due to structural problems including scant funding, staffing and

support (Cheney, 2007), children tend to be sent to extended family if there is a problem, as there is no formal foster care system or social services. HCWs are reluctant to get involved in potential cases of child abuse, as they fear reprisals from the family, and feel that most cases are not dealt with properly by the police or justice system.

> "You know, the general care of children has so many factors that can surround it. The socioeconomic status, the social dynamics, especially instabilities, so on a broader perspective, I must say, some children are abused, some children are battered, we still have cases of child battering. Beaten by their own parents. Some children are abused by their own relatives sexually. Those cases are there but isolated… And, early marriages- [children] drop out of school and nothing is done. So, all those issues that are really complicating the issue of children… These cases usually go unreported, because the law is a bit reluctant, the onus somehow is given to the parent to take care of the child, so he's in a position to do all the abuse on that very child." (HCW #45, Official, male, 32)

As the ultimate authority for children remains with their parents, and Uganda does not have a social safety net, if something goes wrong within a family, the children are literally on their own to cope with the situation. In addition, child sexual abuse and rape (or "defilement" if it occurs to girls) is still regarded as a "taboo" topic, with little to no statistics available to determine the extent of the problem (Cheney, 2007). Although this may actually be a driver of children's HIV in Uganda, the lack of open discussion and statistics hampers its investigation at present, and makes it speculative at best.

2C4 Socioeconomic status of children: Opportunity costs often too high to commit to a child's HIV treatment

HCWs observe that low socioeconomic status exacerbates access and adherence problems further, and results in parents "giving up," with resulting HIV treatment default.

> "When the child is started on drugs it's a lot… the challenge comes when there is no food. That caregiver will try to pull out but can't pull out, because the child has already started [on drugs]. Then money to buy some necessities for that child because [he or she] has to be kept well, has to wash, has to bathe, has to go to school, everything. But when it comes to… [a] lack of money, that's a challenge to the caregiver. Then there's also social problems, for locally where that

person is staying, the community say, 'ah for you, you're used to caring for those [HIV positive] people, for us we can't even touch them.' With time [caregivers] lose that attitude, [and] say, 'ah, I know, any time he will die, why should I care?'" (HCW #35, Nurse, female, 35)

The combination of HIV-linked social stigma with the serious financial and time challenges of being a full-time caregiver on top of subsistence farming, may lead children's carers to become despondent, give up, and default on children's treatment (Kipp, et al., 2007). Emotionally, this may be resulting from a mixture of grief, depression and a sort of distancing from the child as a form of self-preservation in the event that the child then dies from HIV.

5.3: Implications of demand and supply constraints on professional identity

Most HCWs see their work as a positive and rewarding experience, despite the workplace difficulties experienced, and felt that their professional identity has been improved with the advent of ART drugs.

Table 5.3: Global theme: Implications of demand & supply constraints for professional identities

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Positive motivations for becoming a health worker (5.3.1)	3A1 Being a health worker has personal, financial & social benefits	-health care work a "calling" -well-paid job -reliable job	-rationale for job choice	-HCWs motivated to do their work
3B Positive Impact of ART on professional image and personal coping (5.3.2)	3B1 ART has improved personal outlook on the profession & practice	-ART gives us hope -ART helps us cope with the job	-ART has had a positive impact on us personally	-ART improved work conditions and morale of HCWs
3C Professional identity reframed as "heroic worker" (5.3.3)	3C1 Reframed a prior threatened professional identity to a positive identity	-heroism -self-esteem -respect -patient recognition	-"heroic worker" identity a result of ARTs in clinical practice	-positive identity can improve care provision
3D Remaining fears &	3D1 Psychological	-problems with treating	-clients difficult to deal with at	-acknowledge need for

anxieties about HIV practice (5.3.4)	anxieties related to dealing with clients	clients -clients "don't care" -counseling skills lacking for difficult situations	times -client resistance to behavior change suggestions -lack of skills in counseling difficult clients	professional development in counselling & client skills
	3D2 Fears related to medical & social complexity of sick children	-children difficult to treat -children complex due to social issues	-fear of working with sick children -problems dealing with caregivers	-need for more training for complex clients especially families & children
	3D3 Workplace stress resulting from system problems	-external stress -coping with stress -stress affects services	-working conditions create stress -ways of coping with stress	-burnout remains a risk for HCWs

5.3.1: Motivations for becoming a health worker

3A1 Being a health worker has personal, financial & social benefits

For HCWs, their motivations for becoming a health care worker vary but are generally positive and pro-social. Whilst most HCWs focus more on the volitional or "calling" aspects of the job, a few focus more on the pragmatic benefits such as good salary or their position being "advertised" at the time they were seeking employment.

> "I wanted to treat the nation." (HCW #22, Nurse, female, 31)

> "It was a call from God… It was a call, if it wasn't a call the way we're being stressed up, then very tired, then report the following day to do the same work, following year, following month and so on…" (HCW #26, Nurse, female, 35)

> "Ah, it was the job which was available." (HCW #21, Support Staff, male, 24)

> "At least if I get enough salary and my children complete school… yeah, I need my children to complete school on this service I am doing for the community." (HCW #26, Nurse, female, 35)

Many cited multiple reasons for becoming a health worker, with the combination of being able to help and be of service to others whilst being remunerated relatively well by Ugandan standards, being a key combined rationale for taking up this line of work.

5.3.2: Impact of ART on professional image and personal coping
3B1 ART has improved personal outlook on the profession & practice
ART is seen by HCWs as a very positive force, which has restored their capacity to be competent professionals and help others effectively, by having an effective tool in their work with clients. ART has also helped in terms of changing the representations of HIV not only amongst HCWs, but also more slowly amongst the public, with HIV currently going through a representational change from being a harbinger of death decimating the population, to a treatable illness, with the help of the drugs.

> "If [the patient] has started taking [ART] drugs, he or she can be as usual. Like any other normal person, in the way they live normally… like any other healthy person." (HCW #22, Nurse, female, 31)

> "Nowadays there is a big difference, because now the ART drugs are available to help those people who have [HIV]. We now have testing facilities and when someone goes and tests and finds that he has it, they start the drugs there and then and they get a good life." (HCW #1, Community Health Worker, male, 34)

ART has been a boost to the professional image and personal self-esteem of HCWs, as they are finally able to operate to the full scope of their job, in that they can offer patients more than simply a place to die: now they can offer effective treatment and improved clinical outcomes resulting in better health and prolonged life. However, ART has also reinforced a more paternalistic way of providing health services, with HCWs seeing themselves as being the chief "problem solvers," and their patients as having little agency over their illness, other than to comply and be "good" patients or "therapeutic citizens" (Ngyuen, et al., 2007). In some cases, HCWs take both the credit and the responsibility for patients being successful on ART.

> "[Patients] taking ART… They're all doing well, those ones who are on care. They're doing well because we monitor them- because almost every month they're supposed to come and we solve their problems early." (HCW #27, Clinical Officer, male, 48)

Such views run the risk of ART being co-opted as a way of maintaining and controlling the status quo health system social order, where patients remain as passive recipients of care, instead of active participants in negotiating their own health goals and outcomes with HCWs (Ngyuen, et al., 2007). Despite the hope that ART can also be used as a tool to decrease HIV stigma in society, it is too soon to tell if it can be harnessed to combat the negative and stigmatizing representations of HIV still in use in Ugandan society (Castro & Farmer, 2005). Given the historical Ugandan social context of paternalism and rigidly enforced social hierarchies, this may be expecting too much of ART, without broader social changes to harness and support its potential as a catalyst for social change.

5.3.3: Professional identity reframed as "heroic worker"

3C1 Reframed a prior threatened professional identity to a positive identity

With the advent of ART, HCWs have been able to reframe their professional identity to a more positive, "heroic worker" identity, as a way of coping with continued difficult and depressing working conditions, resulting from the system constraints they face on a daily basis. Capitalizing on the prestige and higher social status of being a HCW and the personal satisfaction that comes from helping others has helped develop this identity.

> "Being recognized as a nurse, people- when you're moving, keep on calling, eh nurse, nurse, my nurse, you see people kneeling down [as a gesture of respect within the culture]. Eh, I feel good. Then another thing, as [I] am working, even if am not motivated inside myself, I feel am motivating myself- because even if I stay here for the whole day I don't mind, so long as my client… is doing well."
> (HCW #35, Nurse, female, 35)

HCWs can also have very strong positive emotions from their work, though experiencing the feelings of power and satisfaction from healing the sick, which can be a powerful motivator for continuing to work in the profession, in the face of the logistical and personnel difficulties discussed previously in this chapter.

5.3.4: Fears & anxieties about HIV practice

3D1 Psychological anxieties related to dealing with clients

Upon discussion with HCWs, as in other parts of the world, they are not taught how

to handle difficult clients nor conflict resolution skills as a part of their basic health worker training. As I can personally attest, such skills tend to be learned on the job, unfortunately often through negative workplace experiences. This is a definite oversight in health worker training programmes globally, but beyond the scope of this thesis. However, the anxiety faced by HCWs in relation to how they feel patients perceive them is realistic, as problems originating from higher up in the health system have to be addressed by them on the front lines, with patients who are stressed and ill, and may not understand the "behind the scenes" problems going on.

> "Patients… they despise us. [They] may come with this problem from at home. If, when you try to help him… he sees that you are telling him a bad thing [something he doesn't want to hear]. When it comes to drugs, when they are finished [out of stock], [patients] just say that, 'you are the ones who have taken the drugs, you have them… so that we should go [to private clinics] and buy [them], before getting them for free here.'" (HCW #34, Nurse, female, 37)

Regarding the allegations of drug pilfering and profiteering seen here and in Chapter 6, a drug delivery was observed at the clinic during a participant observation session, as will be discussed in Chapter 8. The shipment was less than expected, in that it did not include some key drugs which were expected, and that the clinic received less than what was on the manifest, which the delivery agent could not explain. The staff unpacked the shipment together and co-signed for drugs, which is standard clinical practice, and no pilfering was observed during this episode. However, there is no guarantee that the staff did not take drugs later to sell privately or at another time, and the lack of accountability throughout the Ugandan health system, including Medical Stores supply, means that drugs and supplies could disappear at any point in the supply chain with impunity.

3D2 Fears related to medical & social complexity of sick children
For HCWs, fears related to the medical complexity of treating children with HIV have lessened, now that international treatment protocols have become standardized and set, after several years of changing clinical treatment guidelines (UNAIDS, 2010b). Instead, they have fears about dealing with the social complexity surrounding HIV infection in children. The need for improved counselling skills in the face of emotionally-charged situations and clients is now their main concern.

"It is worse for children because children need a literate caregiver who should explain it to them at some point, because they do ask questions like 'why are you making me take drugs?'… Something is wrong, they don't know what. And the worst question is 'where did I get this from?'… He doesn't know why he's taking the treatment. The caregiver may not explain, he's this illiterate person, and you may find it very difficult to explain. And some of the explanations have emotional connotations. Perhaps the caregiver is the grandmother who wouldn't want to go into the details on how the mother, who happens to be her daughter, died." (HCW #45, Official, male, 32)

As their professional identity would come under threat from being caught in a practice situation they don't feel capable of handling, the safest course of action for HCWs to protect their identity is to avoid that situation altogether. The fear of being caught in messy, and potentially unresolvable, family dramas, and being unable to help or act appropriately becomes a practice barrier keeping HCWs from engaging in this needed aspect of their work, either more fully or at all.

3D3 Workplace stress resulting from system problems

For HCWs, repeated situations of workplace stress can lead to burnout and result in poor quality and service delivery, as being "too exhausted to care" is itself a symptom of legitimate psychological burnout in health care professions (Harrowing & Mill, 2010). Burnout is also difficult to treat, and there are no workplace employee assistance programmes available for HCWs in Uganda. In addition, as being a health worker is a well-paying job, HCWs may be dependent on their income, or supporting extended family on their income, and so would be unable to quit or find another job that pays as well in Uganda.

"Okay I may say the worst problem here is that we're understaffed, you find like one person attending like three departments and when you're going home you're almost collapsing, because you're very, very tired even you have not taken lunch, you can imagine such a situation-- we're understaffed." (HCW #26, Nurse, female, 35)

Burnout may also be a way for HCWs to cope against extreme stress situations, as burnout in essence shuts down an individual's emotions, in order prevent feelings of extreme suffering and emotional pain. Whilst it has negative practice implications for patients, it may have a protective effect on HCWs suffering under extreme stress.

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5.4: Relevance for children's HIV care access & adherence

This chapter has explored the SRs which HCWs see as both facilitating and hindering children's access to ART and HIV services within their own clinical context. It has also discussed the impact of these factors on their own professional identity, as it relates to their facilitation of children's HIV access to their services.

For HCWs, children's HIV care access is hindered by three major contextual factors. First, they see a general social context where there is little positive or health-centered social capital. This social environment is also disempowering to children, in that children were historically seen by society as only being valuable for their economic outputs, as opposed to their own intrinsic humanity. Many HCWs felt that such ideas are still present in some families, and impact negatively on many aspects of children's lives including their health and social needs, as parents often make difficult choices based on the family's immediate economic needs, with children being the most vulnerable to the effects of these decisions, such as being unable to go to the clinic for care, or being pulled out of school to work.

Second, HCWs discuss the wider social context of the Ugandan judicial system, where there are few legal frameworks to support children's access to health services, and little to no funding for help on the ground in times of need or dangerous situations such as abuse. HCWs feel that they cannot intervene by themselves in these situations, and that there is a need for a functional social services system to support them in such cases. Finally, the social context of their own practice environment is such that they are limited by serious materiel and personnel shortages, which directly and negatively impact on the quality and quantity of care they can provide to potential clients.

HCWs also give examples of how children's access to HIV services is hindered by the negative SRs about HIV and children which are currently in use in Ugandan society. HIV is still seen as a highly stigmatized adult-centered disease, reflecting how it is a representation which contains core ideas which may be difficult to change without corresponding broader social changes (Abric in Deaux & Philogene, 2001), such as open engagement from the building of social capital. HCWs discuss how "ignorance" about children and HIV absolves people from having to address

children's HIV treatment needs, as these needs do not exist and therefore do not require treatment access. As children are seen as the blameless victims of HIV, contracting it from their guilty parents, this further stigmatizes parents by putting serious social pressure on them to keep their family's HIV status a secret, instead of seeking help which could result in all of them being "outed" by going for HIV treatment.

One potential facilitator to increase children's HIV service access identified by HCWs is that of their own improved social identity, to that of a "heroic worker," which could be capitalized on even further to build social capital and the social connections which would support a more health-centered community. This renewed sense of professionalism could be channeled into broader social leadership on community health issues, where HCWs could use outreach to further engage the community, by discussing and challenging the extant SRs of children and HIV in the era of ART. However, doing this would require an increased level of staffing to sustain outreach, as well as professional development support, such as skills training in client counselling and personal stress reduction and coping skills, which could be taught through workshops or professional development sessions. Increasing and stabilizing system resources to address materiel and personnel shortages, would also support HCWs in increased practice or outreach roles. These additional supports would be needed to encourage HCWs in going further in their professional practice, as currently, there is a reluctance to take on more responsibilities without correspondingly more support.

Conclusion

This chapter has taken findings from the research with HCWs to examine the confluence of the underlying wider social context, participant social identities and the collectively negotiated social representations, to determine their broad impact on children's access to HIV services. Several interventions can be suggested, in order to capitalize on the opportunities to improve children's HIV service access and medication adherence, as seen by HCWs. Facilitating these interventions would help both HCWs and health service users move towards each other by starting to create a health-enabling social environment, which could increase social capital and could help encourage children's access to HIV services.

More broadly, harnessing the wider potential of children's ART as a "newsworthy" item, through media reports and child-focused stories, could help to include children in the wider HIV media picture from which they are currently excluded. This could be a first step in publically acknowledging the existence of HIV-positive children, and could begin to create public discussion and debate over this social occurrence. Caution would have to be taken to try and limit stigma, due to the negative SRs seen in this chapter.

Supporting HCWs in increasing their leadership skills and further improving their professional identities by providing additional "soft skills" training, such as in counselling and self-care to protect against burnout, could help them to feel more comfortable in providing services to children and families, as well as recasting them as community health leaders. Further reframing the professional identity of HCWs to include social advocacy work, and using their higher social status to advocate for children with HIV, as well as to address HIV stigma more generally, could also help improve access and adherence for children with HIV. Providing increased outreach services for HIV/AIDS testing and treatment, and potentially combining it with a home-based social support system network, which could include a child protection response component for crisis situations, would be a significant help for children and families. However, this and the above interventions would likely require a realignment of national and district-level HIV interventions, to ensure a more effective coordination of services, including addressing the long-standing materiel and personnel shortages.

The findings discussed here have been reflective of the HCWs who participated in this study, and should be considered in concert with other participants' perceptions of the barriers to children's HIV service access. Chapter 6 will present the data findings from the next stakeholder group, the adult carers of children.

Chapter 6: Social representations held by Adult Carers

Introduction

As outlined in Chapter 1, the wider aim of this thesis is to examine the factors that facilitate or hinder children's access to HIV services in western Uganda, as seen by the three main social groups which are users and providers of HIV care. Chapter 5 has explored health care workers' (HCW) social representations (SRs) of these factors, by looking at their SRs of the positive and negative aspects of health services, their view of the wider community context of pediatric HIV, and the impacts of HIV, specifically the advent of ART, on their own professional identities and practices as health service providers to the community.

In this chapter, the spotlight now turns onto the children's carers, who are adults over the age of 18 years and the primary caregiver of at least one child under age 15 in their household (UNICEF, 2010), with participant demographics found in Chapter 3. As discussed in Chapter 3, participant HIV status was not asked given concerns around stigma and the inability to independently verify HIV serostatus. Of the 45 total participants, 27 (60%) are regular users of the local government health clinic and 18 (40%) are not, yet overall their responses are similar in terms of content and variation, reflecting the culturally and contextually shared nature of SRs. In seeking to understand why the participants might or might not take children to services, semi-structured in-depth interviews (N=30) and focus groups (N=3) were used, which aimed to elicit the SRs of health services (as discussed in section 6.1), HIV (see section 6.2), and children (in section 6.3).

Thematic analysis of the resulting transcripts highlight 3 global themes (Attride-Stirling, 2001) that map out the symbolic space in which carers think and act, in relation to children in their care, HIV, and health services. These 3 themes relate to:

1. <u>Perceptions that supply side constraints prevent demand opportunities</u>, which if addressed, could work to increase children's access to HIV care.
2. <u>The view that HIV/AIDS is the main threat to a positive social identity</u>, which results in health choices which negatively impact on children and families.

3. <u>Carers' beliefs that they can't protect children from HIV</u>, denying children's HIV risk to help themselves cope with this troubling reality.

These themes relate to the research questions of this thesis as they help to illustrate:

- The SRs of HIV, children, and health services, as seen by children's caregivers.
- How these representations have an overall negative impact on children's access to HIV services, as children's health choices continue to be managed by adults.
- That continued social stigma, fear, and jealousy or "treatment envy" towards HIV-positive people has a very negative impact in society, with particularly bad consequences for women in serodiscordant relationships or whose male partners refuse to test for HIV.
- How HIV is seen as a major threat to maintaining a positive identity as a carer of children, as it implies you do not care for or control your child effectively enough to prevent HIV infection in them.
- That there is extreme tension and resistance on the part of carers to acknowledge children's risk for HIV, due in part to a long-standing cultural reluctance to deal with child and youth sexualities.
- How schools have become the primary place where children learn about HIV, as carers generally do not discuss it at home, and clinicians typically do not have access to children without the approval of their guardians.

6.1: Perceptions that supply side constraints prevent demand opportunities

As will be discussed in this section, the key issues framing adult representations of the health service are centered around concerns over associated "opportunity costs" in accessing health services, perceived inefficiencies in the provision of care, and mistrust of health service providers. These are reflected in the three organizing themes and the basic themes as outlined in Table 6.1 below.

Table 6.1: Global Theme: Perceived supply side constraints prevent demand opportunities to increase children's access

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
1A Public system access difficult for families due to high incidental costs but private & traditional systems not good either (see 6.1.1)	1A1 Private clinics easier to access/use but cost more than government clinic	-private clinics better supplied -private clinics easier to access but cost -pay on credit	-private clinic usage significant despite extra costs	-people paying to get faster, more "reliable" care services
	1A2 Need money to access care regardless of provider	-government clinic free -health care costs -transport costs	-incidental costs high to use government clinic	-government service still "costs" to use, in terms of time & effort
	1A3 Traditional medicine cheap & easy to access but not as effective	-traditional vs modern (Western) medicine -traditional medicine cheaper -traditional medicine not reliable	-traditional medicine seen as lower quality option but cheaper & easier to use	-people want best quality for least "cost" -convenience wins out over quality (if have to choose)
1B Drug supply irregular at clinic & has negative impact on care (6.1.2)	1B1 No/not enough drugs at government clinic	-no/few drugs at clinic -HCWs not giving out drugs/supplies	-poor logistics: drug provision & monitoring -public expectations vs provider capacity	-irregular drug supply in some areas taken to be the case in all areas
1C Mistrust of services due to perceived profiteering of HCWs (6.1.3)	1C1 Allegations of HCW profiteering	-some HCWs have side businesses -HCWs not good workers -HCWs unmotivated -no system accountability	-allegations may be real or just gossip -wages of HCWs not enough relative to personal & family needs	-mistrust damages provider-user rapport -public may not use clinic as a result of allegations

6.1.1: Public system access difficult for families due to high incidental costs, but private & traditional systems not good either

This organizing theme explores how, despite the provision of "free" health care services by the Ugandan government, there are in fact many "opportunity costs" associated with health care use, which can be prohibitive to the carers accessing services. These exist across all health service providers, whether public or private, and merely differ in the amounts required and types of costs involved. This section will show how, according to children's carers, no one health provider meets their needs in a cost-effective and high quality way. For carers, the main issue becomes one of choosing the "least bad" service provider out of their limited options, as carers perceive all the local health services to be flawed in some way. Concerns related specifically to the government-run clinic included perceptions that drug supply for all drugs is erratic, which is linked to perceptions of HCW corruption, fuelling sentiments of mistrust and a reluctance to use clinic services.

1A1 Private clinics easier to access & use but cost more than government clinic

The data from the carers suggests that private clinic usage may be widespread, despite high levels of poverty, where over 70% of the district population lives on or below the international poverty line of $1.25 USD per person per day (African Agency for Integrated Development, 2010). As the local clinic had erratic and unreliable drug supplies, many participants instead opt for private clinics, where they can have immediate access to drugs and care for a few dollars. The reasons given for this choice reflect how private services are perceived as being more flexible, more reliable, and with faster turn-around times when compared to the government clinic, despite an additional cost. For carers, paying to be seen immediately at a private clinic is preferred to waiting all day for free services at the government clinic, particularly when you may find that no drugs are available at the end of the visit. In addition, private clinics also offer convenient "payment plans" for their fees which better reflect carers' lived economic circumstances.

> R: But you may go to the [private] clinic and get drugs on credit- that is the clinician knows you. Then you go back to the village, do some work, earn money, and pay the bills later on…
> I: So, you now like going to [private] clinics, because they treat you on credit.

> R: Yes, if you have, like, a bunch of *matooke* [starch bananas] you are planning to sell the following day, and you visit them for treatment, they have to give you drugs. Then you pay later, after selling the bunch of *matooke*. (Adult #38, female, 37) [*A bunch of matooke at market could fetch up to 20,000 UGX or $8 USD.*]

This quote suggests that carers do value high quality services, and when choosing how to use their limited income to meet their health care needs, will choose the provider with the better reputation for quality versus cost, convenience, and flexibility to meet their needs and lived reality. The implications of this are that the government-run clinic is not seen as a high quality health provider, and is inconvenient to use despite its lower overall usage costs, which will be discussed further in section 6.4.

1A2 Need money to access care regardless of provider

As seen previously, accessing health care in Kabarole district often involves relatively high opportunity costs to obtain treatment, regardless of health service provider used. For carers, transport costs were also highlighted as a concern, with most participants who lived near the interview location about a 20-minute walk from the clinic, or just over 1 kilometer in distance. Other areas in the clinic catchment area are up to 3 kilometers or about 1 hour of walking away. Many carers stated that, if ill, they would need to use paid transport to access the clinic, and that the costs were prohibitive for them.

> R: [We use] motorcycle transport [to access the clinic].
> I: What's the cost?
> R: Cost is 2000 UGX [$0.80 USD *each way*], that's from here but others are up there- you move [up] the mountain, then those ones could use about 5000 UGX [$2.00 USD].
> I: So it's the cost or the physical getting to the clinic…
> R: That's a problem. (Adult #13, male, 24)

Although the main costs in accessing health care were transport and drugs, carers also noted there are additional types of "costs," in terms of the time away from their work to be seen at health services. Given that the vast majority of carers are small scale subsistence farmers, spending the whole day waiting to be seen at the government-run clinic, as is commonly the case, is seen as being cost prohibitive, as it would result in the loss of a whole day's wages, in terms of work and crop harvesting. The loss of a day's wages, when combined with additional costs for

transport and drugs, makes "free" health care quite expensive for the participants in this study, who often resort to using alternate, cheaper, non-clinical forms of treatment.

1A3 Traditional medicine cheap & easy to access but not as effective

Given the high costs involved with Westernized clinic medicine, participants see traditional medicine as being a cheaper option, despite it also being seen as of lesser quality and reliability than the Westernized medicine available elsewhere. In this local context, carers suggest that traditional medicine is used more as a result of poor health service options, than as part of a belief system as in other African or global indigenous cultures. Instead of a cultural "clash" between local and Western medicine systems, participants here markedly prefer Western medicine, but are often unable to afford it, or obtain it due to shortages, and so use traditional medicine as a cheaper substitution.

> "Now, in most cases, we use traditional medicine, because modern medicine is sometimes very expensive. Because you might find like Coartem [for malaria] is out of stock at the health unit, the health workers say that drugs are not there. Drugs are out of stock. Then finally, you go to the [private] clinic, and they ask you for 6000 UGX [$2.40 USD for treatment], you see? You say, 'Ah, let me go home and take my bitter herb.' You resort to using local herbs." (Adult #6, male, 35)

As in the quote above related to malaria, the respondent first uses the free government clinic but finds it is out of drugs, and so then tries the private clinic which is unaffordable, and finally resorts to home-based traditional medicines, which may or may not work, but are affordable and physically there. In this regard, despite best intentions to use the government clinic and preference to use it first, a chain of difficulties result in the carer resorting to the "third-best" option which may or may not work, due to a combination of system materiel shortages and poverty.

6.1.2: Drug supply irregular at clinic & has negative impact on care

As seen in 6.1.1, carer perceptions of high costs and poor service provision at the government clinic are factors which act as a structural barrier to caregivers accessing health services. This is further exacerbated by ongoing clinic difficulties in providing drugs, due to a lack of a stable drug supply from further up the national

supply chain, as is discussed in Chapter 5. Carers are well aware of the problems of drug stock-outs, and are highly critical of their occurrence. Although carers acknowledge that antiretroviral treatment (ART) is provided well and for free, they also reflect that other types of drugs are less well provided, cost money, and are regularly in short supply. Allegations of corruption are given as the reason for this incongruence, in the absence of any official explanations or discussion over the parallel funding and supply streams, as discussed in Chapters 5 & 7.

1B1 No/not enough drugs at government clinic

The unreliable service provision of drugs is seen as a major flaw by the participants. They link poor drug supply to profiteering, due at least partly to the lack of open and honest communication between HCWs and the public, in relation to the problems they attest they are having with supply logistics from Ugandan National Medical Stores, as discussed in Chapter 5.

> R: The only problem is that they always tell patients that drugs are out of stock.
> I: That's the only reason stopping you from visiting the health unit?
> R: Yes.
> I: Now, what do you think can be done to improve healthcare services, so that you all access them happily?
> R: Umm, nothing can be done. Now you see, we are being told it's not that. It's either a lie, or they say that drugs are sent to the health unit, but doctors take drugs to their own private clinics. We cannot manage to solve that problem. The clinical officer takes drugs from the health unit. How can we address that issue?
> I: A clinical officer takes out drugs?
> R: Umm. [Yes.] (Adult #19, female, 25)

The irregularities in drug supply are here taken by the participant to be an example of profiteering, when the problem may truly be out of the hands of the local HCWs, as discussed previously. This further reflects problems in care management and service integration, as adult and pediatric HIV drugs are not affected by shortages, due to their separate provision from an international non-governmental organization (NGO), discussed in Chapter 4. Although the discrepancies in drug supplies here are due to separate supply chains, the public is unaware of this, as there is either poor communication, or a lack of proactive communication, between health care workers and the public. This is also an opportunity for shared advocacy for better

drug supply from Ugandan National Medical Stores and the government, which is not being capitalized upon, but could be in future.

6.1.3: Mistrust of services due to perceived profiteering of HCWs

During the interviews, allegations of staff "profiteering" were reported by some of the participants. Although such allegations are difficult to verify, and beyond the scope of this thesis, the researcher concurs that the "optics" of the current work environment at the government clinic could be seen as questionable. Upon interviewing a senior official (see Chapter 5), it was acknowledged that across the district, some staff members do engage in side business ventures, including running private clinics off-property. Although the official could not say for sure that no profiteering was taking place, chronic drug shortages did make carers question whether staff were indeed pilfering drugs and/or other supplies, and is a finding which deserves careful further study.

1C1 Allegations of HCW profiteering

Although these allegations are beyond the scope of this research to investigate, they do have an impact on participant perceptions of HCWs, how they provide care, and trust.

> R: Ah, when you reach the health unit, they have to tell you that, "you go to Dr. X's [name redacted] [private] clinic." If you don't have money, will you really go to X's clinic?
> I: No.
> R: That's it, you go back home and die. Eh, that's all.
> I: Now, is X an employee at the health unit?
> R: Don't prompt me, X is a clinical officer of the clinic.
> I: Eh! A clinical officer…
> R: Don't tell him, because he might beat us from there, at the health unit.
> I: We won't tell him, that's why I told you about confidentiality. Because so many people- you aren't the first person to tell us such…
> R: [Interjects.] When you go to the health unit, after reaching there, you find him at the health unit, he registers you, if he sees your skin itching so much, or when you are in much pain, he tells you to go to Dr. X's clinic. After taking a few steps, like from here to there, he bypasses you riding his motorcycle. When you reach X's clinic, you find there the same person, same face. Ah, he treats you! Ah!
> I & R: [Laughter.]
> R: Eh, he treats you and you go back home…If you don't have money, and say that, "I don't have money." He asks you first, that,

"you are going to X's clinic?" Then you reply, "I don't have money."
He says, "go back home." You go back home also.
I: Oh my God.
R: Umm, we have always come back home without treatment, we
even stopped going there. (Adult #24, female, 58)

Again, there is an increasing need for open and honest communication, and better public relations by HCWs, as a lack of communication can feed mistrust, and further damage service provider-service user rapport and trust, which is needed to maintain service access. As shown above, some participants reported no longer using the clinic as a result of these perceptions of corruption. Once trust has been broken, it can be very difficult to get service users to return to using clinical services, and highlights the need for open dialogue between HCWs and the public over realities of service provision, expectations, standards of care, and possibilities for improvement.

6.2: HIV the main threat to a positive social identity, which results in health choices which negatively impact on children and families

This global theme reflects how HIV is the main threat to carers' social identity, as it becomes a type of "symbolic annihilation" where the repercussions of being HIV-positive were regarded with more fear and dread than the disease itself, due to it being a de facto social "death" (Campbell, et al., 2005). The representations discussed in this section reflect emotions including fear, stigma, and a kind of paranoia over one's HIV status and being "found out" to be HIV-positive in society. This toxic social mix of stigma, fear, and paranoia contributes to a general social climate that does not support people seeking care and services for HIV, which is then extended to children by default. As the social implications of being "outed" as HIV-positive carry too high a price to pay, it becomes less likely that carers will access HIV testing and treatment for themselves, let alone their children.

In addition, the advent of ART may actually be exacerbating stigma further, as it is now difficult to know socially who is HIV-positive, unlike before ART. Efforts to improve the quality of life for people living with HIV may actually be causing a further backlash against them, seen in the form of "treatment envy" that HIV-positive people are able to access better services more easily, as they are seen as being a

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priority for care providers. This jealousy over the additional resources given to HIV-positive people, including ART, is a new development in the struggle against HIV.

Table 6.2: Global Theme: HIV the main threat to a positive social identity, which results in health choices which negatively impact on children and families

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A High levels of HIV stigma remain in community (6.2.1)	2A1 High levels of HIV fear & stigma are widespread in society	-HIV stigma -fear of HIV -reluctance to test for HIV -"hiding" HIV	-not testing for HIV at local clinic for fear of being "outed" with HIV	-stigma & fear preventing HIV service uptake for adults & children
	2A2 Women bear the worst impacts of HIV stigma	-unintended impact of PMTCT -sociocultural norms "blame" women for HIV	-serious social consequences for being a HIV-positive woman	-won't bring kids in if will be "outed": too much risk
	2A3 Fear of HIV spreading in community by behavior of some HIV-positive people on ART	-HIV risk in community -fear of HIV spreading -Behaviour of HIV-positive people	-Fear over risk of ART drugs increasing HIV -Social/health "benefits" of ART drugs put others at risk	-Potential backlash against HIV-positive people & ART -continued stigma limits service use
2B Social role confusion due to ART use in community contributes to fear (6.2.2)	2B1 Can't physically tell anymore who is HIV-positive due to ART	-HIV-positive appearance improving -HIV treatment helping -HIV treatment hurting -HIV changing	-HIV treatment obscuring who has HIV -perceived "taking advantage" of ART effects	-fear at risk of HIV spread from people on ART -backlash against ART
2C Jealousy & "treatment envy" from increased HIV resources & attention on disease (6.2.3)	2C1 More resources for HIV than for other illnesses	-HIV programming -HIV resources	-Funding focus on HIV as opposed to other illnesses	-resentment at lack of funding for other problems
	2C2 HIV-positive people doing better than HIV-negative	-HIV support -HIV caregivers -HIV-positive get preferred	-"Treatment Envy" as HIV-positive seen as being an "advantage" in	-potential for backlash against HIV programming

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	ones due to more clinical support & resources	treatment at govt clinic	getting care	

6.2.1: High levels of HIV stigma remain in community

Despite many years of efforts to address HIV stigma in Uganda, with a variety of programming and educational campaigns, it is still highly entrenched across society (AVERT, 2014a). This translates into a continuing general resistance to HIV testing and treatment, which is the underlying HIV-related social context against which HIV services are offered.

2A1 High levels of HIV fear & stigma are widespread in society

Many carers report high levels of fear regarding testing for HIV, and a reluctance to use the services in their town for fear of being "seen" at the clinic, which would imply that they are there for HIV testing and/or treatment. The geographical location of the clinic is a high-visibility area, next to the main road and the main weekly market where everyone goes to conduct trade. Although this is an excellent location in terms of physical access, its very location and visibility carries high social risks. Many carers related stories of people going to another location, such as the next local town, to get tested for HIV, due to the fear of being "found out" by their friends if they tested locally.

> I: Why do you fear being tested?
> R: Ah, we get scared. You just think if you are tested HIV-positive, you will get scared, and die then and there. (Adult #40, female, 30)
>
> R: You find some people getting HIV treatment from a different place, because they fear being seen by fellow village mates, when they go to the health unit for drugs. They fear being recognized as HIV-positive victims.
> I: Umm, so they fear going to the health unit for treatment, and then go to faraway places.
> R: Yes, they go far away. (Adult #41, male, 19)

This fear and stigma at being seen as a clinic user, with its implied message that you are HIV-positive, is likely not helped by the clinic having a dedicated day for HIV services, which could "label" everyone in attendance as users of HIV services, even though this may not be the case, as non-HIV services are still provided on this day. Given the continuing social stigma of HIV, carers would benefit from the clinic

changing to a more integrated model of care (Wells, et al., 2011), where HIV services could be easily accessed anytime, which would help mask who is there for what treatment, and thereby reduce the risk of stigma.

2A2 Women bear the worst impacts of HIV stigma

Although HIV stigma is generalized, the consequences of being a woman with HIV, particularly if your husband or partner is HIV-negative, are very serious and potentially life-destroying. Participants stated they believe that women would be divorced or kicked out of the family home by their husbands, if they went to the clinic for PMTCT services, and were found to be HIV-positive. Although women accessing PMTCT are supposed to bring their husbands along for a joint HIV test, this does not usually happen, as the men refuse to go with them for testing. Pregnant women who think they may be HIV-positive are often lost to follow up, as they do not go back to the clinic for subsequent visits, because the socioeconomic consequences of being HIV-positive would mean they are rejected by their husband and his family, kicked out of the house with no income or resources, and left to fend for themselves with or without their children.

> R: Eh, he can divorce her. That's where he gets, gets the courage of going for an HIV test too. If he's tested HIV negative, he divorces his wife. When the man is negative and the woman positive, he chases the wife away. He cannot stay with his wife. Why is it so? I also don't know why. As a woman, you can tolerate your husband, but men are never patient. They can't allow their women to stay in the home.
> I: It's a must he has to divorce his wife.
> R: He divorces his wife.
> I: Except when he's tested positive too.
> R: Yes, if he's tested positive, he will keep quiet, he doesn't say anything to the wife. (Adult #39, female, 38)

> "For me I think the family members would have advised my husband- according to how I look at it- they would have advised him to send me away, or maybe to leave me there with my children because I have nowhere to put my children… That is what they would have said- if they would have found their son without the disease. But if they had found their son sick and for me I am healthy, they would have kept quiet." (Adult #10, female, 32)

The gender divide in terms of HIV testing gives women a huge social disadvantage, as legally, HCWs are supposed to test every pregnant woman for HIV unless she "opts out," as a part of the prenatal services package (Dahl, et al., 2008). This

further fuels men and society "blaming the woman" for bringing HIV into the household, as she becomes the only one who has tested; although the man may also be HIV-positive, if he hasn't tested, his status is unknown, and he can claim to be the "innocent" party, whether or not this is actually the case. Men are also reported by participants to go and test privately in clinics in other towns, where they aren't known. This gendered social disadvantage puts female carers at risk for not using health services or bringing their children in to be seen, as they cannot risk being "outed," and so may not use services unless this stigma risk can be lessened. In this regard, the economic and survival stakes of being outed as HIV-positive are simply too high, so carers choose not to use services.

2A3 Fear of HIV spreading in community by behavior of some HIV-positive people on ART

Stigma is also being further entrenched as a backlash against people who are HIV-positive and are on ART drugs, as they are seen by some carers as putting the community at risk for increased HIV infection through risky actions.

"Some people are selfish. After taking drugs and looking healthy, he or she becomes good-looking, [and] he or she starts infecting others. Eh, that's how it is, that's why people are saying that if they hadn't introduced HIV drugs, HIV would no longer be existing in the community. That's why they say so." (Adult #24, female, 58)

R: Now, you find a person on ARVs, then when the patient's health improves, or when they start looking good, they regain their normal position. Now you find, like a woman getting married. You find a man or the woman's husband died of HIV/AIDS, but after getting treatment, time [passes] and she gets what? Married… whereby you find her delivering children. Yet she had children before, so she starts losing strength.
I: She becomes weak.
R: Then, after knowing that the second husband had died, she leaves the home. She changes position, goes to another place, and gets married again. Instead of her knowing that, 'I am becoming more weak when delivering, or when I continue conceiving', she can't stop conceiving for fear of being recognized that she is HIV positive. And in most cases, such people, most of them women, they normally get transfers. When they lose someone, the husband from this place, that lady will shift from this place to another place where she's not known.
I: And get a new husband.
R: Yeah. (Adult #6, male, 35)

Despite the long-term rhetoric of being "faithful" to one partner through the ABC Method, the underlying cultural sexual norms of male promiscuity and female fertility, which continue to define one's status in adult society, present surviving HIV-positive people with a serious challenge to negotiate (AVERT, 2014a; Larson, 1989; Birungi, et al., 2009b). In order not to be outed as HIV-positive, because they think the drugs have "cured" their HIV, or to reconfirm their status in society, HIV-positive men may have multiple sexual partners, and HIV-positive women may bear children, as this is a cultural expectation in this society (Larson, 1989; Birungi, et al., 2009b; Taylor, 1998), as seen in Chapter 4. However, carers recognize this and fear it may also exacerbate the spread of HIV, which is a legitimate fear, given the risks of treatment failure from loss to follow-up or dropping out.

6.2.2: Social role confusion due to ART use in community contributes to fear
Although ART is readily available, and has helped save people's lives and improve their quality and quantity of life, it is also changing the way that HIV is "seen," through masking the physical signs of HIV infection. Carers suggest that now, no one knows who has HIV and it worries them, as before ART became available, they could tell who was HIV-positive and take precautions to keep themselves safe. To them, ART has broken down the comforting social distance between "us," the HIV-negative people, and "them," the HIV-positive people, by getting rid of the physical signs which acts as a barrier to help to tell people apart (Campbell, et al., 2005; Joffe, 1999). This has led to increased fear and paranoia about who has HIV and who doesn't, which feeds people's anxieties and fears regarding the HIV levels in their community, and the impact of HIV on the overall safety of their families and themselves in this unsure social environment.

2B1 Can't physically tell anymore who is HIV-positive due to ART
Prior to ART, the physical effects of progressive HIV infection would be unmaskable signs that the individual was suffering from HIV, including wasting or thinness, skin rash or sores, skin and hair pigmentation changes, and recurrent minor illnesses (Mugyenyi, 2008). ART has improved the physical appearance of people with HIV, but has also broken down this physical "code" that worked to contain and manage the illness in this society, but which resulted in a sort of social segregation of people who were HIV-positive. Participants expressed worry and fear that they could no

longer tell who was HIV-positive with just a glance like in "the old days," and resentment, as the weight that patients put on as a side effect of ART is seen as being culturally attractive and a sign of health and wealth (Larson, 1989).

> "Now if there was no ART we could identify the patients easily, but now drugs are there [to] make them look healthy." (Adult #43, male, 19)
>
> R: In the past, HIV patients, I used to see them, they were very thin. But these days, HIV patients are healthy, they are looking good. Umm.
> I: Umm, they are so good-looking.
> R: That's it. [Laughter.] You can even consider that people, among HIV-negative people, the patient looks more healthy than HIV negative people. (Adult #40, female, 30)

Of note is that the concerns expressed here have changed from the pre-ART era, and relate to having sexual relationships and partnerships with HIV-positive people, than contracting HIV from casual social contact. Carers are ultimately worried that HIV-positive people are spreading HIV in the community through increased opportunities for sexual contact, whereas before, the physical signs of HIV were unattractive and acted to socially segregate them and minimize the risk of HIV infection through sexual contact.

6.2.3: Jealousy and "treatment envy" from increased HIV resources & attention on disease

The underlying paranoia and mistrust concerning HIV in the community is further exacerbated by perceptions of inefficient and unequal distribution of health resources, particularly at the government-run health clinic. Carers feel that HIV-positive people get more resources and attention than HIV-negative clients, which causes deep resentment in those who are negative, as HIV is still seen as a punishment for immoral sexual behavior, as discussed in Chapters 2 & 4. As the very people who engaged in immoral behaviors and contracted HIV are now seen as being "rewarded" for it by better health services, with those who maintained "correct" behavior in society now being disadvantaged by receiving less care and attention, "treatment envy" results. This is further underscored by a wider sense of social competition, common in many societies, where people may resent those who

are doing better than they are, particularly if it is seen as an "undeserved" success (Campbell, et al., 2005; Mbonye, et al., 2013).

2C1 More resources for HIV than for other illnesses

Due to additional foreign donor funding over what the Uganda government provides for health services, HIV services are prioritized and better-funded. This occurs despite clear overall need at the clinic in terms of increased staffing, drugs, and supplies for common illnesses and basic health needs, such as malaria or respiratory illnesses. The quote below reflects this HIV-skewed and highly vertical funding and distribution system.

> R: Yes, services concerning HIV/AIDS are good, HIV patients are given good care.
> I: Eh, HIV patients have benefited a lot.
> R: Yes. But for other patients with cough, malaria, or other diseases, they aren't given much care or attention. Their attention and care is limited. (Adult #5, male, 48)

This resentment is often directed at the HCWs who are seen as being the most immediate agents of this unfair system, as the carers do not appear to recognize that there are in fact two parallel supply and funding chains at work. With no one from the clinic openly discussing this with the wider public, they may not know why this occurs or how the health system works. Regardless, the health system in its current state is unintentionally favoring HIV-positive people, and putting the majority of the population at a comparative disadvantage for health services, which may be further entrenching stigma and resistance to HIV services uptake. There is a clear need for a move to diagonal or integrated system funding and design, in addition to increased public engagement over how health care is administered and funded in Uganda.

2C2 HIV-positive people doing better than HIV-negative ones due to more clinical support & resources

Again, being HIV-positive was felt by carers to give a comparative advantage in accessing health services, but only for health services, due to the stigma and negative connotations of being HIV-positive in society. "Treatment envy" is the result of this resentment at increased clinic-based support, and the additional

resources available for HIV-positive people, as compared to those suffering from "everyday" illnesses such as malaria or respiratory infections.

> I: According to you, HIV drugs have helped patients so much.
> R: Yes. HIV drugs helped them a lot.
> I: You see them looking good.
> R: Yes, they are good-looking, eh. They even look better than me! [Laughs.]
> I: You see them fat?
> R: Yes, they are so healthy, they've put on weight... I also went [to the clinic] and said, 'eh, as I have lost a lot of weight, I want you to test me, and tell me the truth. If I'm HIV-positive, I start drugs early.' They told me that, 'we cannot start someone on HIV drugs unless he or she tests positive.' They refused to start me on drugs, but [I] also wanted to start taking HIV drugs! [Laughter.] (Adult #37, female, 38)

Such resentment not only leads to further stigma against HIV-positive people, but may also contribute to a greater backlash against clinic services, if they continue to be seen as being unfair and unresponsive to non-HIV related services.

6.3: Carers believe they can't protect their children from HIV and so deny children's HIV risk to help themselves cope

The global theme in this section reflects the tensions felt by carers in being ultimately responsible for children in the "HIV era," and is shown through the organizing and basic themes which discuss their representations of children and HIV. There are multiple ways in which carers ultimately distance themselves from the issue of children's risk for HIV altogether. Whilst some outright deny HIV exists in children as a sort of defense mechanism against the possibility, others distance themselves from being responsible for their children's HIV risk by placing the responsibility on schools, where an HIV curriculum is taught to children starting in primary level 3 (Government of Uganda, 2002). These SRs ultimately link to feelings of confusion over the parental role in the HIV era, with parents worried about losing control of their children, and losing them to HIV.

Table 6.3: Global Theme: Carers believe they can't protect children from HIV and so deny children's HIV risk to help themselves cope

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Denial of	3A1 Adults	-children can't	-children with	-reluctance to

children's HIV risks links to a lack of dialogue on youth sexuality (6.3.1)	"deny" children with HIV exist 3A2 Adult denial of youth sexuality	get HIV -HIV-positive children "hidden" -youth aren't sexual -youth not sexualized by choice -transactional sex	HIV exist but "not here" -youth "not supposed to be sexual" in Ugandan society: taboo subject	acknowledge HIV risk for children -youth sexuality linked to HIV spread -transactional sex & sexual abuse/rape a "hidden" issue
3B Education about children's HIV risk is inadequate overall (6.3.2)	3B1 HIV education for children is inadequate for their needs	-HIV education school-based -no media on children and HIV -carers rarely teach children about HIV -carers can't talk about HIV to children	-HIV school curriculum at odds with local social norms -no at-home HIV discussion -no real media content on HIV & children	-HIV education needs of children not being met -carer HIV education needs also not being met
3C Battle between traditional ideals & modern realities of raising children in the HIV era (6.3.3)	3C1 Children are "good" but at risk for behaviours which could lead to HIV infection 3C2 Adults feel their parental authority is under threat, but remain in control	-children are "good" -some children do bad things -HIV risk for children -children's rights impact on family dynamics -children still dependent on adults -adults make big decisions for family	-most children are well-behaved -some children misbehave & partake in risky behaviours -adults guardians in charge of children's health care -society not set up to handle "emancipated minors" in health care	-children are seen as good if they obey their parents -some are involved in HIV risk behaviours -carers worry about "controlling" their children in the HIV era -adults hold economic power which you need to access care

6.3.1: Denial of children's HIV risks links to a lack of dialogue on youth sexuality

In denying children's HIV risks, some participants hide behind wider idealized notions of children as being "good" and obedient, and therefore "exempt" from sexuality and HIV, versus those who are "uncontrollable" and therefore at risk for HIV (Campbell, et al., 2005). Further, carers generally did not want to discuss

issues concerning "defilement," the male rape of a female minor, or the sexual abuse of children, despite these topics being reported on in the wider media. Although the vast majority of participants would not openly discuss this in the interviews, a couple of participants discussed cases they knew of off the record. This may be due to historical taboos regarding the discussion of young children and sex (Taylor, 1998), as discussed in Chapter 4, or due to personal and social discomfort with the subject. Participants were marginally more open to discussing HIV risks from transactional sex for gifts or income, particularly related to girls.

3A1 Adults "deny" children with HIV exist

Whilst some participants deny that HIV-positive children exist, or that children were even at risk for HIV infection at all, others acknowledge that children could be infected with HIV by their parents, but did not want to discuss children's sexuality further.

> "Some children are born with HIV, that's what people say. But some of us who are ignorant, we cannot believe that it's the truth, the child was born with HIV." (Adult #5, male, 48)

> "You know positive children, always, within the village, they always talk about them, where their father or mother dies of HIV/AIDS, then when the child falls sick- that's the time they start talking about the child. And they don't feel comfortable in the community when they are talking about HIV/AIDS." (Adult #6, male, 35)

> R: Mmm, people are talking about them. But for us…we have not received any child suffering from HIV/AIDS.
> I: You don't hear anybody talking about them?
> R: Ah, at our place we have not got any case of a child suffering from HIV/AIDS.
> I: Your village is a very unique village.
> R: Eh, it is a very special village. [Laughter] (FG Mixed #3-1, female, 20)

Although this denial could be a basic psychological defense mechanism, it could also be the result of years of media messaging in Uganda, framing HIV as an adult disease acquired mainly through sexual activity, with a converse lack of messaging that children are vulnerable to HIV as well.

3A2 Adult denial of youth sexuality

The sexuality of children and youth was not something participants generally

wanted to discuss, but which the participant quoted below sees as a big concern in regards to transactional sex.

> "Silimu [HIV] is going to kill us… When you give a child enough pocket money when going to school, that alone can act as security to enjoy himself or herself. But when the child doesn't have the basic necessities, that child will easily fall prey to AIDS because he or she will be looking for assistance. And when a girl meets a boy and he gives her like 500 [UGX, about $0.20 USD] to buy what she needs, she will give in to the boy and she will become infected." (FG Mixed #3-5, female, 19)

Whilst child abuse and defilement are beyond the scope of this thesis, transactional sex is a concern for participants, due to high levels of poverty and the very real risks to girls who are often not financially supported in their schooling by their parents. This may be linked to a continuing historical social pattern, where parents who only have enough money for one child to continue on in education past the upper primary level, typically pick the oldest male child regardless of ability or interest, as he is seen as the one who will inherit the family name and homestead and look after the parents in their old age (Taylor, 1998). This means that girls who want to continue on in school are left to finance their education on their own, and often do through "sugar daddies," older men who give them money or gifts for sex (Samara, 2010).

6.3.2: Education about children's HIV risk is inadequate overall

Some participants recognize that children need HIV information, but feel they are unable to provide it themselves, and that schools and the media should provide children with this information. This links back to underlying historical cultural taboos about parents not discussing sexual matters with their children, which clashes with the realities of living in the HIV era (Taylor, 1998). However, with the onus being on schools and the media to educate children about HIV, the blame can also be placed on them when they fail to do so effectively, which protects the parental identity against the risk of failing to protect their children in the HIV era.

3B1 HIV education for children is inadequate for their needs

Historically, sexual education of minors was the role of the parental aunt and parents did not teach their children about sex (Taylor, 1998), but with the realities of

life in Uganda as discussed in Chapter 4, this relative may be in another town, out of the country, or no longer alive to fulfill this role. Schools now do this through the Government of Uganda's HIV curriculum (Government of Uganda, 2002). However, as will be discussed in greater detail in Chapter 7 concerning the children's data, legitimate criticisms have been levelled against this material, in that the content does not adequately address children's educational needs about growing up in the HIV era in Uganda.

> "Eh, now parents fear to disclose to their children- as I have told you that everyone know HIV/AIDS is through sexual intercourse- now parents feel shy about sexual words to teach children or to tell children, [so] they refuse to talk to their children. So in homes if there is someone who can talk, they're few, like me I can't and others can't because they are shy." (Adult #11, male, 45)

> R: Ah, yeah, now at school they take it as a lesson. That, 'they taught us about HIV/AIDS at school.'
> I: [Interjects] 'They taught us something about AIDS.'
> R: But [for] someone [to] say that, 'let me call children,' and he or she gathers them somewhere, then says, 'we have come to train the young ones on HIV/AIDS,' I have never heard of that calling. Now, like every parent bringing his or her children to educate about HIV, it has never happened here. (Adult #6, male, 35)

As carers feel unable to talk to their children about sex generally, and schools may not be doing so in an way that meets their learning needs or lived reality, this leaves children at a very real risk for misinformation or a lack of information about sex and HIV altogether, which puts them at risk for HIV infection. This will be further discussed in Chapter 7, from the children's perspective.

6.3.3: Battle between traditional ideals & modern realities of raising children in the HIV era

There is an underlying tension in carers' view of children, between the idealized notion that children should obey their parents and be "well behaved," versus the recognition that this does not always happen. At present, carers blame "others" for disrupting this social norm, with schools and modern influences such as the media seen as sources of corruption. In essence, there is a competition for influencing children, between the family which would historically have been in control, and modern social life where peer groups and wider social and media influences may have more of an impact on the child's behaviours and choices. This uncertainty as

to whether they still have control of their children or not, results in a threatening identity conflict for the carer, which is resolved through blaming the "other" for HIV risk and reasserting parental supremacy.

3C1 Children are "good" but at risk for behaviours which could lead to HIV infection
Most participants see children as being inherently good and well-behaved within the family unit, but at risk for negative external social influences, such as negative peer pressure, which could result in HIV infection.

> "The children who don't go to school have no opportunity of hearing about [HIV] because they don't go to school and they will not have any audience to sit with their parents to tell them about [it]… That is the cadre of children disturbing other people's children in the villages and infecting them with the disease… They will persuade your child as much as possible [to have sex] until they end up infecting him/her with [HIV]. That is the biggest problem we have in the villages. Children who are not in school are the ones spoiling those who are in school." (FG Men #1-3, male, 50)

However, concepts of "spoiled identity" and blaming the "other" for spreading HIV, are still being linked with HIV infection risk (Joffe, 1999). With this representation, "good" children are portrayed as vulnerable, innocent, and not "street smart," especially compared to "bad" children who engage in risk behaviours. This allows for a positive carer and family identity to be preserved in the face of a major threat, by ignoring other possible explanations or factors for children engaging in sexual behavior, such as childhood experimentation, child abuse, or transactional sex.

3C2 Adults feel their parental authority is under threat, but remain in control
Further, carers are torn as they remain legally responsible for their children's wellbeing, but feel they are losing their influence over them in terms of social control. Although this may be going on within the household, carers are still seen by society as having the final say in decision making, and ultimate social responsibility in terms of their children. This is further reinforced in terms of making health care decisions for the family, where the carer has the social and legal power to make health decisions for their children.

> "The life of the children in the villages depends on the parents of these children and how they are treating their children… There are

some parents who care and others who don't care about their children's welfare." (FG Mixed #3-2, male, 36)

"If the father doesn't believe that he can fall sick, do you think he will think his children can also fall sick? They don't bring these children." (FG Men #1-3, male, 50)

At present, the "traditional" heterosexual family structure with parental, and particularly male, authority is still the norm in Ugandan society. This is reinforced by wider social structures, including the lack of an "emancipated minor" treatment policy or protocol in the Ugandan health system (Cheney, 2007). This effectively means that legally, children can't access health care without the approval and support of a parent or adult guardian. As children are economically dependent on adults as well, these are definite barriers to any independent health services access.

6.4: Relevance for children's HIV care access & adherence

This chapter has examined the factors that facilitate or hinder children's access to HIV services from the perspective of children's guardians. In doing so, it has revealed the underlying social climate regarding HIV, the SRs commonly used about children and HIV and health services, and the role maintaining a positive caregiver identity plays in both family-centered and wider social dynamics.

The findings here illustrate how adult carers remain the main health care access decision makers within the family unit, and how their perceptions about health services are generally negative and prevent them from bringing children to the government-run clinic to be seen. This is due to a number of overlapping representations, which reinforce each other and create a generally negative view of health services and society as a whole. Carers hold perceptions of health services as being poor value for the costs involved, and poorly provided with questionable ethics. Their views reveal a rampant and deeply entrenched HIV stigma in society, which further inhibits clinic use out of fear of being labelled as HIV-positive, and encourages further stigmatization, particularly of women, through internalized feelings of fear, blame, and treatment envy.

Carers also see HIV as a threat to their positive parental identity, as they are unable to fully and effectively protect their children from it, and so fail at one of their main parental tasks and roles in society. This is due to HIV in children being linked by them to either poor parental care, through child sexual abuse or vertical transmission by not accessing PMTCT, or poor parental authority, in that the children are sexually active and at risk for "lateral" HIV transmission from age mates or transactional sex. This is further complicated by a historical and cultural norm of lack of communication surrounding sexual education, where it was taboo for parents to teach their children about sex (Taylor, 1998). This is now being done by the primary school system, but in a way that has raised concerns as to its content and effectiveness (Human Rights Watch, 2005).

Given that adult carers are tasked with the authority to make health care decisions for their children, children's access and adherence to HIV services will be hindered by their negative perceptions of HIV and health services, and their lack of identification with the HIV services offered in the community. As HIV is seen as a direct threat to their parental authority, and a positive social identity is based upon remaining in control of their children, the risk of HIV in "their" children is negated or denied at all costs. However, this identity is fragile at best, for although it is a useful coping mechanism at present, wider social changes resulting from the HIV era are increasingly challenging this identity, and remain to be resolved. Carers did not see society as trustful, positive or helpful to them, reporting tenuous social connections and little social capital upon which to draw in crises.

The main HIV-linked social change which threatens carer identity is that of changing social and power dynamics both within the family unit and in wider society, due to the realities of living with HIV in what is fast becoming the ART era. Now that HIV-positive people can survive and live long lives with ART, older SRs and mores surrounding HIV will need to be readjusted, as society itself is changing. The role of parents and families may also have to change accordingly, as HIV is skewing traditional life patterns and relationships, in many cases leading to worse social circumstances and outcomes than in the previous eras, particularly for women and girls. One example of this is in transactional sex, where despite carers remaining the head of the household legally and socially, in terms of economics their authority

is undermined, as they cannot afford to pay for their children's needs. Transactional sex can undermine parental authority in real social and economic terms, as well as putting children at risk for HIV infection.

However, there are interventions which could help carers negotiate these changing dynamics, by strengthening their threatened identity and improving their outlook on services and society. Programming which could help address the underlying negative SRs and fears held by carers, and act as facilitators to increase service usage for children, could include training in coping strategies or skills such as conflict resolution training, to give them a psychological and identity "boost," which appears to be needed, before any further social changes can be managed.

Finally, the threatened identity and negative outlook on society held by carers is exacerbated by isolation, in that there is a significant lack of social capital and trust between carers and other stakeholders such as health services, schools, and local officials. Stronger connections and better communication between carers, schools, health services, and officials could help to build a level of social capital which could then help to renegotiate the relationship between carers and HIV-related services. Using this social capital to then facilitate open discussions about children and HIV, such as through the Community Conversations intervention model (Campbell, et al., 2013b; Ellis, 2000), could help provide a community-based social space for concerns and fears about HIV and children to be discussed. A later, ultimate goal could be to have health services and schools work with carers and children together in order to combine school-based HIV programming with clinic-based health services outreach.

Conclusion

The data presented here reflect the underlying impact of SRs, social identity, and social context on HIV service uptake for children in this community, as seen by children's carers. Examining how these intertwine reveals their perspective on the lack of general social capital, and the overall social climate towards children and HIV, which at present does not facilitate children's access to HIV services, but in fact hinders it outright.

The health system context, as carers see it, suggests that improving clinic services and communication with the public is an area for interventions, which could help to increase access to the clinic. There is a need to realign services to make them more user-friendly for carers and children, which could also help HCWs, given the findings in Chapter 5. There is also a need to create high quality services, with a better reputation for quality versus cost, convenience, and being "in tune" with carer's needs and lived reality. Creating better social connections between health service providers and uses could also help to strengthen social capital and trust between these isolated groups, and increase children's HIV service uptake.

For carers, the representations in use about living with HIV and using health services are very negative, and HIV-positive children are conspicuously absent from the picture as this constitutes a threat to the parental identity of being a good carer. This is another area for potential community intervention, either through the media, through outreach work by HCWs, or through facilitated Community Conversations (Campbell, et al., 2013b; Ellis, 2000). There is also a need for new representations, created by both service providers and users, and reflective of their needs and experiences as discussed here. In addition, psychosocial interventions that would reinforce a positive social identity in relation to health services use, would give carers an emotional boost, and help them better cope with caring for children in the difficult social world of HIV. These could be some of the first steps towards helping carers renegotiate their relationship with not only health services, but also their children, whose views will now be seen in Chapter 7.

Chapter 7: Social representations held by Children

Introduction

This chapter will explore the data findings resulting from the draw-and-write exercise with children, the final stakeholder group of the three that participated in this research study. The findings here reflect children's social representations (SRs) of health services (in section 7.1), HIV (section 7.2), and children affected by HIV (see section 7.3). Section 7.4 will provide a further theoretical analysis and integration, related to children's HIV treatment access and adherence within this community setting.

As discussed in greater detail in Chapters 3 and 4, the setting for this study is Amooti town, which is served by a main government Health Centre III, and which also contains 2 government-run primary schools. As pupils could attend either school, both were sampled to assess for potential differences within the individual school social settings, as discussed in Chapter 3. One school is considered by locals to be more "urbanized," as it is located close to the main trading market, and so is denoted by the prefix U for quotes and drawings, with the other school located approximately 20 minutes' walk away from the main market, and considered more "rural," hence the prefix R used in the quotes and pictures.

In working with the children, a draw-and-write exercise was used to elicit open-ended responses to the task and question, "draw a picture and write an accompanying story about a child who has been affected by HIV/AIDS in any way." As this technique has been used successfully in other sub-Saharan African (SSA) settings, and offers a child-friendly way of engaging children in research, it was selected as the method to be used for this demographic group (Campbell, et al., 2014; Campbell, et al., 2010). Children aged 12 years old (N=82) were selected as the target age group, as children this age typically possess a high level of fine motor skills and cognitive understanding, yet are still socially and developmentally considered children (Campbell, et al., 2010; Skovdal & Ogutu, 2009; Howarth, 2002a). The primary school setting was chosen as this is the main social space where children are formally taught about HIV, through a national HIV curriculum which starts in primary level 3 (Taylor, 1998; Government of Uganda, 2002).

Here, drawings and stories (82 works, 6 exclusions for N=76) are grouped together as primary documents for analysis, with the frequencies of themes discussed included in Tables 7.1, 7.2, and 7.3 for reference, as well as throughout the chapter. Six draw-and-write works were excluded from analysis, due to content which did not in any way reflect or connect to the theme of the exercise. One example of the excluded works is the piece below, where the child has illustrated and described what was learned in school the previous day, as well as a child's liked and disliked activities and foods.

Figure 7.1: Drawing from Participant U6

"[Our teacher] taught us about seasons yesterday. He said that there are two seasons in a year. There's a rainy season and a dry season. He said that people plant their crops during the rainy season. People harvest their crops during the dry season. [The girl] likes playing net ball but she doesn't like skipping. She likes cakes but she does not like lemons. She likes sweets but she does not like oranges. [She] likes cakes because they are sweet. She does not like lemons

because they are sour. She does not like fish because it has many small bones." (Participant U6, female)

Whilst such works have no content directly related to the exercise goal of exploring the SRs held by children about children and HIV, it is recognized that they are what the children chose to express at the time of the research exercise. This may have been due to an unwillingness to create a work which reflected the exercise goal, boredom with the research exercise, or simply the desire to use the research exercise for personal creative expression. This work is presented to reflect the full scope of works produced by this exercise, to acknowledge the variation in content produced, and to act as an example which addresses the rationale behind the exclusion of these works from further analysis.

For the 76 works which included content on children and HIV, thematic analysis of the corpus produced 3 global themes which are clustered around representations of health services, HIV, and the effects of HIV on children and families (Attride-Stirling, 2001). These global themes are:

1. Health services are not effective in the fight against HIV/AIDS, as seen through personal, lived experiences.
2. HIV/AIDS continues to have terrible impacts on our society, which are felt deeply by children and families.
3. The world is an unsafe place for children due to HIV/AIDS and we are at risk, and adults appear to do nothing to resolve this.

These themes reflect the research questions of this thesis by illustrating:

- The SRs of HIV, children, and health services as seen by participating children.
- How the SRs generated are negative and induce tension, anxiety, and fear over prospects for a healthy future.
- That health services are seen as being ineffective, with no acknowledgement of antiretroviral treatment (ART) being accessible or useful.

- How children's data findings capture disconnects between official HIV educational rhetoric and their lived reality.
- How children's outlook on future health prospects are generally negative and fatalistic concerning HIV in society.

As will be explored in sections 7.1 to 7.3, the representations expressed in these works reflect children's understandings of HIV as an illness with negative social and personal impacts, and with little sense of comfort or resolution portrayed in the stories or pictures. The resulting key findings of this chapter will show how the children's representations of HIV/AIDS still reflect the initial representations of HIV in the early HIV era in Uganda, as discussed in Chapter 4, where HIV was seen as a disease which maimed and killed, with health services unable to help. Despite the rollout of ART in this community, drugs are rarely mentioned by the children and do not have a major impact on their produced works, or on their conceptualizations of HIV. The draw-and-writes also suggest that the children do not feel safe from HIV anywhere in their society, and at times express a sort of despair and fatalism over the preponderance of HIV in society, and its negative effects on their lives and their families.

7.1: Health services are not effective in the fight against HIV

This global theme emerges from dataset drawings which make reference to the provision of health services in the community, although the draw-and-writes contain less of a focus on health services as compared to data from the health care workers (HCWs) and adult carers. Although HIV was the specific focus of this research exercise, children were free to express any aspects of HIV's impact on children they wished, with many choosing to portray personal or family experiences with the illness. Their works also suggest that they see health services as not being effective in the fight against HIV, with people managing their illness at home, as opposed to using the clinics for care.

Table 7.1: Health services are not effective in the fight against HIV

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence

1A HIV/AIDS has negative impacts across society (see 7.1.1)	1A1 HIV is an illness with negative impacts across society	-HIV as illness -Negative impact of HIV on activities of daily life	-HIV seen as the negative reality of life in Uganda	-children live in the HIV era as their reality -suggests current need for A & A should also increase
1B Health system not effective in the fight against HIV/AIDS (7.1.2)	1B1 HIV services, including ART drugs, are difficult for people to access and use	-healthcare costs -opportunity costs -no/few drugs at health clinic	-people can't "afford" to access health system	-opportunity costs will need to be reduced to increase A & A
	1B2 Health system options do not help those with HIV	-traditional medicine bad -clinic medicine not working	-neither system works for people with HIV	-health services need to be improved to increase A & A
1C People manage HIV "at home" not at health clinics (7.1.3)	1C1 People cope with the effects of HIV by themselves "at home"	-HIV illness experienced "at home" -absence of medical/clinical imagery/stories -main settings for pictures the home setting	-children observe health care decisions of adults -adults don't use the health clinic	-people don't use the clinic for HIV needs, so A & A not increased -HIV-positive are cared for "at home," not in society or the clinic: unmet & unknown need

7.1.1: HIV/AIDS has negative impacts across society

This organizing theme examines how HIV is seen by children, as revealed by its portrayal in their drawings and stories. The focus on HIV within the stories and pictures reflects the goal of the research exercise with the children, which was to explore their understandings of HIV and its impact on children. However, the content of the draw-and-write exercise was left up to the children, to give them the opportunity to express themselves as they felt comfortable. The content in the pictures and quotes here reflect the negative impacts of HIV across society and on children and families.

1A1 HIV is an illness with negative impacts across society

The works produced here range from more extreme to more mundane portrayals of HIV within family groups and in society. Some children represented HIV as an all-encompassing force which threatens their society, almost as if it is "eating up" or annihilating their society through the deaths of so many. Given the widespread negative social effects of HIV in Uganda discussed in Chapters 1 and 4, it makes sense for children to portray HIV as having very negative impacts on their society.

An example of the more frequent negative portrayal of HIV in society is seen in this picture and its story, which portrays the clinical signs of an HIV-positive individual, namely skin rash and a thin, wasting appearance with a skeletal rib cage acting to visually demarcate the HIV-positive child in the picture from the others. This motif appears frequently in the works produced, and is discussed further in section 7.2.1.

Figure 7.2: Drawing from Participant R1

"I have drawn a family who [has] a child with AIDS." (Participant R1, female)

The story below illustrates the most extreme negative impact of HIV on a family, that of the threat of an entire family clan being wiped out by HIV. Of the works

created, this can be considered the worst-case-scenario, and it appears in some of the works produced.

> "[This] family… has many problems. First of all, in that family there's neither a mother nor a father. Mum and Dad died of HIV/AIDS, and there's no family member left because they all died of HIV/AIDS. And in their clan, there's no one who is HIV negative. Even the young children get pregnant at an early age and they deliver HIV positive children. That's why they die at an early age." (Participant U9, female)

7.1.2: Health system not effective in the fight against HIV

The works which make up this organizing theme reflect negative experiences with the health system in the provision of HIV services, including a lack of service provision. Unfortunately, of the works which discuss health services, the portrayal is generally negative. The health system is seen by the children as functioning poorly for people who are HIV-positive, as services are difficult to access and expensive in terms of opportunity and actual costs.

1B1 HIV services, including ART drugs, are difficult for people to access and use

Of the works produced by the children, overall, only a few mentioned ART drugs but focused mainly on the unavailability of ART, whereas the vast majority of works did not mention ART at all. Also of note is that, of the works which included ART, none portray the successful use of HIV drugs in relation to long-term survival. Works which mention health services do so in the context of difficult or failed access to care.

This quote very bluntly summarizes the child's negative family situation, where a relative who is HIV-positive does not have access to ART medication.

> "My sister has AIDS. I don't [have] any medicine to give to her."
> (Participant U31, male)

In this story, an HIV-positive couple has difficulty adhering to their ART treatment course, and in the end, default on their treatment and die.

> "A man and a woman went to hospital to test for HIV. When they reached there, the health worker told them to first complete taking the drugs, then go back to hospital… They went back home and took drugs, the drugs were finished, but they refused to take the next

dosage given to them. When they reached home, they finally died."
(Participant U41, female)

Below, this more complex work juxtaposes a picture heavy with text with the child's own personal, family experience with HIV, through the deaths of the parents and the elder sister from AIDS. Whilst the quote is succinct in its discussion of the impact of HIV on the family, the picture is rich in HIV-related imagery and text, contrasting how people access health services for HIV, with the family deaths from it. With the title, "Let's avoid AIDS," the upper left section shows an HIV patient sitting under a tree. The central images consist of houses and graves, with the graves of the child's mother, father, and grandmother marked. Figures are shown tending to the graves, with a sick child being visited in a house by a man. The bottom right scene shows a man going for HIV testing.

Figure 7.3: Drawing from Participant U26

"My dad died of HIV/AIDS. Mum died of HIV too. We remain 5 children…Our elder sister engaged herself in sexual acts, after a short time, we heard that she had died of HIV/AIDS. That was my story. I have remained." (Participant U26, female)

1B2 Health system options do not help those with HIV

The stories and pictures here suggest that, despite the difficulties involved in accessing health services, when they are actually used by people, positive health outcomes do not result. This occurs regardless of the service provider accessed, whether government, private, or traditional. Poor care outcomes, often ending with a patient's death, are also portrayed as impacting negatively on the lives of children and families.

This story portrays the in-hospital treatment for the child's grandfather, where the grandfather is taken to hospital after falling ill, but dies shortly after being hospitalized. Although the author does not specifically mention the grandfather's HIV status, given that the grandmother previously died of AIDS, it is possible that the grandfather may also have died of AIDS, or an AIDS-related illness.

> "After one year our grandmother died with [the] disease of HIV/AIDS. One day our grandfather got sick. We took him to the hospital. He was soon dying. After one hour when they were cooking [food] for him, they called… [he] was dead." (Participant U8, female)

In contrast, in this quote the HIV-positive family is still alive, but is unsuccessful in accessing ART medication at their local clinic. Traditional healers are then tried as an alternative treatment option, but with no success.

> "This family has suffered very much with HIV/AIDS. They went to the clinic and failed [to get medicine, so] went to witch doctors. Up to now, they are still suffering." (Participant R37, female)

The picture below shows the child's father being taken to a hospital and treated, but unsuccessfully, with the father's grave pictured at the family homestead in the bottom of the drawing. The accompanying story here captures the social and emotional impact of HIV, as felt by this participant when health services could not save the father's life.

> "AIDS has no cure. AIDS kills the young ones and the adults. My father [died] in 1999 because of AIDS. So I am an orphan, I am the only one remaining in this world. I have written this story, because I am an orphan, for me I want children to avoid AIDS, AIDS kills" (Participant U1, female)

Figure 7.4: Drawing from Participant U1

7.1.3: People manage HIV "at home," not at health clinics

This organizing theme reflects works which represent HIV/AIDS as a disease which is experienced primarily "at home," where the care involved takes place. Here again, HIV is rarely portrayed as having a positive outcome, and health services are not seen as helping those living with HIV.

1C1 People cope with the effects of HIV by themselves "at home"

The works here explore the "at home" effects of having an HIV-positive person in the family. Whilst a range of outcomes are covered, the experiences are generally negative in terms of personal, emotional impacts on children and their families. The story below discusses how HIV impacted on the family of the deceased parent, with the children left behind now being cared for by a grandparent, but still negatively impacted by the death of the mother.

"To this family, there's AIDS, the mother of the children died on Friday and they buried her on Wednesday. Their grandfather took them to school to learn. The children stayed learning but they are suffering." (Participant U13, male)

In the below picture and its accompanying story, a homestead setting is drawn with several figures in front of houses. Three figures are shown fully clothed and standing, with the fourth figure, appearing naked and emaciated, seated on a mat with a cup nearby. Although there is no specific written reference to the emaciated figure as being the child, such a visual motif appears in almost half of the pictures with such a label; this motif will be specifically discussed in section 7.2.1. The brief "story" describes the picture as that of an HIV-positive child being tended to by family members at home.

Figure 7.5: Drawing from Participant R18

"The family which I [have] drawn [has] a child which was sick [with] HIV/AIDS." (R18, male)

The quote below is a frank discussion of the child's family situation concerning the HIV-positive family members, as well as an HIV-positive friend who died. The quote outlines the range of options in responding to HIV infection, ranging from being HIV-positive but not on drug treatment, to being HIV-positive and on drug treatment, to dying.

> "I don't want to hide anything from you. My uncle is HIV positive but he doesn't have drugs, he is healthy, he has not yet fallen sick. My sister is also HIV positive, and she's on HIV drugs, and I saw a girl… she was suffering from HIV, she's now dead." (Participant U10, female).

The child in this quote discusses finding out about the mother's death from HIV only when visiting relatives and being confronted with her grave.

> "I went to my Mum's place. When I reached there, I found out that she had died of HIV/AIDS. I asked my relatives where her grave was and they showed it to me." (Participant U34, male)

Although this global theme explores the children's SRs of health services, particularly for HIV, there is considerable overlap between their views and those of the adult participants in this study in Chapters 5 & 6. Whilst some children are aware that ART exists in the community, the difficulties in its access and use are discussed, similar to the adult carers in Chapter 6, and in opposition to the potential positive course of clinical treatment discussed in Chapter 5 by the HCWs. Here, the clinical course of HIV resulted primarily in the death of the infected individual, after an illness experienced primarily in the home setting, and with ART noticeably absent or failing the patient. Children's draw-and-writes did not generally portray HIV services in a positive way, and their own representations of HIV appear to be negative in most cases.

7.2: HIV/AIDS continues to have terrible impacts on our society

The focus of this global theme is on the negative SRs of HIV itself, as seen through the eyes of the children. Their works illustrate how the older, original representations of HIV are still predominant, that of it being a killer disease, and that people bear the marks of HIV through the physical signs of illness (Joffe, 1993; Kitzinger, 1995), vividly illustrated by the children in the visual drawing exercise and in their written texts. The children also see a link between HIV and poverty, in how

people are able to cope and live with HIV or not, suggesting that if you have money, a decent life with HIV is possible as you have the means to cope. Women and girls are also singled out and portrayed in a contradictory social position: on the one hand, as being hit especially hard by the effects of HIV, but on the other hand, blamed for driving the HIV epidemic through prostitution. Other works reflect the current Ugandan HIV transmission realities of the "sexual network" of multiple concomitant relationships and social sexual violence.

Table 7.2: HIV/AIDS continues to have terrible impacts on our society

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A HIV maims & kills people (7.2.1)	2A1 HIV/AIDS kills	-deaths from HIV -graves at home from HIV deaths	-idea of HIV=death -HIV killing all/everyone	-HIV equated with death, little mention of ART -risk A & A being seen as futile
	2A2 HIV-positive people are the walking dead	-HIV skeletons -People living with HIV -HIV physical appearance	-HIV-positive people are scary skeletons (both adults & children)	-pre-ART physical HIV signs & symptoms still in use -risk A & A being seen as futile
2B HIV & poverty inextricably linked in our society (7.2.2)	2B1 HIV exacerbates poverty and vice versa	-risk behaviours vs personal safety/wellbeing -HIV treatment -HIV resources & programming -lack of financial resources	-low SES leads to risky behaviours & HIV infection -HIV treatment & support expensive	-link between HIV risk & poverty not adequately addressed by services -A & A limited by finances & opportunity costs
2C Social contradictions about women, girls & HIV (7.2.3)	2C1 Negative impact of HIV on women & girls	-polygamy -faithfulness vs infidelity -rape or defilement risk for girls in community -females more	-male norm to have multiple sexual partners -male privilege not questioned	-girls socially disadvantaged -girls have higher HIV risks than boys -girls may be less likely to access care

	2C2 Women are negatively associated with HIV infection	at risk for HIV -sociocultural norms "blame women" for HIV -impact of PMTCT -prostitution	-women forced to bear the blame for HIV from society	-stigma may prevent girls from accessing HIV care -unintended consequences of PMTCT & HIV messages

7.2.1: HIV maims & kills people

This organizing theme is split across two representations of HIV/AIDS: first, that HIV kills almost indiscriminately, and second, that if HIV doesn't kill people, it maims them and turns them into a sort of "living skeleton" or "walking dead" type of figure. Examples of both conceptualizations were present at both schools, although there was a location divide, where pupils from the more urbanized school portray HIV as a killer disease, but pupils from the more rural school portray HIV as turning people into living skeletons.

2A1 HIV/AIDS kills

A large number of works portray HIV as a killer disease, affecting the whole population and killing indiscriminately in terms of age, gender, and the like, including works which discuss several family members dying of HIV/AIDS, often across age ranges. The quote below gives a more lyrical, generalized representation of AIDS as a killer disease.

> "AIDS, AIDS, AIDS is the killer. Killing young, young and all. Killing poor, poor and all. Misery. Be careful." (Participant R31, female)

In contrast, this story reflects the child's personal experiences with HIV/AIDS killing family members, and hints at the frustration and exasperation faced by this child, at the prospect of AIDS killing so many people in so many places.

> "AIDS is a dangerous disease and it has killed so many people. What can we do to control HIV/AIDS in the community? My grandmother died of HIV, HIV/AIDS killed her. What can we do for HIV, as it has killed many people in this world? My aunt died of HIV/AIDS." (Participant U11, female)

2A2 HIV-positive people are the walking dead

The other representation of HIV/AIDS portrayed by children in their works is that of HIV/AIDS as an illness that maims the people infected with it, by turning them into a sort of "walking dead." This was expressed was through both words and visual elements which centered on specific motifs which mimicked the physical signs of latent HIV infection, that of skin rashes, often drawn as dots on the skin, and a thin, wasting, skeletal appearance often with ribs drawn as visible on a naked torso. The story below, along with its accompanying picture, illustrates the physical manifestation of HIV as a skin rash on the affected child. In this picture, the child may have been portrayed as being bare-chested by choice, so that the dots on the skin and ribs can be better seen by the viewer.

> "Once upon a time there lived a man and his wife and their child. Their child was suffering from one of the STDs which is HIV/AIDS. And one of the signs [has] come out from the body, which is skin rash." (Participant U35, female)

Figure 7.6: Drawing from Participant U35

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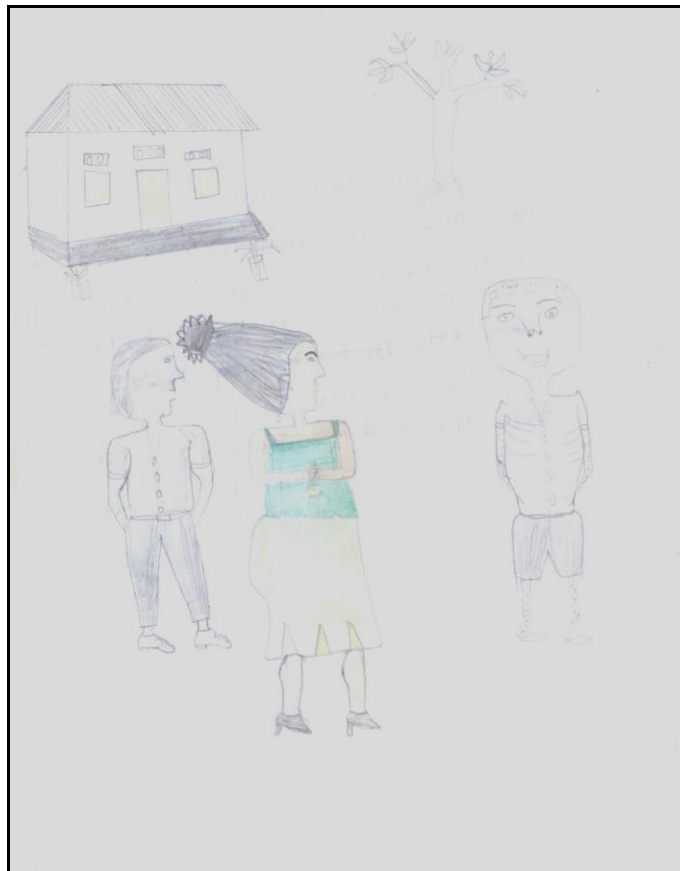
The quote below further discusses the link between physical signs and HIV infection status, with the specific mention of scabies and bones as being linked to HIV.

> "[Some] have scabies. Others have bones coming out. The ones who have scabies, they have AIDS. The ones who have bones coming out, they have AIDS." (Participant R20, female)

7.2.2: HIV & poverty inextricably linked in our society

A few works link HIV/AIDS and poverty together, and portray HIV infection as exacerbating the precarious life situation of an already-at-risk impoverished household.

2B1 HIV exacerbates poverty and vice versa

Here, the negative socioeconomic impact of HIV infection is most felt by the surviving family members, upon the death of the main breadwinners.

The quote below discusses the impact of HIV on the family's income, in terms of the costs associated with dealing with the illness and its after-effects, such as the death of a patient leading to difficult economic choices for the survivors.

> "They took him [to] our home and we buried him. He left [my mother] maize. When they had dried, after one week, they harvested the maize. [As] they planned for that money, my mother said, 'let us buy some flowers and we put them there, and they [are] finished.' Up to now, my grandfather and my grandmother died when suffering from HIV/AIDS." (Participant U8, female)

This story reflects how HIV has disrupted traditional life patterns, particularly in terms of the family-based, informal social support system, as Uganda does not have a formal social safety net. Here, HIV/AIDS has not only robbed the elderly woman of her family, but also of her social and economic support system. She is now left alone to run her homestead and cannot keep up with the chores required on a farm.

> "The old woman's husband died with their 2 children because of HIV/AIDS. She's now suffering because her children died. The old woman lives alone in the house. In the morning, she wakes up and prepares tea. Later on, she goes to graze her cows, and she stays for the whole day without eating anything other than the tea she took

in the morning. If she leaves the cows alone, they might escape and eat people's crops." (Participant U25, male)

7.2.3: Social contradictions about women, girls & HIV

This organizing theme reflects two contradictory representations of the impact of HIV on women and girls portrayed in these works. On the one hand, females are shown to contract HIV infection through heterosexual relationships with men, possibly unknowingly, but on the other hand are also portrayed as being a potential source of infection through high-risk sexual behaviors such as prostitution or multiple concomitant relationships with men. Although the actions of local males are mentioned in passing, they are not subjected to the same level of scrutiny as seen in the examples below.

2C1 Negative impact of HIV on women & girls

Some works focused on the negative impact of HIV on women and girls, specifically portraying women's HIV infection as being contracted through a male sexual partner.

The quote below reflects one participant's story about a friend who was sexually active and contracted HIV and died. Although the quote does not mention transactional sex specifically, it is possible that the friend was in a transactional sex relationship, exchanging sexual favors in lieu of cash for transport, as has been noted amongst adolescent and young women elsewhere in Uganda (Samara, 2010).

> "Even my friend was HIV positive, she used to love staying with boda-boda [motorcycle taxi] men. In the end, she died of HIV."
> (Participant U10, female)

The below story describes how a girl contracted HIV from a boy she had a sexual relationship with, and was unknowingly infected with HIV, with deadly results.

> "One day a girl was walking alone and a boy came with flowers. That boy had HIV, and he slept with the girl, then the girl died because of AIDS. And [the] girl [did not] know that the boy had AIDS."
> (Participant U19, female)

2C2 Women are negatively associated with HIV infection

A more damaging representation that emerges in some works, is that women are reservoirs of HIV infection, contrasting sharply with the above representation that

women can be unknowingly infected. This may be an interpretation reflecting original Ugandan HIV messaging campaigns regarding the use of prostitutes and the spread of HIV.

The quote below is succinct in its message about having sex with HIV-positive women, and the blame ascribed to them, but is in the minority of views expressed by the children concerning women and HIV.

> "We are supposed to stop fornicating with women who are HIV positive." (Participant U12, female)

However, this story reveals an equally blunt, alternative perspective on "HIV blame," with the wife and mother blaming the HIV-related death of the husband and father not only on him, but also on the "other" women or prostitutes involved. The death acts as a catalyst for a frank discussion on HIV/AIDS between the mother and the children.

> "The father of the home… was infected with HIV. He later died and left his wife and children behind. The woman called her children and told them that, 'you should protect yourself from getting HIV. Your father died of HIV. You shouldn't be prostitutes, your father was a womanizer and he contracted HIV.'" (Participant U40, male)

The picture below with its explanatory story is more unusual in terms of visual content, as it was the only one featuring a scantily clad woman, particularly one juxtaposed next to a grave labelled "AIDS." Although the story provides little context, merely that she and her family died of AIDS, it is unclear if the lady in the picture had spread the illness or was herself another of its victims. The odd contrast between the visual picture and the written text is suggestive of potential promiscuity underlying the situation.

> "This lady died with AIDS. The family was [infected] with HIV. The whole family died. She was called R [name redacted]. They had five children and all of them died." (Participant U15, male)

Figure 7.7: Drawing from Participant U15
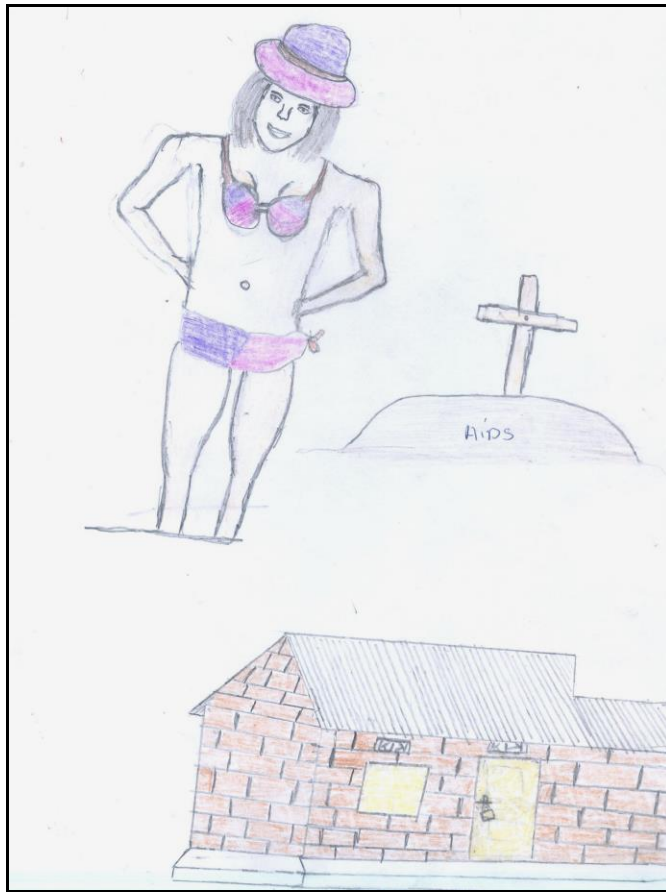
Here, children reflect SRs of HIV which are overwhelmingly negative and similar to those of adult carers in Chapter 6, acknowledging the power of HIV to kill and maim indiscriminately. There are generally no alternate representations of HIV portrayed here, unlike that of the HCWs in Chapter 5, where the SRs of HIV are changing to that of a treatable illness. Only in section 7.3.2 below does an alternate representation of children surviving HIV infection emerge in 2 of the works, which could signal the start of a shift in experience and perception. However, older representations and socialized stereotypes are still being internalized by the children, with stigmatizing SRs about HIV and women and girls reproduced here, which may further reinforce gender inequalities and patriarchal hegemony if left unchallenged.

7.3: The world is an unsafe place for children due to HIV/AIDS and we are at risk

The global theme discussed in this section suggests that children see HIV everywhere they turn and feel that they are not safe from it, as the risk is everywhere, from in their own families to the wider community setting. They express hopelessness at the negative impact of HIV on their own families and childhoods, with many speaking of their own direct experience with HIV in the family very openly, and with a real sadness and loss which comes through the drawings and stories. Some works featured the current HIV prevention messages from schools, which when contrasted with the real-life stories, do not reflect the children's lived realities of HIV in the community.

Table 7.3: The world is an unsafe place for children due to HIV/AIDS and we are at risk

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Children are not safe from HIV anywhere (7.3.1)	3A1 Children are at risk for HIV	-dependent children at risk for HIV -child abuse in family -spread of HIV in family -polygamy spreads HIV -children can't get HIV -HIV-positive children "hidden"	-physical risk of HIV infection -emotional risk from effects of HIV in family -dependency (care & financial support) creates HIV risk	-children at risk for HIV but least likely to get care -adults not helping HIV-positive children -A & A not likely to increase on its own
	3A2 Nowhere and no one is safe from HIV	-avoiding HIV -behaviour of HIV-positive people -HIV risk in community -children are sexual/sexualized -adults aren't safe to be around	-society is not a safe place to be for children -nowhere is safe from HIV/AIDS risk	-adults & other children seen as sources of HIV -HIV too prevalent to be stopped by A & A
3B HIV has had a negative	3B1 Childhood is negatively	-childhood -family -impact of HIV on	-HIV has disrupted our lives	-need high level of resources to

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impact on children (7.3.2)	impacted by HIV	childhood negative -family caregiving		cope well with HIV/AIDS -A & A not accessed without resources
	3B2 HIV causes suffering and loss for children	-children's suffering & loss from HIV -orphanhood -extended family affected by HIV	-families are destroyed by HIV/AIDS -HIV destabilizes families	-children affected by HIV suffer greatly -Families not accessing A & A well
3C The HIV education messages in schools do not resonate with children's lived reality (7.3.3)	3C1 HIV prevention messages do not resonate with children's lived reality	-HIV education -HIV prevention -some families & caregivers do talk about HIV to children -Christian religion	-HIV education doesn't reflect reality -HIV fueled by social factors not lack of knowledge	-school-based HIV education not reflecting children's lived HIV experiences -HIV education not helping A & A

7.3.1: Children are not safe from HIV anywhere

This organizing theme reflects the fears children express about HIV in society, and a sort of resignation to having a constant state of risk in their society due to the presence of HIV everywhere, from in the family through vertical transmission, to in the streets through sexual violence or risky sexual relationships. There are no works which portray safe spaces in society that are HIV-free.

3A1 Children are at risk for HIV

The works featured here reflect the very real and direct HIV risk that many children face in this society, and suggest that adults accept that HIV occurs in children, but may be choosing not to act on this situation.

The story below reflects the child's personal experiences with an HIV-positive child, in this case a cousin. The negative experiences with the health care system and the death of the child underscore the deadliness of HIV for children in particular.

> "My uncle's child was HIV positive and later died. They first took the child to hospital and they spent one month there, the child died and

we buried her. AIDS is a killer disease, most people die of the disease called HIV/AIDS." (Participant U20, male)

Despite the lethality of HIV in children, as discussed in Chapter 1, this quote suggests that whilst the public is aware of children being HIV-positive, they choose to do nothing about it, a worrying reflection of wider social realities discussed in Chapters 5 & 6.

"All the children were infected with HIV/AIDS… Other people don't mind about children dying of HIV." (Participant U12, female)

3A2 Nowhere and no one is safe from HIV

The works discussed here portray a world that is full of HIV, with basically no safe locations or places where HIV is not present, and no people who are unaffected by it. The quote below discusses how everyone in society is at risk from HIV/AIDS, that no one is immune or out of harm's way. Its portrayal of HIV as a "killer" that comes for anyone and everyone is further discussed in section 7.2.1.

"HIV came to kill all of us. Let me tell you the most painful thing about HIV, HIV doesn't fear anyone. You find it even in children, even in women, it doesn't fear them, you find it there." (Participant U10, female)

In this short story, the social risk of sexual violence is portrayed in a very matter-of-fact way, almost as if it is being normalized within the wider social context. That any 12-year-olds would be including a discussion of rape in their works was unexpected, and given that there were 2 works in total which discussed this, their occurrence raise the question of the level of sexual violence in the community at large.

"There was a woman walking. She saw a man and she remembered that the other man raped [and] let her go." (Participant U21, female)

One participant chose to use a more humorous and playful tone in writing a story addressed to "Mr. AIDS," and creatively expresses a frustration at so much effort going into fighting AIDS, with so little results, a sentiment echoed by many HIV researchers as well.

"Mr. AIDS, some doctors have tried to fight against you, but you are still a problem to the world. Now what can we do? You have killed many people and most of them are our mothers, the parents and

others… I can see you in the whole world. However, Mr. AIDS, many people have learnt about you at school. But why is it that you cannot reduce?" (Participant U7, male)

7.3.2: HIV has had a negative impact on children

Although children were not asked to disclose HIV status for themselves or in their family, many chose to do so, often to discuss the negative impact HIV has had on their own childhood and their family situations. Most of the representations were negative and emotional, centering around a disruption of the family dynamic through death and suffering. However, two works are positive in nature, where HIV is portrayed as being a treatable illness that children can survive, instead of a death sentence.

3B1 Childhood is negatively impacted by HIV

Many children chose to write personal examples of how HIV negatively impacts on their own childhoods, the vast majority of the effects being highly negative with multiple deaths in a family. The quote below was entitled "Misery and peace in a home," and the author wrote simply and plainly about the personal impact of HIV in the family.

> "My grandfather died, my uncle died and my brother died, we are now two children with our mother." (Participant U33, male)

This quote further expresses the extent of the spread of HIV in the author's family, where only three children and a grandparent are left from the original family unit.

> "My mother and father died of HIV/AIDS, they all died. Very few children remained because HIV/AIDS is a bad disease. There are only three children remaining with their grandmother." (Participant U39, male)

The picture and its quote below show a group of HIV-positive children sitting in the foreground, marked by the physical signs of HIV infection, here skeletal bodies showing ribs. The other children playing football in the background are drawn as healthy looking children, and do not interact with the children in the foreground. In this case, "suffering" may not only refer to the infection, but also refer to a low quality of life, marked by illness and exclusion from play.

> "I am drawing [a] picture about HIV/AIDS… I am drawing children

which suffer from AIDS." (Participant R5, male)

Figure 7.8: Drawing from Participant R5

However, despite the vast majority of SRs about children and HIV being negative, there are 2 works which provide an alternate version of the reality of children and HIV which are positive. These alternative SRs portray a different side of the HIV lived experience, that of children surviving familial HIV and successfully growing up into adulthood. Although it is unclear if these are generalized representations or lived experiences, they are important in that they suggest there is an emerging consciousness about surviving HIV infection and successfully living with it.

The first story is a simple tale of child survival in the face of HIV exposure risk, where the father dies of HIV, but the child survives into adulthood, marries and has a family.

"There was a couple with one child. The man married a HIV positive

woman, got infected with HIV and he died. The child grew up, got married and delivered a child." (Participant U36, male)

The second story is more detailed and elaborate, and outlines an HIV-positive girl, who faces stigma and abuse at school but takes control of the situation and engages the teachers to support her. Receiving verbal support from the teachers further encourages the girl to keep attending school and to dream of becoming a judge.

"This man is very rich but he has a wife who has AIDS, and that wife got pregnant and bore a girl who had AIDS. That girl [said], 'some children used to abuse me that, 'you will not get anybody to marry you.' I was not happy. I reported them to the teachers and the teacher said, 'leave them and study hard.' I became happy. I went to school. I studied hard and I [want] to become a judge.'" (Participant U30, male)

3B2 HIV causes suffering and loss for children

Here, the majority of the works portrayed the impact of HIV on children as being negative, with much suffering, sadness, and loss. The quote below may be discussing the author's own experience of orphanhood and implies worry and fear over an uncertain social and economic future.

"I don't have a home. I stay in people's homes. I am an orphan with no father. Where will I go?" (Participant U3, female)

The story and picture below reflect the lived experience of children "left behind" after family members die from HIV/AIDS. Here, the grandmother is supporting the surviving children, and decides to talk to them about HIV/AIDS prevention in a very direct and open way, directly confronting the family's HIV history which is literally at their feet in the picture, in the form of graves. This contrasts with findings from Chapter 6, where many adult carers related they were uncomfortable discussing HIV with their children.

"A man and his wife died of HIV, those are their graves. They left behind four children with their grandmother. One day, they sat down with their grandmother on the mat and they discussed ways of avoiding getting AIDS. She told them, that 'AIDS killed your father, that is the grave.'" (Participant U38, male)

Figure 7.9: Drawing from Participant U38

7.3.3: The HIV education messages in schools do not resonate with children's lived reality

The final organizing theme discussed here reflects a gap between the "official" HIV education and prevention messaging taught to the participating children and the "unofficial," everyday life experiences with HIV which they discuss in their works.

3C1 HIV prevention messages do not resonate with children's lived reality

The prevention messages discussed here by some participants are in sharp contrast to what has been portrayed in the works throughout this chapter. Although only a few works discussed HIV prevention messaging, the contrast between the official advice about HIV prevention, and children's lived reality in terms of HIV risk and situational prevalence in their community, is striking, as in the quote below.

> "Prevention of HIV/AIDS: Do not share sharp instruments."
> (Participant R10, male)

Another quote gives advice about "sensitizing" the community about HIV/AIDS, in this case, discussing HIV openly in society.

> "We are all supposed to sensitize the community about HIV/AIDS."
> (Participant U12, female)

The following story and quote provides an example of the typical HIV prevention messaging children are taught in primary schools, but which does not effectively work in Ugandan society, as seen in Chapters 4-6. Here, the prevention message that both partners should get an HIV test before marriage, and remain faithful to each other after marriage, falls apart when it is combined with the real-life dynamics of a polygamous household, where one of the wives is HIV-positive, and passes it on to the husband, resulting in the deaths of two of the three of them. The picture shows the man and one of the wives holding hands in a home setting in the upper section, with another individual sitting alone at a grave marked "AIDS" below.

Figure 7.10: Drawing from Participant U16
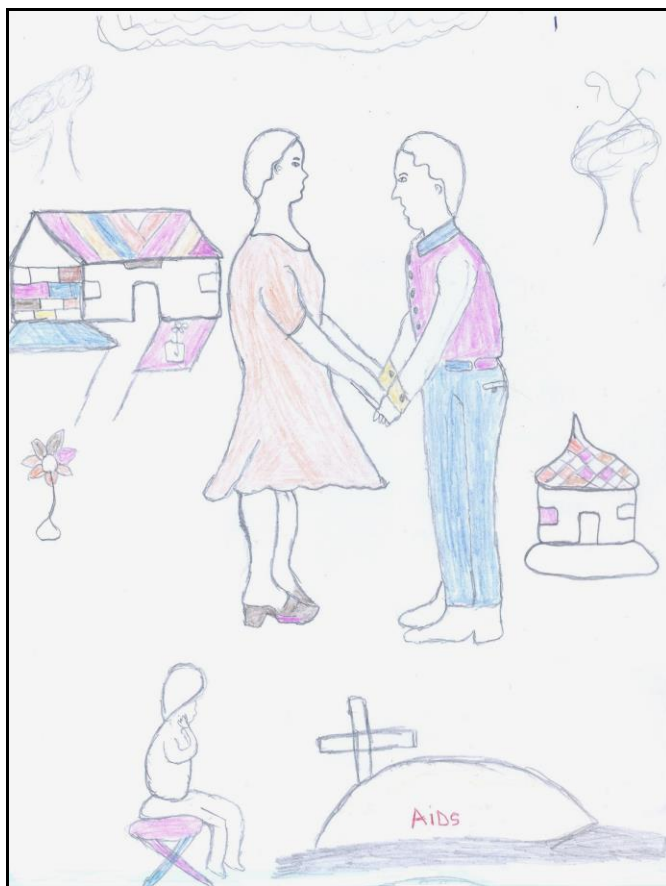
"Test together for HIV before marriage and remain faithful to your partner. It is very important, whether you have HIV or not. This helps you to plan your life and make good decisions [This] man and his wife, they died because they didn't want to live alone. The man [had] another wife, [and] that wife was suffering from HIV/AIDS. They suffered from AIDS and after suffering from AIDS he died with his wife." (Participant U16, male)

Children discuss in this global theme concerns for their safety and future, as they see a world full of HIV, and feel at risk for infection, with no HIV-free social spaces in the community represented in the draw-and-writes. Although the vast majority of the works reflect very negative impacts of HIV on children and families, there is a small glimmer of hope in the presence of an emerging alternative narrative, albeit in a very small minority of works, where children adversely affected by HIV manage to survive and succeed despite a social milieu of great risk and difficulty. In addition, HIV prevention messages taught to children in the educational system, and as discussed here in a small number of works, fall short of the lived realities of HIV described at length by the children, in terms of relevance to the social world they see.

7.4: Relevance for children's HIV care access & adherence

The SRs discussed in this chapter reflect both the underlying social climate in which the children are growing up, and the way they see themselves in their own social world. Although children in Uganda are not legally empowered to access health services completely on their own, such as through emancipated minor legislation (see Cheney, 2007), they are still potential current and future health care users within the system. This necessitates a consideration of their views, at least as future health service users and eventual health decision makers in their own right. The representations explored in this chapter also serve to triangulate the findings from the other stakeholder groups, namely the HCWs and adult carers in Chapters 5 & 6. The findings discussed in this chapter therefore have broader implications for children's access and adherence to HIV services and treatment.

In terms of the SRs of health services discussed in section 7.1, the children who participated do not hold positive views of health services, with the worrying implication that this could have a negative impact on their own current and future health service usage, as they grow up and make service access decisions for

themselves and their families. They see services as being unable to effectively treat people for HIV, regardless of health provider, and ART drugs or effective HIV treatment is essentially not mentioned, with only 2 participants portraying positive messages of living with HIV out of the 76 relevant works. This could reflect the difficulty people have in accessing ART, either in the past or at present, the preponderance of negative SRs about HIV infection present socially, or a lack of exposure or awareness about ART, particularly as it is not discussed in PIASCY (the Presidential Initiative on AIDS Strategy for Communication to Youth), the Ugandan national HIV/AIDS curriculum (Government of Uganda, 2002), as it was produced before the advent and availability of ART and has not been altered or updated to reflect the new realities of living with HIV in the era of ART.

Instead, HIV-positive people are portrayed here as when HIV first appeared in Uganda (AVERT, 2014a), either as visibly suffering or absent through death, with health services and treatment portrayed as either not having worked prior to death, or not in the picture at all, with HIV-positive individuals cared for at home. These overwhelmingly negative representations of health services as being ineffective in the fight against HIV are concerning findings, in terms of potential long-term programming and health services uptake, as well as in terms of social capital, trust and social connectedness between stakeholder groups. Despite this, however, the fact that there were positive messages included at all is hopeful in considering potential future SR trends.

The children's representations of HIV seen in section 7.2 are overwhelmingly equated with death or maiming, with again, no mention of ART or of living positively with HIV except for the 2 works as mentioned above. The fact that almost all the children in this study portray HIV in a fatalistic way, as a disease which is essentially inevitable and will turn you into a living skeleton before eventually killing you, suggests they may also be internalizing a high level of HIV risk tolerance (Joffe, 1999). This does not bode well for encouraging or increasing HIV testing and treatment uptake by system users, and may require additional future programming to challenge this outlook. The works also contain an underlying resignation and ambivalence towards HIV tempered with a sense of sadness, loneliness, and loss (see also Skovdal & Ogutu, 2009), with some participants choosing to discuss their

personal experiences with familial death and losses to HIV, outlining how HIV has had a very negative impact on their society, by weakening interpersonal and familial bonds. The linkages to poverty and the negative impact of HIV on women and girls, also reflect back on how children see HIV in the wider social world around them, outside of their own immediate family circumstances.

Although the extreme nature of many of these SRs of HIV could be challenged as being exaggerated for dramatic effect, as has been discussed in other research studies (Campbell, et al., 2014), I feel this is not the case. The breadth and depth of the SRs discussed here, including the level of detail in the works, the personal content of many of the works, and the fact that the works corroborate and triangulate many findings from the previous data chapters, suggest that the children participating here are attempting to realistically portray the impact of HIV on children, including themselves, as much as possible. To do so for such a highly stigmatized illness as HIV is admirable, and deserves to be given as much respect and consideration as the data findings from the adults, given that they have been much less forthcoming with their views in comparison.

In many works seen in section 7.3, the children explore living in a world filled with HIV, which is portrayed as running rampant through their community, leaving social destruction and despair in its wake. The works are filled with underlying emotions of fear, sadness, despair, and hopelessness, yet are still forthright and open in the way they discuss the negative impacts of HIV on children and their families. This is portrayed through the destruction of a stable family life, hierarchy, and social support system, which is made worse as Kabarole district has minimal social capital resources, and no formal system of social services as the family is the only source of support in the area, as discussed in Chapter 4 (Kaler, et al., 2010). The participants are very open about HIV-positive children being in their community, with many discussing their own familial experiences with HIV, but also portray HIV-positive children as being somewhat ignored by adults and often not getting the care they need. Works suggest that living a "positive" life as an HIV-positive child is viewed as highly unlikely, unless there is a stable and supportive family, in terms of finances and the costs of living with HIV.

The contrast between the negative lived realities of HIV expressed here by the children, and the HIV prevention messages mentioned in some works, is striking and concerning. Although PIASCY, the Ugandan national school HIV curriculum taught to children from primary level 3 onwards, is designed to be comprehensive (Government of Uganda, 2002), it has been critiqued as being "out of touch" with the reality of HIV/AIDS in Uganda (Cheney, 2007; Human Rights Watch, 2005). The data presented here suggest that children are aware of and able to articulate the discrepancies between the HIV prevention messaging they are exposed to at school, and the wider social context of HIV/AIDS in which they live. Such a gap between what children are taught about HIV, and what actually occurs in their lives regarding HIV, is not only unhelpful, but may in fact be dangerous, as it is not providing them with useful information relevant to their lived experience and levels of social risk extant in the wider community.

Conclusion

Working with the children to discover their representations during the draw-and-write exercise provided a fascinating glimpse into their social world, as they are considered to be not only the first generation in Uganda growing up fully in the HIV era (Mugyenyi, 2008), but are also the first generation growing up at the dawn of the ART era in terms of HIV treatment capabilities. The honesty and candor of the children is moving, as they proceed to "tell it like it is" and let the research team into their world, at least for a little while during the exercise. The works presented here ultimately express disillusionment with society, and the ways in which HIV has had an extremely negative impact on the lives of children, their families, and their society. Compared to the HCWs and adult carers in the previous chapters, the children were very open about what they have seen and experienced already in their young lives regarding HIV, often presenting personal stories and situations. However, the long-term effect of growing up surrounded by HIV remains to be seen. As they have been so negatively affected by HIV in their families and their community for so long, it is not surprising that they perceive the world as being inherently unsafe and official services as being unhelpful.

Although, as has been seen in previous chapters, massive changes would be needed at several levels to improve children's HIV service access and uptake, there

are smaller changes that could be implemented easily and cheaply at first, to set the stage for the bigger social changes needed to adequately address children's HIV service needs. To begin, altering the current national HIV school curriculum to better reflect children's lived realities in the HIV era, as well as the development and availability of ART, would be a potential place to start. The children's realistic and forthright views could even be used as the basis for this new curriculum, which would give them a voice and a platform with which to engage with the adults in their lives about the lived HIV realities they have all experienced in different ways. A more inclusive curriculum could also become the basis for wider engagement between local stakeholder groups, in that children, adult carers, and HCWs, as well as teachers and local officials, could begin a bigger social dialogue about children and HIV. As will be discussed in Chapter 9, a new curriculum could potentially also serve as a vehicle for wider social dialogue and be a catalyst for broader social change regarding HIV service uptake for children, which could contribute to increasing social capital, trust, and cohesion between children and adults in this community.

Chapter 8: Exploring the care environment of the local clinic

Introduction

This chapter explores how health services are provided in a local community social space, through the analysis of ethnographic observations undertaken at the main government-run health clinic in Amooti, Kabarole district, the setting of this research study. The clinic is a Ugandan Health Centre Level III, which is a general outpatient day clinic staffed with Clinical Officers, a cadre of health care workers (HCWs) who act as General Practitioners in lieu of Medical Doctors, as well as Registered Nurses, Community Health Workers who do outreach, and ancillary Support Staff, and it provides HIV services for adults and children, including HIV testing and counselling, CD4 counts, and antiretroviral treatment (ART) services (Kabarole District Local Government, 2010). The clinic provides general care services during daylight hours, as well as specialized days for particular services, with the HIV "clinic day" being on Wednesdays.

This focused clinical ethnography seeks to examine which aspects of the local clinic setting facilitate or hinder pediatric HIV service access and adherence. The underlying assumption for this chapter comes out of research which suggests that supportive care environments promote access and adherence to HIV and health services, by helping HCWs to provide good quality care to clients, which impacts on the service user-provider interpersonal dynamic by encouraging service user trust in the health service, leading to a corresponding uptake of services (Campbell, et al., 2011a; Stein, et al., 2007; Kangas, et al., 1999). Determining which factors in this setting either hinder or encourage service user system trust and uptake of services will be key findings for this research study.

Another underlying assumption comes out of my background as a Registered Nurse from Canada. In terms of my nursing education and my clinical training and practice, I have been fortunate to work in many high quality care settings, where best practices and high clinical standards are the norm, supported by a well-funded, relatively well-staffed and well-supplied health system. These "best case scenarios" have allowed me to see and experience best practices possible in health care provision, and the resulting positive outcomes for clients and HCWs alike. In

addition, theoretical perspectives on nursing care provision in Canada use the Social Determinants of Health, and family-centered nursing as care provision models which encourage good nurse-client rapport, and a consideration of family and social dynamics as being essential parts of health interventions (Labonte & Schrecker, 2007; Wright & Leahey, 2013).

I acknowledge that this is a luxury most care providers globally have not had, and that many are struggling to provide good quality care under extremely poor working conditions, consisting of low levels of funding, low levels of staffing, and inadequate managerial leadership and top-down hierarchies which may not allow staff members to work to their full scope of practice or capabilities. As a result, I position myself as being sympathetic to both health providers and users, but also mindful of the positive care which can result from a health system which is well-equipped and well-run. Observations made here attempt to capture the clinical practice realities seen, and consider them in light of what best practice could be, given better funding, staffing, and clinical leadership.

As discussed in Chapter 3, the data for this chapter are sourced from field notes kept during 40 hours of participant observations at the clinic during its operational hours, which are generally Monday to Friday between 10am to 5pm. Eight observation sessions of five hours each (8 x 5 = 40 hours) resulted in 72 pages of handwritten field notes, for 36 typed pages. Notes were then further analyzed for relevance to children's HIV treatment access and adherence in this community. To conduct the ethnographic observations, a research assistant (RA) and I would go to the clinic at the start of the day, to ask permission to observe for a five-hour session. As we had conducted the in-depth interviews with staff members previously, they knew us and were comfortable with our presence at their workplace, and we had no problems in securing access.

The session would vary depending on what was occurring at the clinic, but a typical session would see us sitting in the same areas as clients, walking around the grounds, and talking with the HCWs and clients where appropriate, with the RA translating as needed. Overheard conversations were also translated by the RA. I wrote down field notes when observing, but did not write down conversations at the

time, as this could have caused fear and mistrust, instead noting the general conversation flow and adding content after. Although this process worked well, limitations included an inability to be in several different areas at once, which may have led some events to be missed by our observations. However, through multiple sessions, we were able to capture a good sense of how the clinic works on a day-to-day basis, as will be discussed here.

One glaring omission noted by us is the lack of children attending the clinic. Although problematic for this research study, it does, however, present a starting point for these observations, as it is the lack of access to children's HIV services which is of concern. Underlying questions for this chapter therefore include, why this is the case, and what is going on at the clinic that children are not present in any significant numbers. Given the previous chapters, particularly Chapter 6, the data findings suggest that if adult carers are having negative experiences with the services they receive for themselves, they may not bring their children in for health services at the clinic. With this as one potential underlying rationale for the lack of children presenting to the clinic, this ethnography will take a lack of children at the clinic as being the clinical norm for this setting, and focus on the experiences of the adults in attendance, exploring what may influence them to not bring children in for HIV services.

The data findings discussed here were analyzed using thematic content analysis influenced by Attride-Stirling's (2001) Thematic Network Analysis (TNA), with 3 global themes emerging as related to health service provision and children's access to HIV services. These global themes are:

1. The relational environment of the clinic is intimidating and unwelcoming to carers, with a rigid relationship and visit hierarchy which is not family-friendly.
2. Procedural limitations result in long waits for carers, which may be unappealing to carers with children.
3. Resource shortages discourage clinic usage by carers, as material and staffing shortages impact negatively on service provision capabilities of HCWs.

These data findings also reflect back on the research questions by exploring:

- The extent to which the local clinic fails to offer a supportive social space that optimizes the provision of care by HCWs, who are unable to provide reassuring and comforting treatment of vulnerable and frightened carers and children.
- How the institutional context of the clinic provides service providers and users with a few positive experiences but many more negative ones.
- How these experiences primarily reinforce the negative representations service users bring from outside of the clinic, and do little to challenge them or create new, positive ones.
- The negative impacts on children's HIV access and adherence, and how the clinic ultimately hinders HIV service access and adherence for children and families.

In review, the preceding chapters looked at the social representations (SRs) of children, health services, and HIV as held by both health service providers (in Chapter 5) and health service users (in Chapters 6 & 7). The data suggest that SRs may frame how people choose to access HIV and health services for children in either positive or negative ways, as reflected in hopes, fears, concerns, and perceptions of service provision. Examining the clinical practice environment in concert with the SRs expressed by health service stakeholders, provides insight into how well clinic services resonate with users' worldviews and perceptions of their own health care needs, and provide a safe, supportive space for these needs to be met.

Research by Campbell & Cornish (2010) and Skovdal, et al., (2011a) suggests that symbolic, relational, and material contexts can influence the extent to which health service users and providers might regard a health clinic space as being a supportive social environment. This is a useful frame for this chapter, particularly the discussion of the research findings in sections 8.1-8.3. In this chapter, the relational dimensions of health care provision, as seen through the interpersonal dynamics and relationships between HCWs and clients will be discussed in section

8.1. In section 8.2, procedural dimensions of care, in particular operational procedures and patient flow will be discussed, as both service providers and users are affected by procedural difficulties. Finally, in section 8.3, the resource or material dimensions, including supply logistics will be discussed, as it directly influences HCW capacity to provide good quality care. Section 8.4 will then analyze these findings alongside the SRs discussed previously, to consider how the clinic does not at present provide a safe and supportive care environment for children's access and adherence to HIV care. Although some positive instances of good quality care emerge from the data, overall, the findings reflect the challenges and difficulties faced in providing and accessing health and HIV services, but also point to potential changes which could improve provider-user trust and service uptake.

8.1: The relational environment of the clinic is intimidating & unwelcoming to carers

The first theme emerging from this analysis highlights how the relational environment of the clinic is intimidating and unwelcoming, as seen through observations of staff-client interactions. The relational environment in this context was the observed interpersonal relationships and day-to-day interactions between service providers and users in this clinic setting. Here, interventions for HIV carry significant risk for social stigma, particularly HIV testing for mothers who attend the clinic for antenatal care (ANC). A lack of private spaces for service provision may also exacerbate these fears of stigma further, and intimidate carers, acting as a barrier to clinic access. In addition, the clinical social environment is not welcoming to underserved groups, particularly adolescents and men, despite the unmet care needs of these groups.

Table 8.1: Relational environment of the clinic is intimidating & unwelcoming to carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
1A HIV interventions carry risk of stigmatizing carers (8.1.1)	1A1 Legal requirements for HIV testing may fuel stigma for carers	-ANC HIV testing required -Ugandan law -Hiding HIV status	-Uganda requires HIV test at 1st ANC visit: women don't return	-high risk for loss to follow up of carers -may pass HIV to baby

1B A lack of privacy may reinforce stigma & intimidate carers (8.1.2)	1B1 Clinic layout does not provide private spaces for service provision	-privacy -lack of private spaces -out in the open -HIV day	-physical layout a problem in providing safe, private spaces -specific day for HIV clinic	-setting may hinder disclosure & service use
	1B2 Limited privacy in one-to-one care and counselling	-"one-to-one" -private counselling -private care	-role of privacy in HIV testing & counselling -HIV stigma	-privacy best for children's or family counselling
1C The clinic social environment is unwelcoming to children, youth & men (8.1.3)	1C1 Adult-centered services are not child- or family-friendly	-parents' committee -maternal health -not child friendly -mother-child interactions	-services geared towards adults needs as caretakers of children	-may be barrier for families to use services -clinic programming not child- or family-friendly
	1C2 Majority of programming for women & babies, none specific to underserved youth or men	-peer mothers programme -mainly women -few men -men don't use the clinic -few youth	-clinic services focus mainly on women -men & older children unintentionally excluded	-need for programming for school-age children -need to target youth & men more

8.1.1: HIV interventions carry risk of stigmatizing carers

As per reports from both staff members and health officials, Ugandan legislation requires pregnant women to be tested for HIV at the first ANC visit, unless they "opt out" of such services (Dahl, et al., 2008; AVERT, 2014a). However, adult carers in Chapter 6 emphasized their fear of finding out one's HIV status, due to the resulting negative social and personal consequences of being HIV-positive. This legislative and clinical practice may therefore further exacerbate HIV stigma, by creating an unsupportive clinical environment which does not address service user fears and concerns, let alone address issues of informed consent and free will for HIV testing, which have become a broader social issue given recent government HIV legislation (BBC, 2014b).

1A1 Legal requirements for HIV testing may fuel stigma for carers

In Uganda, health care centres are generally required to test women for HIV on the first ANC visit unless they expressly "opt-out" (Dahl, et al., 2008; AVERT, 2014a), which causes problems for health service users and providers alike. For users, a fear of continued HIV stigma in society leads to serious social consequences for a woman found to be HIV positive, regardless of the HIV status of her husband, as discussed at length in Chapter 6. Ways in which carers cope with such a dilemma include not going back to the clinic for subsequent prenatal visits, "losing" their ANC cards which have their HIV status recorded on them, or using other clinics for subsequent visits but not declaring prior visits to other clinics, as this observation attests.

> Talking with one of the HCWs, apparently HIV is a required test for ANC services in Uganda, and this is enforced on the first visit. Unfortunately, some women only go for one ANC visit, and so don't come back to get the results of the test. Some don't want to know the results of the test, and some even hide or "lose" the ANC card that has their status on it for future visits- or go to a different clinic or town to get checked and give birth in the hopes their status won't be found out. (Obs 2)

This results in problems for HCWs, as they face a difficult choice in having to comply with this legislation, knowing that it may cause problems for their clients, and act as a further barrier to HIV care access. As previously acknowledged in Chapter 5, this legal requirement also has a negative impact on the development of a professional working relationship with their clients, as expressed here.

> Chatting with staff members, they admit that [required HIV testing] causes problems with clients, but that not testing also puts everyone at risk: the woman and the baby for not getting proper health care, and the HCWs who risk HIV exposure when treating an HIV-positive woman giving birth. (Obs 2)

Providers here are essentially caught in the middle, knowing that their professional practice requires them to follow this legislation, which could help them to protect themselves and their clients from HIV, but that it also may fuel HIV stigma and drive patients away from services. At present, providers are not able to reconcile these problems, which results in stressful workplace situations, repeated on a regular basis. It is important to note that HCWs felt concern over their legally required

testing which may instead act as a barrier to clients accessing care, as opposed to accepting it outright.

8.1.2: A lack of privacy may reinforce stigma & intimidate clients

A private setting for health care, including HIV services, is neither physically possible nor supported in clinical practice methods. In Chapter 6, adult carers make repeated reference to fears over HIV stigma, and have a strong motivation to keep one's HIV-positive status secret for fears of a withdrawal of social and economic support from family members. This reflects previous findings regarding the importance of privacy in HIV care settings in Uganda (Kyaddondo, et al., 2013; Rwemisisi, et al., 2008) as well as in other sub-Saharan African (SSA) care settings (Hejoaka, 2009; Msellati, 2009). Although privacy can be difficult to achieve in many clinical settings, in relation to HIV care, a lack of privacy, particularly for HIV test results and disclosure, may lead to social stigmatization of clients and a resulting rejection of clinic services out of fear of being "outed" as HIV-positive (Campbell, et al., 2005; Hejoaka, 2009).

1B1 Clinic layout does not provide private spaces for service provision

The physical layout of the clinic is open-plan, as opposed to having more closed-off or private areas for waiting or being seen, and most areas of the clinic are visible from any position taken (see Figure 8.1). The exception to this is a meeting area in the back, and the lab, which are only opened by staff to facilitate meetings or lab services. People generally wait in a large, open courtyard, typically on benches around its edges where there is shade and shelter from the rain.

An example of the activities openly observable by anyone attending the clinic is seen in this quote.

> There are 3 people queuing at the dispensary, still about 10 adults and 4 young children to be seen in OPD [outpatient department]. The dispensary is open and giving out drugs. The clinical officer is seeing 3 men in her office. Two ladies are waiting at the back by the lab for the lab technologist. (Obs 8)

Given the physical layout of the clinic, private areas are virtually non-existent, which could cause problems if staff needed to provide one-on-one care, such as in HIV

test counselling or facilitated HIV status disclosure for families (Rwemisisi, et al., 2008; Myer, et al., 2006). It is easy to observe people, and people-watching gives those with a long wait something to do, which could lead to gossip and conjecture about why people are there, which was cited by carers in Chapter 6 as a barrier to their accessing the clinic.

1B2 Limited privacy in one-to-one care and counselling

Given the above conditions, care given in this setting is never fully private, and leads to questions about its appropriateness, particularly for highly stigmatized illnesses such as HIV. As in Chapter 6, a lack of privacy appears to be off-putting to carers, and may act to undermine HIV service usage for already-stigmatized and high risk groups even further, as clients could be inadvertently "outed" or perceived to be HIV-positive by others waiting to be seen for non-HIV services.

The example below shows how HCWs conducting HIV testing could unwittingly put carers at risk for being inadvertently "outed," or at risk for being gossiped about by others attending the clinic for non-HIV reasons.

> The lab technologist comes out to ask how many of the ladies waiting have never tested for HIV and about 20 (half) put up their hands. (Obs 2)

In another example, an attempt at providing a private service is made but fails due to the clinic infrastructure limitations, as outlined in section 1B1.

> [The midwife] calls the next lady waiting into her office and closes the door, although the window in front is wide open. At least an attempt at privacy has been made- although you can hear everything being said. (Obs 7)

Here the attempt at providing a private consultation is undermined by an open window and a large queue of other clients waiting right outside the window, who are able to hear everything being discussed. Whilst other clients may not be able to see the care intervention physically taking place, they could observe the person going into the office, and could hear everything said about that person's health. This lack of privacy and risk of being "found out" as being HIV-positive may well intimidate users, given the negative social consequences of having one's HIV status discovered.

8.1.3: The clinic social environment is unwelcoming to children, youth & men

Observations suggest services are unfriendly to key groups, including children, families, and men, as most clinic services appear to be oriented for women with very young children or babies. As more recent programming in Uganda advocates for a family-friendly approach to children's HIV services, in order to increase service uptake by families for children (Luyirika, et al., 2013), the implications of a lack of family-centered care, as is occurring at this clinic will be considered here.

1C1 Adult-centered services not child- or family-friendly

At present, most services provided by the clinic are adult-oriented, and there is no specific programming to cater to the needs of families or children. In addition, the nature of service provision, as will be discussed in depth in 8.2, leads to long waits, typically lasting all day, which would not be attractive to parents with children, as the children not being seen would have to come along to the clinic, or would have to be left at home for the entire day.

> There is a problem where clients rush to get here to be earlier in the queue and then wait for hours to be seen, often all day. Carers with children wait alongside everyone else, no priority is given to them. It takes a long time to be processed through the system, and it all adds up to a long queue and grumpy patients. I wouldn't want to wait here with children. (Obs 8)

The clinic also has no resources specifically for children, such as areas where they could play, or any additional supplies for them such as food or activities to occupy them. Whatever children have is only what parents have brought along for them, which is often not much. In terms of waiting to be seen and comfort services, the clinic space is not a family-friendly, welcoming space for families and children.

1C2 Majority of programming for women & babies, none specific to underserved youth or men

Observations suggest the clinic is used mainly by women and their babies or children less than a couple of years old. At-risk groups in need of HIV services, such as men and older children or adolescents are rarely seen at the clinic, and they "stand out" if they do appear at all. The lack of services for at-risk groups is problematic, as the district HIV rate is reportedly rising and it may be from these at-risk groups.

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Talking with the RA, the HIV rates in the region are going up, and it's mostly the youth, especially students in the secondary school. No one is sure if they had it from birth, or if the girls are getting it more recently from "sugar daddy" boyfriends who pay for their school fees and give presents in exchange for sex. (Obs 2)

The vast majority of people here are women, the men are only roughly about 5 to 10% of the people here by my count. It makes me realize how skewed the interventions for HIV have been- all towards women, like it's a woman's disease. No one has involved men or children, or changed the message to reflect that HIV is their problem too. Their absence is conspicuous. (Obs 7)

Most clinic programming is focused on either HIV services on Wednesday, or on antenatal services, which includes prenatal clinics and well-baby clinics with vaccination for children on Tuesdays and Thursdays. Drop-in outpatient services are always offered for illnesses and minor accidents, and these are used more regularly by men and mothers with older children. Adolescents are exceptionally rare and generally not served at all by the clinic. Children attending school were rarely observed at the clinic during the course of this ethnography, although they would have had to come during its opening hours for local medical attention, as there are no after-hours medical facilities available in town at present. The nearest after-hours medical facilities are at hospitals at least 30 minutes' drive out of town.

8.2: Procedural limitations result in long waits for carers

Another core theme in the analysis of ethnographic observations relates to the procedural dimensions of clinic usage, in that HCWs struggle to provide good quality HIV services for their clients. In this clinical setting, both HCWs and attending adults with or without children are negatively affected, as HCWs are currently unable to improve their work outputs, due to an under-supported and under-staffed clinic environment, coupled with outdated, ineffective patient management techniques. This results in a poor patient care experience which may dissuade users from returning to access services, particularly with children.

Table 8.2: Procedural limitations result in long waits for carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
2A Clinic	2A1 Inefficient	-inefficiencies	-poor service	-parents

patient flow not well regulated & leads to poor service outcomes (8.2.1)	patient management	-priorities -patient flow	experience	may not bring children at all
	2A2 Long waits for carers to be seen create backlogs for services	-waiting -huge numbers -"2 stage processing" -backlogs of patients	-clients wait all day to be seen -poor patient management & waiting creates a backlog	-too long for parents to wait -clients may leave without being seen by staff
2B Outreach programming suffers from a lack of staff (8.2.2)	2B1 Providing outreach services "loses" 1-2 staff members for the whole day	-outreach -"losing" staff to outreach -choose between clinic & outreach	-to provide outreach services, the clinic loses staff	-can't provide both outreach & in-clinic services at same time
2C Records system inadequate for work needs of HCWs (8.2.3)	2C1 Patient records system inadequate with inaccuracy risk which slows clinic work	-patient files -notebooks -clinic log book -paperwork -catching up	-risk losing or not accounting for patients & care provided -poor system of reporting & monitoring	- risk for service duplication or omission -parents may not wait with children -clients may not wait to use services

8.2.1: Patient flow not well regulated & leads to poor service outcomes

At the clinic, poor management of patient flow results in a negative experience, marked by long waits and repetition of procedures, due to inefficiencies in moving clients through the steps to complete their health care. The long waits are seen by adult carers in Chapter 6 as a barrier to clinic access, which is exacerbated by low clinic staffing levels and a lack of structural support for HCWs. As HCWs are short staffed and oversubscribed in terms of patient numbers, and busy simply trying to manage the flow of people, they do not have the time or energy to innovate or change their clinical processes to improve patient flow and care outcomes.

2A1 Inefficient patient management

As observed below, service users are processed through the clinic in small groups similar to colonial-era practices, or in mass vaccination campaigns (Kuhanen,

2005). Whilst this can work if a clinic has a full staffing complement so that people can be seen, treated, and moved through the clinic quickly, this is not the case here, as the clinic is less than 50% staffed. This mismatch between staffing levels and the patient care processing model in use, leads to long waits for service users and large workloads for staff, and creates a poor service experience when compared to alternative care models such as individualized, follow-through care (Wells, et al., 2011).

> The general clinic side still has about 20 adults and children waiting to be seen, and the nurse is making slow progress. However, as she has seen people, they then go to queue to wait for her at the dispensary! This pattern emerged last week: queue to be seen or assessed, then go queue for a service, intervention, or drugs. This isn't effective as it would get people finished sooner to see them and give them the intervention all in one go. (Obs 3)

> The way they conduct the clinics here, is inefficient for the amount of staffing, as the HCWs report they are operating at less than half staffed. But clinically, processing people in groups only works if you have a full level of staff. Stations have to be run individually, with one HCW seeing people clinically, another HCW giving out drugs, one could do the records, and so on. But in having to do all jobs at once and not modifying how you do the work, a lot of time and efficiency are lost. (Obs 5)

In Chapter 5, HCWs revealed that the clinic is supposed to be staffed with 19 licensed HCWs, but is only operating with 9 health-related staff members, for a vacancy rate of 53% (10 of 19 positions remaining unfilled). This means they are only staffed to 47% capacity, or less than half their capacity, which exacerbates poor patient flow, and creates an unsustainable practice environment. Given these staffing realities, this style of patient management is not working well for health service users or providers.

2A2 Long waits for clients create backlogs for services
As discussed above, HCWs are using a service model which does not work well for processing clients through the system. When combined with the chronic staffing shortage, it results in long waits for clients, typically lasting the whole working day.

> People arrive first thing in the morning, will wait all day to be attended to, and then go home late, hopefully having been seen and treated with drugs. (Obs 4)

Reducing wait times, especially the all-day waits, for clients would not only result in improved satisfaction, but would also give staff a professional boost as well (Wanyenze, et al., 2010). As HCWs note in Chapter 5, when their clients do well, they feel personal satisfaction at having provided good quality care for them. Long waits are also discussed by adult carers in Chapter 6 as having a negative impact on their desire to use the clinic services, particularly when combined with a lack of drugs. In observing the clinic, it is noted that when carers do choose to use health services, they end up in a sort of "log jam" of people waiting at multiple points of service to access care, as seen below.

> Everyone waits at least twice, instead of using a patient follow through model where you see, treat, and discharge one person at a time completely. Here people wait to be seen initially, then wait again to receive drugs or treatment, and often wait a third time to be finally discharged. (Obs 4)

When carers do bring their children to the clinic for services, the waits and inefficiencies may also combine to put children at risk for unsafe clinical practice, as seen here.

> It is another two-stage process, here the HCWs are first doing all the paperwork and weights on the babies, and then after everyone has had the paperwork done, give the injections. But what if you register everyone, chart it, and are then short the vaccination doses and so cannot give them? That is a medication error according to nursing practice guidelines. (Obs 5)

This process, where patients queue up first to be assessed, and then a second time to be given their treatment or drugs, reflects wider system inefficiencies both in system design and low staffing levels, through the creation of multiple bottlenecks where long patient waits occur. As seen in the second quote, such problems can also put HCWs and children at risk for medical errors, which could cause harm, or have far-reaching, unintended health consequences, such as a child being unvaccinated and then at risk for diseases which can cause harm or lead to death.

8.2.2: Outreach programming suffers from a lack of staff
A chronic shortage of HCWs at the clinic, culminating in a staffing level of only 47%, has led to a reduced quantity and quality of health services provided by HCWs. As

they would ultimately have to do twice the work to make up for such a staffing shortage, this has a negative impact for service providers and users.

2C1 Providing outreach services "loses" 1-2 staff members for the whole day
HCWs are already stretched very thinly on the ground at the clinic. Attempts to provide additional services above and beyond the most basic of clinic-centered care have a correspondingly negative impact on staffing capacity to deliver care, both in terms of quality and quantity, as the quotes below discuss.

> The lab technologist is heading off on a boda [motorcycle] with some testing supplies to do some outreach at one of the villages. There are still about 40-45 ladies waiting to be seen at the ANC- the same ones. Things have been moving very slowly, and they've now lost her to the outreach. (Obs 2)
>
> A boda [motorcycle] pulls up and is being loaded with the vaccination cooler, we confirm after talking with a staff member, there is a vaccination outreach happening in a far-off village, and one of the nurses is going out there on the boda. (Obs 6)

Conducting outreach services, which are desired by both HCWs and the adult carers interviewed in Chapters 5 & 6, comes at a high price for both HCWs and service users, namely the loss of at least one staff member for the entire day of work. Without additional staff resources to support it, outreach work is difficult to facilitate through the clinic, if not outright unfeasible and unsustainable at present.

8.2.3: Records system inadequate for work needs of HCWs
This theme reflects how HCW workload and capacity to manage patients is negatively impacted by a poor and outdated client records system, which also puts clients at risk for medical errors and inaccuracies in their client charts. Although the system is functional, HCWs related in Chapter 5 that it is inadequate for both clinic and client information needs, in terms of keeping track of clients overall, as well as keeping track of the individual progress of clients and their health. This is relevant for HIV care, as good clinical records help clinicians to monitor patient adherence to ART (Wanyenze, et al., 2010).

2D1 Patient records system inadequate with inaccuracy risk which slows clinic work
As described here, there are challenges in using the patient records system

currently in place at the clinic. The system is paper-based, using clinic log books, which are dated client registers with the visit details written in, as well as paper school exercise-style notebooks kept by patients themselves, with information about their previous visits written in them at the time of visit, and updated at the next visit, if the patient brings it.

> Talking with staff, it's hard for them to keep track of clients, and they are not happy about the registration system. Often, people don't stay and so don't get seen, and there's no record of the lost visit or way of tracking them. (Obs 1)

> There's no actual filing system- the visits are recorded by date in the clinic register, and in a personal notebook the patient brings to have updated. Notes are made in the patient's book and the file is then traced back to include the new information. It works, but is very time consuming and not always accurate. Doesn't help that, according to staff [members], some patients give false names! (Obs 2)

This style of record keeping has a major risk for lost or incorrect information, which could have a negative impact on patient care and management. Also, HIV-positive patients keeping their own records at home may put the patient at risk for stigma or related social problems, particularly if the person has not disclosed to other family members or is being treated in secret. The risk of HIV stigma may lead clients to use false names to obtain treatment, as mentioned above and by HCWs in Chapter 5, which can cause further confusion over patient care and treatment, and provide the clinic with incorrect information about its clients.

The related paperwork burden experienced by clinic staff members is also very high, with the simple task of finding a client's previous visit information taking up a large amount of clinician time overall. Observations suggest that using the inefficient records system, as well as trying to catch up on paperwork yet to be done is a major struggle for HCWs, which increases their workload further, and has the potential to cause further waits for clients, as HCWs need time to find the client's records before they can provide care.

> The in charge [clinical officer] and one of the nurses are in the OPD clinic area going through the patient registers, with about 10 people waiting in the waiting area. Two other nurses are in the clinical officer's office, talking and looking at some patient record books. (Obs 6)

> The last few clients are waiting to be seen for today. The midwife is back in her office going through more client record books. She takes some papers and goes to the HIV clinic area, back to the desk where the other nurse is sitting. The clinical officer is doing more paperwork. (Obs 8)

Staff members appear to have difficulties in balancing the large number of clients waiting to be seen and the resulting large amounts of paperwork. It should be noted that the clinic does not have an office assistant or clerk to manage paperwork or client files, resulting in this task falling to HCWs to carry out themselves, on top of their heavy patient load resulting from being short-staffed by over 50%.

8.3: Resource shortages discourage clinic usage by carers

The final key theme from this analysis examines how systemic shortages negatively impact on carers, by HCWs being unable to provide a high quality and quantity of care to clients. Although service providers are directly impacted, service users are indirectly impacted, which may lead adult carers to reject using the clinic due to poor health care provision and limited care possibilities and options within the system itself. There is also a general feeling from HCWs that they are being set up to fail, as they are caught between health users whose care needs are not being met, and a system that does not provide enough for their own practice needs either.

Table 8.3: Resource shortages discourage clinic usage by carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
3A Poor management & lack of staff impacts negatively on care given (8.3.1)	3A1 Not enough HCWs in clinic	-short staffed -town council funding	-too few staff for too many people	-low staffing leads to low quality care
	3A2 Staff members doing "double duty" at clinic	-"double duty" -working two areas at once	-staff move between areas, open/close accordingly	-staff can't fully run clinical areas for clients
	3A3 HCWs working erratic hours & not enough	-staff come late -staff leave early -staff	-staff presence not reliable & constant -staff burnout & disillusionment	-negative perceptions of HCWs -clients won't bring

		disappear		children
3B Supplies are received "irregularly" which hampers care efforts (8.3.2)	3B1 Not enough supplies to regularly provide good care to children	-no supplies -no drugs -immunization days	-chronic supply shortage impacts on children's care	-care seen as unreliable & not good
	3B2 HCWs prioritize interventions due to supply shortages	-priorities -interventions -shortages	-not enough supplies for all client needs	-clinic not able to provide for children reliably
	3B3 Profiteering or corruption risk observed	-government corruption -profiteering -in charge officer's clinic	-perceptions of staff corruption -shortages blamed on staff alone	-clients may not use services if seen as corrupt

8.3.1: Poor management & lack of staff impacts negatively on care given

This finding reveals the impact of a lack of proactive management within the clinic, including chronically unmet staffing and recruitment needs, and a lack of discipline and work-related morale amongst HCWs, leading some to maintain erratic work hours, which places stress on other staff members and clients alike. Whereas HCWs in Chapter 5 acknowledge that ART has given them a renewed hope in their clinical practice, this hope is tempered by the day-to-day practice difficulties which result from a lack of supportive management, and simply not enough HCWs to do the job.

3A1 Not enough HCWs in clinic

As discussed at length in Chapter 5 and throughout this chapter, HCWs feel their work is negatively impacted by chronic staff shortages, and observations at the clinic do reflect this. Interestingly, adult carers are also acutely aware of the impact of this shortage on both the quality and quantity of care provided, as seen in Chapter 6. In many instances, staff members struggle when there are large numbers of clients, particularly on the 3 days set aside to hold "clinics" which focus on specific illnesses or particular user groups, namely the HIV "clinic" held on

Wednesdays, the ANC "clinic" held on Tuesdays, and the well-baby vaccination "clinic" held on Thursdays.

> Looking at the patient flow and numbers, if they'd have just a couple more HCWs, they could be on top of things- even 2 more people would make a big dent in the workload. (Obs 2)

> The HIV clinic day is always busy with too few workers, and the same with ANC day. Talking with the in charge [clinical officer], they're supposed to have 3 midwives, but recruitment is very difficult, as most younger staff want to go for advanced training, or to work in the cities and not rural areas. Also, the local councils decide health funding, and they won't fund more staff, even though the clinic says its numbers of patients are increasing. (Obs 4)

As noted previously in section 8.2, whilst carers are negatively impacted by long waits and lower quality services, here staff members are negatively impacted by a lack of system and management support, as seen through a lack of incentives or more active recruitment to counteract the challenges of attracting new staff to rural/remote areas.

3A2 Staff members doing "double duty" at clinic

Due to low staffing levels, staff members are regularly observed moving between several departments in the course of a day, which is regular practice in many health systems. Such flexible staffing patterns work if patient flow is manageable, for example, if one area of patient care is very busy but another is not and the staff member can be safely "floated" from the one section to the other (Fernandez, et al, 2012). Here, however, the general shortage of staff members result in lower quality and quantity of care provision at every service delivery point, as HCWs are stretched too thinly for good quality patient care coverage.

> Whilst patients wait to be seen, a couple of the nurses including the lab technologist leave them to go put together [HIV] testing supplies, making sharps disposal boxes of cardboard. I see no other staff members around who could do this for them. (Obs 6)

> The lab technologist is in the dispensary at the moment, she's running between the lab and the dispensary, as the in charge [clinical officer] is seeing patients in the OPD, where there's now 8 adults and 5 young children waiting. (Obs 8)

As the clinic is only staffed to 47% of its capacity, HCWs are essentially forced to cover two work positions instead of one to meet client demand and cover just the most basic care needs, which often results in them running two physical areas of care provision at once. Not only is this potentially stressful to staff members, it also runs the risk of them providing poor or even unsafe care to clients, and is a major complaint of both HCWs and the adult carers in Chapters 5 & 6.

3A3 HCWs working erratic hours
Adding to patient flow difficulties is the observation that some staff members show up for clinic duties irregularly and are not very reliable in terms of their hours of work. In particular, three staff members had noticeably irregular working patterns over the course of the observations: one nurse who tended to "disappear" for extended breaks on a regular basis, a midwife (who was over 60 years and the only one at the clinic) who did not usually show up at work before 11 AM and often was later in arriving, and a clinical officer who was also running a private clinic and was often absent from the government clinic for extended periods throughout the day, as will be discussed in section 3B3.

> The midwife is not yet here, she usually shows up around 1100. (Obs 2)
>
> Sometimes staff members start work early and things move at a steady pace, but today has been very erratic in terms of workflow. Didn't help that the midwife didn't show up until about noon. (Obs 6)
>
> Other staff members are not around as far as I can see, they may have gone for lunch somewhere, or gone home. They tend to just disappear and reappear at will, and I don't see them letting others know, although I hope they do. But for most of the staff members, I've not seen that happening. Even the midwife has just left. (Obs 6)

These erratic working hours and absences add further to the workload of other staff members, or result in longer waits for clients to be seen, and were rarely discussed or corrected amongst the staff members themselves, as noted in Chapter 5. Such actions may run the risk of negatively impacting other HCWs further, by potentially demoralizing the workplace and contributing to staff burnout and disillusionment (Harrowing & Mill, 2009). Adult carers are also aware of these staffing issues, and suggest in Chapter 6 that it influences them to not use the clinic.

8.3.2: Supplies are received "irregularly" which hampers care efforts

The serious and chronic lack of material supplies appears to have a very negative impact on clinic care options. HCWs are forced to choose which interventions they will provide to clients, despite significant overall need. In combination with unproven allegations of corruption, the chronic supply shortages further damage the clinic's reputation amongst users, as discussed by several adult carers in Chapter 6.

3B1 Not enough supplies to regularly provide good care to children

Not only are supplies notably low throughout the observation sessions, but all of the study participants, from HCWs, to adult carers, to children, remarked on chronic supply shortages and the inability of HCWs to provide quality care as a result (Chapters 5-7). This is directly observed in one session as seen here.

> Talked with the staff members, and the reason the immunization/baby clinic finished so quickly was because they didn't have enough vaccines for everyone. Some children got their immunizations and vitamins but others didn't get done as they didn't have the doses in stock. (Obs 1)

In contrast, another observed child immunization clinic day sees both positive client-staff and staff-staff interactions, and good-quality clinical care given, as this time HCWs had enough supplies to be able to do their jobs properly.

> [HCWs] gave out the full complement of vaccinations today, polio, TdP, measles, plus vitamins to help the measles vaccine, and said they did 100 babies. There was definitely a lot of waste to concur. Some children were only getting a few of the vaccinations, some were getting all, but they try to give as many as they can in one go, in case the carers do not or cannot come back a second time. (Obs 5)

When there are enough supplies in stock to give proper medical care to all the children present, there is an almost palpable sense of relief felt by all, with HCWs visibly relieved and happy about the day's events at the end of the clinic day.

3B2 HCWs prioritize interventions due to supply shortages

Another negative result of the chronic supply shortage discussed above, is that staff members base interventions they can carry out on the limited resources they have. How many clients would actually receive the services they came to the clinic for, is

regularly dependent on the actual supplies and drugs in stock, or more frequently not in stock, and is a continual source of stress and disappointment for HCWs, as noted in Chapter 5. In one observation, the opportunity to conduct outreach HIV testing directly results in a shortage of ANC HIV testing done at the clinic that day, due to a lack of testing kits available in stock.

> The clinic was supposed to do HIV testing of initial ANC visits, but it wasn't done as there were no test kits in stock. The few kits they had were taken out to an outreach HIV sensitization session held with a religious group. At the outreach, about 90 people were tested. They would have done more but they also ran out of test kits on site. (Obs 2)

In clinical situations where there is great need all around and too few resources with which to meet it, there are few "right" answers or guidelines to follow. Here, HCWs are left to muddle through the decisions on their own as best as they can, with little support from more senior staff or management. Although HCWs here are willing to do HIV testing, and have clients who are also willing to be tested for HIV, a system-based lack of supplies results in a lack of capacity to facilitate the intervention, with both health service providers and users failing to have their objectives met.

3B3 Profiteering or corruption risk observed

There is a disconnect between the perceptions of material shortages seen by adult carers in Chapter 6, some of whom believe that staff members are profiteering by taking supplies for their own use, and the explanations given by HCWs in Chapter 5, that they are short-supplied by the government from the outset. The optics of this situation are further complicated by the in-charge clinical officer running a private clinic about 1.5 kilometers away from the government clinic where he is employed, which confirmed the information given by the adult carers in Chapter 6.

> The in charge [clinical officer] left a couple of minutes ago to go into town. When asked, he told me that he runs a private clinic in town. There are many stories I have been told during this research of clinical officers in government clinics doing that, and often taking the government supplies for their own stock. I hope that's not the case here, but I don't know. (Obs 2)

Although there was no directly observed evidence of profiteering or theft during the observation period, the reputation of the clinic and the clinical officer in question

was negative, given the presence of the private clinic and the observations of adult carers that drugs not in stock at the clinic were in stock at his private clinic (see Chapter 6). However, as the national government drug stockist, Uganda Medical Stores, only sends out supplies and drugs every 2 months, it is also feasible that a chronic shortage situation is occurring instead, where the clinic never receives enough supplies to catch up with its shortages in the long run.

I was able to observe one stock delivery, and good clinical procedures were followed in its reception, with multiple staff members checking and co-signing for the arrival of goods, and processing the goods together. I directly observed that many items, particularly drugs, were either denoted on the manifest as being unavailable from Uganda Medical Stores, or were listed on the manifest as being in the shipment, but were then not physically present in the boxes as they were opened, with no explanation given from the delivery driver as to the discrepancy between the manifest and the physical allotment. In drug distribution systems all over the world, there are multiple points where corruption can happen, and without transparency and enforcement of regulations, as well as mechanisms for tracking, it can be difficult if not impossible to tell where theft occurs. As Uganda does not currently have this sort of monitoring in place, it puts the clinic and the HCWs at continued risk for allegations of theft, when it may actually be someone with access to the supplies earlier on in the distribution chain. Unfortunately, such an investigation is outside the scope of this thesis.

8.4: Relevance for children's HIV care access & adherence

Although this chapter has focused more on the barriers and problems underlying the health services delivered, it is important to acknowledge some positive aspects of service provision and use, which encouraged some community members to make use of the clinic. There is generally a good rapport between health service providers and users, as well as between HCWs, with no major conflicts observed on a day-to-day level during the observation period. No major disagreements, arguments, or violence were witnessed during the observations. Such positive interpersonal factors can help to build trust and familiarity, which can help increase clinic usage (Msellati, 2009; Varga & Brookes, 2008). The clinic does provide access to ART for adults and children, with additional support for children's ART

provided by a new partnership with an international NGO which was beginning at the time of this research. This "back up" of services may help to improve the continuity of care, which could assist children and their carers in accessing and adhering to ART (Nuwagaba-Biribonwoha, et al., 2007).

The HCWs at the clinic have a good sense of purpose and commitment to their work, as seen in Chapter 5. Studies highlight this as a positive factor which can inspire service users to access services (Stein, et al., 2007; Kyakuwa, et al., 2009; Holzemer, et al., 2009). Many adult carers do use the clinic, and see it as a valuable resource as per Chapter 6, acknowledging that its limitations are often linked to supplies and staffing. They would also like to have more services available to them, which is a positive sign. However, as the challenges to service provision and uptake currently outweigh the positives, priority has been given to them in this chapter, so that they can be better understood, and ways of minimizing them can be considered.

In section 8.1, the relational dimension of clinic care appears intimidating and unwelcoming to carers, through actions and structures which run the risk of stigmatizing users. Although HCWs recognize that continued stigma is acting as a barrier to accessing HIV care for children in Chapter 5, their clinical relationships with the adult carers here do not counteract these fears, but rather appear to inadvertently reinforce them, which may result in decreased clinic usage by the community, including children (Campbell, et al., 2011a; Uebel, et al., 2013). The clinic also does not provide a safe space for users to be when seeking care, as discussed in Chapter 7 by the children (Uebel, et al., 2013). Further, these observations concur with prior findings that, although concepts of privacy are culturally-mediated (Hejoaka, 2009), in a social environment where HIV remains highly stigmatized, the combination of a lack of physical privacy and a lack of HCW sensitivity to user fears of being socially identified as being HIV-positive, may create an environment of mistrust where some clients may be reluctant to use services as seen in 8.1.2 (Rwemisisi, et al., 2008; Kyaddondo, et al., 2013). HCW concerns about a lack of training to manage social situations such as HIV disclosure, as seen in Chapter 5, point to a need for assistance in counselling families affected by HIV echoed by other studies in Uganda (Rujumba, et al., 2010; Myer, et al., 2006;

Luyirika, et al., 2013). Such additional training could help to support an improved clinical relationship between health providers and users, by making health services friendlier to currently underserved groups, and could contribute to increased social capital and work to build trust between service providers and users.

Procedural dimensions which create an unsupportive care environment for service providers and users alike, discussed in section 8.2, reflect how poor clinical processes can result in poor care outcomes for clients. As also seen in 8.1.1, both HCWs and clients are troubled by HIV testing legislation which inadvertently fuels HIV stigma against women, particularly pregnant women, and results in expectant mothers rejecting health care services and experiencing poor care outcomes (Chapter 6), which fuels frustration and despair for HCWs (Chapter 5). The impact of this legislation in Uganda is mixed, with prior research split over its use given continuing HIV stigma against women (Dahl, et al., 2008; Nassali, et al., 2009; Rujumba, et al., 2010). The HIV stigma fueled by this legislation could also explain why Uganda has poor turnout rates for subsequent prenatal visits, as clients cannot bear the risk of being found to be HIV-positive, due to the fear of negative consequences within the family, as discussed in Chapters 5 & 6 and seen in other SSA settings (Campbell, et al., 2005; Msellati, 2009; Hejoaka, 2009). Given more recent HIV legislation in Uganda (BBC, 2014b), as will be discussed in Chapter 9, further stigmatization could result in decreased service access at the clinic.

For service users, HIV is seen to be a huge threat to parental identity (Chapter 6), and to family stability (Chapter 7), and health services are not seen as being helpful to people living with HIV (Chapters 6 & 7). When further combined with poor care processes, such as long waits to be seen, and a lack of progression through clinic services (in 8.2.1), both clients and HCWs become frustrated, which makes the clinic a negative experience for both. Long waits and poor patient processing results in poor service uptake and use in many HIV care contexts across SSA (Wanyenze, et al., 2010; Luyirika, et al., 2013; Uebel, et al., 2013). In addition, HCWs are thwarted in their efforts to provide good care by a chronic lack of staff resulting in workflow inefficiencies, which is a significant barrier to good quality HIV care provision across SSA (ibid).

Whilst the limitations of the resource dimension discussed in section 8.3 have a significant bearing on HCWs, it is felt by patients of the clinic as well, through a correspondingly negative impact on their health service options and care provision. A lack of staff members and poor management (8.3.1) is seen to be negative by both service providers and adult carers (Chapters 5 & 6), and is a major impediment to creating a supportive care environment, echoing findings from South Africa that staffing numbers and skill mix impact on the provision of high quality HIV care (Uebel, et al., 2013; Yeap, et al., 2010). The irregular supply of general clinic supplies and drugs in 8.3.2, which includes HIV test kits but not ART, is further exacerbated by allegations of corruption and profiteering from adult carers in Chapter 6. Despite HCWs maintaining their innocence in Chapter 5, and despite observed shortages of supplies arriving at the clinic, this constant mismatch between the availability of services and goods and client perceptions, may add to the poor trust environment within the clinic space, and further dissuade carers from bringing children to the clinic for HIV services.

Conclusion

Despite the positive benefits and potential of ART to improve the lives of children living with HIV, the clinic setting observed by this ethnographic examination does not offer a supportive space for service users, and is not supportive of increased access and adherence for children in its present form. Experiences of both care providers and users appear to be generally negative, reflecting client-provider mistrust, continuing HIV stigma, and fears and doubts over the sustainable provision of services. These experiences appear to reinforce negative representations of HIV and HIV care held by service users, as discussed in Chapters 6, 7, and in 8.1, and the clinic environment does not present opportunities to discuss or challenge these SRs. Although there are positive signs in terms of potential for reassuring and effective HIV service provision, such as positive staff-client interactions and HCW commitment to their work, there are significant service provision and uptake challenges which remain.

As the creation of a supportive, caring environment is as much the outcome of the positive engagement of HCWs in their work situation, as between HCWs and clients themselves, increased support for HCWs through an improvement in working

conditions would be an excellent foundation upon which a better care relationship and increased social capital and trust could be created. These findings echo calls for an improvement in work conditions as a way of supporting children's ART scale-up (Wanyenze, et al., 2010; Luyirika, et al., 2013). In the existing literature on children's access and adherence to HIV treatment, the emphasis is often on the patient, and their failed need for care (Bikaako-Kajura, et al., 2006; Horwood, et al., 2010). However, findings here suggest a need for further research on the practice environment experienced by HCWs, and the extent to which the clinical context supports them and facilitates the possibility of effective patient care. As an improved clinical relationship could also be used to build wider social capital and stakeholder trust within the community, creating a care-enabling clinical environment could not only attract health service users and lead to improved health outcomes, but may encourage broader social changes which could lead to a health-oriented community, with increased social capital, cohesion, and trust between stakeholder groups.

Whilst health service providers grapple with serious practice challenges, they also perpetuate clinical practices and interpersonal behaviours which unwittingly make the clinic a fearful and stigmatizing place for their clients. Children's carers, on the other hand, appear reluctant to take ownership of their health needs and express them, out of fears of rejection and a denial of health services altogether. This breakdown of communication and trust leads to unvoiced needs being unmet for service users, and a lack of opportunity for reflective practice and professional growth for service providers. The move to a more open and honest social dialogue, concerning service user needs, health system limitations, and HCW practice challenges, could help to build social capital and trust, and strengthen the care provider-user relationship by both groups working together to develop joint solutions for their shared problems.

Chapter 9: Implications of the study findings

Introduction

This PhD research study has used a social representations theory (SRT) approach to explore the low levels of pediatric access to HIV services in Kabarole district, Uganda, which occur despite the availability of children's antiretroviral therapy (ART) at the local government-run health centre. In sections 9.1 & 9.2 of this final chapter, the data findings from the four previous chapters (5-8) will be integrated with the historical social context from Chapter 4, to consider how the social representations (SRs), social identities and social contexts of this community have combined to create a social *milieu*, or environment, which is essentially health-preventing in relation to children's HIV service access and adherence.

To review, the Research Questions for this PhD research have been the following:

- What are the social representations of HIV, health services and children, as held by health care workers, children's carers, and children in the Amooti area of Kabarole district, Uganda?
- What are the areas of tension or overlap in these sets of representations?
- In what ways do these representations serve to facilitate or hinder HIV service access for children?
- How can a social representations theoretical approach give us greater insight into why children are accessing HIV care less than adults?
- What are the implications of these findings in relation to promoting children's HIV service access and adherence?

These questions will also be used to consider the future potential for improving and increasing children's HIV service access in this community. As will be discussed in section 9.3, if creating a health-enabling social environment which supports children's HIV service access and adherence is to become the long-term social project for this community, Bauer & Gaskell's (1999, 2008) Toblerone model can be used with the current and historical SRs to extrapolate what SRs would be needed to support this goal. Section 9.4 will explore how, in order to help facilitate these SRs, social identities, and social contexts which would improve HIV care access

and adherence for children, there must first be increased social cohesion, the building of social capital, and the development of wider social trust in both people and the system, to allow constructive discussion and debate to begin.

However, due to recent regressive national legislation concerning HIV and human rights (IRIN 2014a, 2014b; BBC, 2014a, 2014b), this is a long term social project which is precarious, as Uganda is at a social "tipping point," where HIV stigma could be challenged and lessened, or could be reinforced, entrenched, or even worsened. Such potential future scenarios will be explored in section 9.5. Ultimately, the choice will be up to the people of Kabarole district and Uganda to decide, with the hope that this small research study has captured the social processes currently occurring, and in doing so, may be used to positively influence future decisions towards a reduction of HIV stigma, increased social cohesion and trust, and improved children's HIV care access and adherence.

9.1: SRs of HIV, health services & children
In this section, the SRs of HIV, health services and children are reviewed to explore potentially shared SRs, which can be the basis for building trust and social capital amongst stakeholder groups. This review will also be used to determine which SRs are divergent, and could either be antagonistic and divisive to society, or act as catalysts for social change through the triggering of discussion and debate over these differing perceptions and lived realities.

9.1.1: SRs of HIV
In terms of how health care workers (HCWs) who participated in this research make sense of HIV and HIV infection, they see a limited social discourse around HIV to that of a stigmatized adult illness which carries connotations of sexual immorality. However, they frame the discussion of HIV around the development of ART and its benefits to their own clinical practice, seeing it as a miracle which has had a positive impact on HIV clinical treatment for their patients. Yet, these positive SRs are also coupled with stigmatizing fears over ART being "spoiled" by HIV-positive people who are not good "therapeutic citizens" and who are abusing this privilege (Ngyuen, et al., 2007). HCWs see HIV as now being a treatable and manageable illness due to ART, where people no longer have to die from the disease like in the "bad old

days." In terms of children and HIV, HCWs position HIV stigma as preventing carers from bringing children in for HIV testing and treatment, with children suffering from a lack of HIV care access. However, this SR does give parents the benefit of the doubt over not bringing children in, by acknowledging that given the constricted social dialogue around HIV and children, some parents may truly not know, or may claim to not know of their own or their children's HIV status, out of feelings of guilt and shame.

For adult carers, there is significant fear of HIV due to social stigma which remains in their community, where HIV is seen as a stigmatized social "death," with negative consequences if you are "outed" as being HIV-positive. Women and their children are particularly vulnerable to HIV stigma, as the clinical push for HIV testing with antenatal care (ANC) services puts them at risk for abuse or abandonment from a male partner who does not want to know his HIV status and refuses to be tested, and who may blame the woman for bringing HIV into the family. Family members are often unsympathetic and unhelpful in such situations, putting the woman and her children at risk for becoming destitute from a lack of financial support. There is also a developing "treatment envy" backlash and re-stigmatization of HIV-positive people who are taking ART and using clinical services. They are seen as being in better health than HIV-negative community members, to the point where they are blamed for putting community members at risk for HIV by engaging in "normal" community activities, such as having personal, sexual relationships with people who are HIV-negative. Community members are no longer able to visually determine who is HIV-positive, and so feel threatened by being unable to exclude them from risk activities such as sexual relationships. For children and HIV, whilst some participants were unwilling to talk about children and HIV, denying it was possible for children to be HIV-positive, others recognized children's HIV risk but typically placed it outside of the family sphere of influence. Carers generally feel that youth sexuality is negative and to be controlled, and that if you as a carer couldn't control your children's sexuality, you had failed as a parent or guardian.

For child participants, HIV is seen as a destructive force which has wreaked havoc on their society overall, and they position HIV as either killing people outright, or turning them into living skeletons and the "walking dead" who are physically marked

out in society as being HIV-positive. These SRs reflect back on the broader social impacts of HIV more than those of the adults in this study. The children also acknowledge the link between HIV and poverty and how one appears to exacerbate the other, with some focusing on the heavy burdens placed on women and girls by HIV infection and risk, similar to the adult carers. Children portray HIV infection as being inevitable in their society, and suggest they expect to become infected themselves. They do not mention ART or capture its positive benefits, but do mention negative situations concerning a lack of ART access in some of the works produced. The children also suggest that children are at almost constant risk for HIV infection, as their society is not able to control HIV or protect them from it. They also openly acknowledge the negative impact of HIV infection on children's lives, either through direct infection or through HIV infection in the family, which results in poor long-term outcomes for the child.

In terms of developing an overall picture for the SRs of HIV, there are disconnects between the SRs of HIV as seen by HCWs and those of the adult carers and children. Data findings from the HCWs capture the positive impacts of ART on HIV care almost exclusively, whereas ART for health service users is either a threatening force which obfuscates the HIV status of others and increases risk (adult carers), or a non-entity which is unobtainable or unhelpful for HIV-positive people (children). The HCWs may be focusing on, or living in, an idealized social world where HIV treatment is possible and effective, whereas service users are split between fearing ART and its social effects (carers), or not even realizing it exists and can help people (children). This large disconnect suggests a lack of open communication about HIV and ART locally, exacerbated by a lack of broader social messages or media coverage about ART, which is virtually non-existent in Uganda, despite ART being available in-country since the early 2000s (Mugyenyi, 2008). In Uganda and Kabarole district, the HIV messages are still reflecting older HIV SRs full of stigma and shame, which continue to frame HIV as an adult disease acquired through immoral sexual acts. This reflects how there has been no real "new," ART-inclusive dialogues from the government despite its availability across the country and locally in Kabarole district (AVERT, 2014a).

9.1.2: SRs of health services

For HCWs, significant difficulties remain in the provision of health services, of which the public is not fully aware. HCWs do not openly communicate this to service users, due to a lack of confidence in handling conflict situations and a desire to look professionally competent. They are, however, concerned about potential clients being able to access good quality care, given the difficulties faced on a daily basis. HCWs discuss the significant challenges they face in their clinical practice due to a lack of staff members and supplies, and are frustrated at this being out of their control, yet having negative impacts on their day-to-day practice, particularly the care they provide to service users. HCWs often feel caught in the middle between an unresponsive health system and management, and the significant unmet needs of service users. Although the clinical situation regarding HIV was bad in the past, it is now much better with the advent of ART, which has become a bright spot of hope in the midst of an under-supported health system. Regarding children and health services, HCWs feel significant stress and conflict over the lack of children accessing HIV and health services. On the one hand, they feel unprepared to provide care to children in terms of the family conflicts which may arise from HIV testing and disclosure, and openly ask for further help and training to provide such services. On the other hand, whilst they believe that children need and deserve HIV services, they feel trapped as they cannot access the children without parental consent, and the carers are not bringing children in to the clinic to be seen.

Adult carers, in contrast, see health services as not meeting their health care needs or wants, regardless of whether it is provided by the government or privately, and feel there is no real value for the incidental costs of accessing services which they have to pay out of pocket. Irregular drug supplies at the government clinic are cited as having a negative impact on the clinic's reputation and inhibiting service usage. Mistrust of the clinic is further reinforced by care interventions which unwittingly propagate HIV stigma, and threaten the maintenance of a positive identity as a carer within the wider community. In addition, resentment over the perceived favoritism of HIV-positive clients results from the availability of HIV supplies and drugs, particularly when contrasted with a lack of services and supplies for non-HIV illnesses, and without an explanation from HCWs as to why this occurs. In terms of children and health services, carers felt that the HIV stigma inherent in the health

system is too much of a social risk for them to bear, and as service provision is erratic when accessed, there are few motivating factors for them to attend the clinic with their children.

The SRs of the health system in the children's draw-and-write exercise are that of not being effective, helpful or useful against HIV infection. Services are portrayed as being difficult for most people to access, and if they are accessed, the outcomes are negative with HIV-positive people typically dying shortly thereafter. HIV is openly portrayed in the home setting, with most people coping with HIV at home but with a reduced quality of life. HIV-positive children are portrayed as being physically sick and unable to play or undertake the normal activities of daily life, in contrast with HIV-negative children who are able to enjoy life to the fullest. Health services are not seen as playing a significant role in children's lives as a result, with no proactive use of health services seen in the works. Health services are represented as being the domain of adults, but which ultimately fail in their provision of HIV care.

In terms of the broader SRs seen in this community, HCWs focus again on the progression of health and HIV services from being awful to better, due to the availability of ART. Although significant challenges remain, ART for them has become one small positive factor that can give hope for continually improving clinical practice, despite the very significant shortages of staff and supplies, and the precarious nature of HIV and health service provision from tenuous external funding commitments. Adult carers and children again are disconnected from this view, as their lived realities reflect only the negative aspects of service provision, such as not enough supplies and staff members. In addition, carers have to negotiate the social risks of accessing the clinic, in terms of their fears of potential social stigma and backlash, regardless of one's HIV status, as the clinic has become overly associated with HIV care. In contrast, children do not report having significant family influence over the decision to access care. As seen in Chapter 8, the clinic has become a negative social space as opposed to a neutral space, as fears of HIV stigma are paramount in users' minds and negatively impact on the possibilities of children's HIV care access and adherence.

9.1.3: SRs of children

HCWs portray children as being generally good and innocent, particularly in terms of vulnerability to HIV infection, which is primarily passed on through mother-to-child transmission. They are concerned about a perceived cultural clash of values in the community, between the traditional use of children as labour for the homestead farm, and the modern era focus on education and paid employment, and are concerned that children may be vulnerable to exploitation by their carers or families. They also believe they are unable to gain access to children in need of health care or social assistance, due to legal frameworks which favour the parents and family, and a lack of child protective services to intervene when things go wrong in the home. Whilst they would generally like to see children more able to access health and HIV services, they feel they do not have the legal mandate or staffing capacity to make this happen.

Adult carers position the SRs of children as a dichotomous split, between those that are "good" if they are obedient and asexual, and those that are "bad" if they are uncontrollable and engaging in sexual behaviours. There was significant reluctance to discuss children's sexuality in this research, which may have been due to cultural history (Taylor, 1998) or personal discomfort with the topic. The denial of children as being HIV-positive or at risk for HIV is linked to a denial of children's sexuality, and a denial of children being put at risk for HIV infection, either through infection at birth, sexual abuse, or transactional sex due to low socioeconomic status (Samara, 2010). The social identities of adult carers appear to be shaped through children's actions, as a "good" carer is one who can control the children in their care and keep them safe from social risks and harm. This captures a major social and personal need for carers to be able to control their children and retain influence over them, until they become adults themselves.

Children see themselves as being at constant risk for HIV infection in a society which is unsafe due to the sheer pervasiveness of HIV. They see children and childhood as being negatively impacted by HIV, with children suffering personal and social losses in terms of reduced socioeconomic and psychological support from adults and families adversely affected by HIV, and feel that the negative social impacts of HIV infection are circumstances beyond their control, over which they

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have little power to act. Another strong dichotomy emerges between healthy, HIV-negative children who are shown playing and actively engaging in daily life, and HIV-positive children, who are portrayed as being sick, physically disfigured, and who are relatively passive characters in the pictures. Only two works portrayed positive or positively resolved outcomes for HIV-positive children, both of which also mentioned significant social support for the child.

Regarding the SRs of children, HCWs tend to accept children as being inherently innocent and worthy of HIV care and social support, but also as vulnerable and dependent on adults, particularly their carers, for access to such support. They do not feel personally or professionally responsible for children's HIV or health services access, instead believing it is up to carers to bring children to the clinic for services. Adult carers have polarized SRs of children, portraying "good" children as being controllable and submissive to adult authority, and "bad" children as being out-of-control and at risk for either contracting or spreading HIV infection to other "good" children. This suggests that these "bad" children have a "spoiled identity" linked to HIV infection or risk (Joffe, 1999, 1993), with carers attempting to distance themselves from this social stigma, shame and "othering" through the denial of children's HIV risk (Campbell, et al., 2005), as they link a positive social identity as a carer with being able to control one's children. Children on the other hand, see themselves as vulnerable to a dangerous world filled with HIV infection risk, with the adults in their lives not only being unable to mitigate this risk on their behalf, but succumbing to it outright, causing them suffering and a precarious socioeconomic future.

9.2: SRs considered with social identities & social context

Turning to examine the SRs discussed above in concert with the social identities and social contexts of the stakeholder groups, the perceptions they hold of their social world and positioning within it becomes clearer. Their social world, or the broader social environment or *milieu* within which they engage as community members, both influences and is influenced by the SRs in use by the stakeholders of this community. Combining the SRs, social identities and social contexts as seen by participants, captures this social world and the interplay between processes

which are personal and psychological, and those which are interpersonal and social, by situating the stakeholder groups within their broader community setting.

In exploring the social identities which emerge from the SRs in these data sets, 2 potential identities emerge, one of which is typically positive and "successful" in terms of meeting personal psychological and interpersonal social goals. The other potential identity is negative, or socially "unsuccessful," and triggers feelings of shame, sadness, and guilt (Reicher in Turner, 1987; Howarth, 2002b). The social context setting is framed by the participants' views on their immediate community or social settings in which they live and act, and the physical sphere in which their lived experiences are situated (Jovchelovitch, 2007), which for this study has been the local health centre where health and HIV services can be accessed. Here, social context combines with and shape identities and SRs, in ways which are generally not helpful for increasing children's HIV care access and adherence

9.2.1: SRs & social identities
For HCWs, the positive social identity which emerges from the data findings is that of a heroic worker, who is able to save patients from HIV with the use of ART, and who is a recipient of respect and gratitude from health service users. This identity reflects a HCW who is a dedicated professional, who tries to remain positive and helpful to clients, no matter how difficult the practice realities may actually be in the clinical setting. In contrast, the threatening, negative social identity is that of an incompetent HCW, who is unable to handle complex family situations concerning HIV infection and HIV status disclosure, and who experiences anxieties over facing conflict with service users. The tensions between these two competing and clashing identities, specifically the desire for the positive one and the fear of becoming the negative one, may also influence workplace stress and burnout (Harrowing & Mill, 2009), and could prevent HCWs from taking on more responsibilities to foster and increase children's use of HIV services. However, the SRs used by HCWs help to build up this heroic worker positive social identity, and appear to bolster their ability to cope with a clinical reality that is tenuous and fraught with risk for clinical and professional failure. The HCW social identity in use here attempts to delicately balance successful professional practice and empowerment through the treatment of HIV-positive clients with ART, with personal fears over a lack of training and

capacity to deal with the social complexities of HIV in children and frustration over a clinical setting marked by chronic shortages and precarious system support.

In contrast, adult carers appear to have developed a social identity from positioning themselves relative to their children and the generalized threat of HIV in society. A positive social identity for carers is where you are seen socially as being HIV-negative, and as having effectively controlled your child and prevented HIV infection in him or her from occurring, thereby maintaining their innocence and health related to HIV. This is accomplished through having a negative or unknown HIV status yourself, and by having non-sexual, innocent, well-behaved, obedient children in an HIV-free family. This positive social identity is particularly important for women, who are at risk for the negative consequences of being in an HIV-serodiscordant relationship, if they are found to be HIV-positive and the male partner is either HIV-negative or his status is unknown. In contrast, the negative social identity of being a "bad carer" is a result of having an HIV-positive status socially known, and is made worse if you have also passed on your HIV infection to your child, who will suffer and potentially die from the disease. This is coupled with feelings of shame and guilt over having polluted and spoiled the child's identity with HIV, through your incompetence as a carer.

As the SRs of HIV still position it as a sort of punishment for immoral sexual actions, the "bad carer" is scapegoated as not only being reckless in terms of his or her own actions, but as also endangering the life of his or her own child. A "bad carer" identity can also come from neglecting a child, which can include allowing them to engage in HIV-risk actions or not stopping such actions from occurring. HIV-positive women who are "outed" in a serodiscordant relationship also take on the negative social identity of a "bad carer," as they are seen as putting their children at risk, with possible social consequences of the children being taken away by the male partner's extended family, in addition to potential abandonment, divorce, or violence (Nassali, et al., 2009). For carers, this rigid dichotomous split of children and HIV infection, combines with social identity to reinforce the need for a HIV-negative social status, which can lead to an unwillingness to risk using health services due to fear over the consequences of stigma and possible withdrawal of what little social support does exist within the family unit and the community. As the community

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social context is seen as being unsupportive, judgmental, and stigmatizing of HIV-positive people, carers strive to create a positive social identity of an HIV-free, effective carer, to protect themselves against the shame, guilt, and fear-inducing consequences of an HIV-positive status, namely social exclusion and a withdrawal of the limited social support available to them in their community.

For children, there is also a dichotomous split connected to HIV status, which shapes the social identities seen in the draw-and-write exercises. A positive social identity for children is seen as being HIV-free, happy, healthy, and "normal," participating in an idealized childhood where you attend school and play with other children, without any sadness or suffering resulting from HIV infection in the family. In contrast, a negative social identity for children is being an HIV-positive child, who is sick and suffering with HIV infection, and is unsupported by adults in society who themselves may be suffering or dead from HIV. This negative identity is frequently drawn in the pictures as a child looking physically sick with skin disorders and physical wasting marked by ribs showing, with many works having a large amount of open space between the HIV-positive children, and other figures in the picture who were labelled as being HIV-negative (see Chapter 7). Whilst this singling out of HIV-positive children may be simply to demarcate the HIV-positive child in the story, it may also be reflective of wider community-based social stigma and the singling out or identification of HIV-positive people, as noted by many respondents in the study. Regardless, the social identities portrayed here link to the SRs of HIV and children, which may be capturing children's internalization of their society's SRs, as they develop their own social identities and become enculturated into society (D'Alessio, 1990; Corsaro, 1990). Interestingly, the social identities and SRs of women and girls are also connected, and capture a potentially heightened social risk for HIV, also seen by the adult carers above.

9.2.2: SRs & social context

For HCWs, their immediate social context is that of their workplace, the government-run health centre, as well as the community-at-large in which their clinic exists and their care services take place. The SRs used by HCWs suggest they see their social context as one where they have a reasonable amount of control over their clinical work environment, but where underlying problems can

arise and thwart care provision efforts. However, most of these problems can be blamed on others, such as with the ongoing staffing, drug supply, and funding shortages. HCWs see the wider community as being outside their sphere of direct influence, although they do welcome the opportunity to conduct outreach services, recognizing the positive impact this has on care provision to the community. However, HCWs generally restrict themselves to their clinic where they have relatively high social control and influence. Limiting their social context in this way helps them to protect their social identity of the positive heroic worker, in control of the immediate environment, and able to limit the psychological risks taken in the work environment, which may also limit burnout (Harrowing & Mill, 2009; Harrowing, 2011).

Adult carers, in contrast, draw upon the wider community as their social context, in terms of social status and standing within the community. In this context, due to continued HIV stigma, people are judged on their HIV status, with HIV-negative people being seen as "normal" and acceptable as part of the wider in-group, and where HIV-positive people are "othered" and assigned to the out-group (Joffe, 1993, 1999), in terms of social cohesion and mutual support. In addition, many carers in Chapter 6 positioned themselves as victims of an unfair wider social system, where poverty and a lack of opportunity combine to prevent them from taking control of their lives, and their health though clinic access. Viewing their immediate social context as stigmatizing, limiting, and disempowering, provides carers an additional rationale as to why they cannot take children to the clinic for HIV services, as it further reinforces their need to not be identified with anyone who is HIV-positive, out of fear and mistrust in an unsupportive social environment. The stigmatizing SRs of HIV, and the negative SRs of health services here combine with this negative social context to present significant barriers to health service usage, particularly for bringing children to the local clinic for HIV services.

Children portray social context in their draw-and-write exercises as being both that of the immediate family, as well as that of society-at-large. Generally, children see their social world as having no safe, HIV-free spaces for them to take refuge, and gave examples of families struggling to cope with the effects of HIV infection, particularly after the deaths of family breadwinners. This resulted in many children

positioning themselves as being at risk for poor long-term outcomes, due to the impacts of the failings of adult society, such as through poverty, transactional sex, and related HIV risks. In a few works, children also positioned their needs as neglected or not being met by the adults in their lives, due to their inability to act from the effects of HIV infection and illness. Children's social identities here reflect a social context where they are relatively disempowered, and have become resigned and fatalistic over the inevitability of HIV infection in their future. The children feel that little help is available socially to support them, with adults and carers seen as being flawed and relatively impotent to help them survive, let alone thrive.

9.2.3: Putting it all together

Examining the SRs, social identities and social contexts as seen by the participating stakeholders, reveals an overall social *milieu*, or social environment, in which stakeholder groups exist and negotiate care practices concerning children and HIV care access and adherence. If, as research suggests, (Campbell, et al., 2005; Campbell, 2003), stigma is "othering" in context, then the direct context here is that of a health clinic and society where the "othering" occurs related to one's HIV status, or perceived HIV status, with an HIV-negative status being preferential and an HIV-positive status being stigmatized as socially unacceptable or undesirable. Given the local history of HIV as a "plague"-like illness which endangers society, and which was initially framed as being a punishment for immoral or illegal sexual actions and behaviours, as seen in Chapter 4, the maintenance of a socially acceptable HIV-negative status then becomes a "status symbol," and a social ideal. This status must be therefore be met and maintained, in order to facilitate inclusion in the few networks of social support which exist, mainly those of the immediate family, neighbours, and the few social groups extant in this community, primarily religious organizations.

This "othering" based on HIV status is further underscored and exacerbated by a material context of chronic health system shortages where few needs are met, and a relational context where interpersonal relationships are fraught with fears, jealousies, and completion for the meagre social support available. The resulting social *milieu* ultimately projects stigma and othering onto those with relatively weak positions in society, namely the HIV-positive, and children, in order to protect the

precarious social identities of more dominant adults, who have few personal or social resources to support them otherwise. To this point, as seen in the data chapters, children have either been totally excluded from the picture of HIV-infection risk, or included in ways which highlight their relative low social power and positioning, that of being "innocent victims" of the dominant adults who have infected them with HIV. This narrow SR framing and the stigmatized othering which occurs along with it, shapes and is shaped by an underlying social environment of extreme deprivation, need, and fear, marked by low social cohesion, social capital and social trust (Barnett & Whiteside, 2006; Putnam, 2000).

Within this social *milieu*, the stakeholder groups position themselves according to their own lived experiences and the "sense making" which has resulted (Moscovici, 2008; Seeley & Russell, 2010). HCWs see an increasingly better clinical world where they have more control and can act on HIV, resulting in more social power and prestige, despite the health care needs of many in the community not being met. Their need for a positive identity and relative control over their environment has been strengthened with the increasing availability of ART, which has become a key part of their lived experience due to its positive personal and social benefits. Adult carers position themselves as living in a social world full of stigma and fear over HIV infection and a positive HIV status, where they see negative social consequences resulting from being found to be HIV-positive, especially for women and their children. Therefore, all efforts must be made to prevent being "outed" as HIV-positive, or to prevent being seen or associated with HIV in any way, resulting in low health services access as the local clinic has become a focal point for HIV stigma risk. Children see an unsafe world full of HIV threats, where adults are unable to help or protect them, with HIV infection as a potential future reality. Their relatively low social status appears to exclude them from influencing adult society about HIV, despite realistic views about the impact of HIV in society, and instances where the status quo SRs about HIV, suffering and death are being challenged.

However, at present in this study, only the children have challenged the SRs currently in use about HIV, and this was from only two of those participating. A lack of highly divergent views and SRs about HIV, suggest the lack of a social space where the SRs of HIV can be challenged and changed to more positive ones which

are inclusive and supportive of children's service access and an HIV-positive status. Ultimately the present social environment does not support a diversity of SRs, with no safe social space where the impact and stigma of HIV could be discussed and debated between the stakeholder groups. The data findings also suggest there is a lack of connection, social discourse and free debate over HIV in this community, which raises questions as to why this is the case. To explore this further, Bauer & Gaskell's (1999, 2008) Toblerone model will be used to provide insights from past and current SRs and social practices, which can then be used to extrapolate potential future scenarios for this community, regarding the potential for improving children's HIV and ART access and adherence.

9.3: Using the Toblerone model: "*Quo vadis*?"

9.3.1: Historical SRs impacting on the present day

In exploring the historical social context as was done in chapter 4, the SRs of HIV, health services, and children appear to be influenced by underlying social conflicts and tension, which has never fully been discussed or resolved in the country at large. Uganda has been a divided country from the start, created in its current form by British interests in East Africa, but with little social cohesion or attempts to unite the population under central government, and with significant underlying regional and ethnic rivalries (Taylor, 1998; Thompson, 2003). More recently, Uganda has had much social anarchy and strife, including a civil war, the social effects of which have never been fully discussed (Mutibwa, 1992), unlike in countries such as South Africa where a Truth and Reconciliation Committee held public hearings into the Apartheid past, and brought about public acknowledgement and discussion of the country's painful social history (Government of South Africa Department of Justice & Constitutional Development, 2009). Instead, in Uganda, no public accountability or acknowledgement of the social discord during the early independence and Idi Amin eras and the recent bush war of the 1980s has taken place (Mutibwa, 1992; Mugyenyi, 2008). In fact, a very different picture emerges from the exploration of Uganda's historical social context in Chapter 4, where social discussion and the airing of grievances is discouraged and suppressed through implied social threats.

In the pre-independence era, there was little social cohesion in Kabarole district, which instead was part of a "kingdom of convenience" for the British, but not one

where people were united (Ingham, 1975). The historical social context is that of subsistence farming, with social support only coming from the extended family clan or scant local social services such as religious institutions or government-run health services (Taylor, 1998). Whilst HIV did not exist, illness was seen as being the result of "witchcraft" or curses, a representation which would reappear in the early days of HIV (Kuhanen, 2010a). Health services were seen as ineffective and biased, with traditional healers treated with suspicion, and government-run Westernized health services gradually accepted as being the less-bad option of the two (Winter, 1959), but with neither option truly meeting people's health needs, as is still a problem today. The SRs of children reflected their relatively low social status, as potential workers for the family farm and old age security for their parents, and are still present in society, conflicting with more modern SRs of children's rights and educational attainment.

Following independence in 1962, a historical social context of extreme social mistrust and little to no social cohesion outside of the family unit emerges in the 1960s-1980s. Reinforced by unpredictable political violence, and followed by the impacts of HIV, the period from 1962-1986 is marked by political tyranny, extreme human rights abuses, violence, and economic and social destruction on a national scale. During this era, open dissent or any form of antagonism including simple debate was unacceptable, as speaking out could get you killed, or at the very least result in social and economic support being withdrawn from you and leading to suffering (Kyemba, 1977). Many who did choose to speak out socially were either killed or exiled, with family members who remained in Uganda suffering through social condemnation, shunning, and a withdrawal of assistance (Kyemba, 1977; Mugyenyi, 2008). The SRs of HIV and health services which emerged at the end of this era were highly negative and stigmatizing, with HIV portrayed in religious tones as a sort of lethal retribution unleashed on those who were engaging in socially disapproved sexual activities, such as extra-marital affairs or prostitution, and with health services woefully inadequate and unable to help stop the massive numbers of sick and dying patients (Mugyenyi, 2008; Kuhanen, 2010b). SRs of children cast them as innocent victims of the social anarchy and chaos swirling around them, particularly if HIV had negatively impacted on their family life.

9.3.2: Present SRs and their implications for children's HIV care

Presently in Uganda, the wider social effects of the conflict years in the 1960s-1980s remain, and may even be worsening politically. The highly negative and stigmatizing SRs of HIV, health services and children remain, and in Kabarole district, are reinforced by limited social support systems from the national government and from civil society, including non-governmental organizations (NGOs) and community-based organizations (CBOs). Social supports outside of the extended family network here are tenuous, as geographic location within the country plays an important role in determining one's access to support. As seen in Chapter 4, in Kabarole district, there are few effective sources of external social or economic support, and despite a large number of small local NGOs and CBOs, the social impact has been relatively insignificant (Kajubu, 2010; Mbayahi, 2012). Participating stakeholders cite their extended family or the government as sources of economic and social support, but this is dependent on keeping up the appearance of being someone worthy of support.

This pressure to engage in "keeping up appearances" reflects a wider social norm that in order to get ahead or simply get along socially, the social status quo of being HIV-negative must be maintained at all costs. Maintaining an HIV-negative status is crucial to being seen as an upstanding member of society, and one who is worthy of social support and positive regard by others (Campbell, et al., 2005; Seeley, et al., 2011). Social actions or discussions which would challenge this norm are suppressed and denied through the use of "othering" and stigmatization, particularly in regards to HIV (Campbell, et al., 2005; Joffe, 1999; Mbonye, et al., 2013), resulting in shame, guilt, and fear over one's HIV status which continues over time. The SRs presently in use appear to reinforce these norms and prevent open communication, discussion, or debate over HIV, as the HCWs and adult carers appear reluctant to risk their high social status, positive social identities and relatively privileged social positions by discussing SRs of HIV and children which may challenge this status quo. Children, on the other hand, with their relatively low social position and power, have no qualms about challenging the status quo in terms of expressing alternative SRs of HIV and children in this research, which may have afforded them a rare, safe opportunity to do so.

Unfortunately, at present there appears to be little trust or social dialogue between these stakeholder groups, and no safe social spaces where the SRs of children and HIV can be openly discussed, debated, and challenged by stakeholders. In addition, there has been recent national legislation regarding human rights and civil liberties which has been very regressive and repressive, in terms of freedom of expression and the expression of alternate SRs, in regards to homosexual lifestyles and women's clothing choices (New Vision, 2014; AVERT, 2014a). This presents a worrying trend for the future of Ugandan society, with the risk of increasing fear and social stigma, and further decreased social cohesion and trust, from increased paranoia and intolerance over sexuality and lifestyle choices which do not conform to an extremely right-wing, neo-conservative political agenda being espoused by Museveni's national government (ibid).

9.3.3: Potential future SRs in Uganda: Quo vadis?

Given these worrying recent trends in terms of potentially increasing social stigma over HIV, speculating on future SR trends can be a useful exercise to explore the possible options Uganda and Kabarole district have in terms of creating a trusting social dialogue which could help improve children's HIV care access and adherence. Considering potential negative SRs which could act to further hinder children's HIV care access and adherence is advisable, given the recent national legislation enacted which risks further stigmatizing HIV and those affected by it or afflicted with it. Using Bauer & Gaskell's (1999, 2008) Toblerone model, potential "next segments" of this broader social project can be considered based on the historical progression of SRs already seen here, drawing on the discussion conducted in Chapter 4.

In terms of positive future SRs, which would help improve HIV care access and adherence for children, several could be developed which would help to reduce stigma and advance the social support of children and adults who are HIV-positive. To start, an open recognition that HIV infection can occur across the lifespan due to a variety of complex social factors, and that blame and shame over HIV infection should not be felt as many of these are situational and beyond the direct control of the individual, would help. For example, inadequate information and risk assessment, sexual abuse, and transactional sex can all lead to HIV infection, yet

they act in very different and socially complex ways, reflecting the need for a recognition of this greater social complexity behind HIV infection and transmission. An open social discussion of the underlying social contexts which can fuel the spread of HIV, such as poverty or gender inequality, could also help to draw attention to conditions which fuel HIV infection and transmission.

Openly recognizing children as being at risk for HIV infection, and including them in HIV messaging, could help support a social examination of the contexts behind HIV infection, and encourage more open debate about these contexts as well. Creating positive SRs of ART and including them in the wider HIV dialogue would help to capture the positive outcomes of ART use and its potential to save lives and improve health, as well as reducing HIV exposure risk. These positive SRs could be further supported by an open discussion of the state of health system funding in Uganda, recognizing the need for health system reform and a frank dialogue about how health care is funded and provided (Oomman, et al., 2007), and what changes could make the system more user-friendly. Such positive SRs could still allow HCWs and adult carers to maintain positive social identities, by distancing them from the broader social contexts which can lead to children's HIV infection, and the health system difficulties which impact negatively on HIV care uptake for children.

Conversely, negative or worsened SRs which may result from recent national legislation curtailing the human rights of homosexuals and women (AVERT, 2014a; New Vision, 2014), could act to hinder and obstruct HIV care for children even further. Further blame for sexualized identities being placed on women in particular is very concerning, as the data findings in this research have captured how women and girls already bear the brunt of HIV stigma and infection risk in this society. Further stigmatizing, sexualizing, and criminalizing women and girls, as could occur through the implementation of "anti-pornography" legislation (New Vision, 2014), could also lead to a backlash against women and further stigmatize them or put them at risk for sexual violence. This could lead to even more stigma and blame being associated with female adult carers of children, due to the increased gendering of HIV as "female." As unmet HIV treatment needs for men did emerge from the clinical ethnography in Chapter 8, an increased association of HIV with women could act to exclude men from HIV testing and treatment even more.

In addition, the finding of ART "treatment envy" emerging from this research is cause for concern, as it could signal an increase in HIV stigma towards HIV-positive people, due to perceived special treatment from HCWs and the health system. An increase in HIV stigma could lead HCWs and carers to try and protect the positive social identities they have further, with adult carers most at risk for social identity being impacted negatively by these SRs. This could lead adult carers to deny HIV infection risk in their families altogether, and reject all health services for themselves and their families, also creating a larger disconnect within the family over HIV status and disclosure. As has been noted in other studies, this may lead to family strife, discord, and mistrust, with negative consequences for the carer-child relationship (Bikaako-Kajura, et al., 2006; Rwemisisi, et al., 2008). If positive outcomes are ultimately to result and improve children's HIV care access and adherence, there is a need to build up social cohesion, social capital, and social trust as a starting point, in order to facilitate the use of these SRs, instead of breaking it down further through continued or worsening social mistrust and fear.

9.4: The need to first build trust, social capital & social cohesion

In order to support the development of positive SRs which will help to increase children's HIV care access and adherence, negative SRs must also be lessened as much as possible. At present, HIV stigma is a highly negative SR connected with a rejection of health services by adult carers, out of feelings of fear, guilt, and shame over HIV infection in their children, and in an attempt to protect a positive social identity in a risky social context where status is conferred through being and remaining HIV-negative. For this stigma to be reduced, the material and relational contexts, or factors, which undermine positive SRs must be acknowledged and ideally acted upon, in order to build the social cohesion, social capital and trust which can encourage a broader community dialogue, and the open social discussions and debates which can help to bring about changed, and hopefully more positive SRs related to children and HIV.

9.4.1: Material & relational factors undermine the symbolic SRs

As seen in Chapter 8, the material context which undermines the development of more positive SRs regarding children and HIV, is that of a health system which is suffering from chronic deprivation and shortages, and which does not have enough

material resources to function at a good standard in terms of quality or quantity. This is most evident within the social setting of the health clinic, where a lack of staff members results in long waits for health service users, and potentially poor care outcomes when seen. This is further worsened by chronic drug and supply shortages, which not only undermine clinic service provision but often result in services not being provided at all, due to stock outs of drugs and supplies such as HIV testing kits. Such situations act to reinforce the negative SRs of the clinic and health services as being unhelpful and difficult to use, particularly given the opportunity costs borne by potential service users, in terms of lost labour or transport costs to access the clinic.

In addition, the relational context of health service provision between health service providers and users at the clinic acts to hinder the potential for increased children's HIV care access and adherence. A lack of trust between service providers and users undermines the development of a good working relationship, which is also seen in allegations of corruption levelled by adult carers. Although no evidence for corruption was seen or found, what is more important are the allegations themselves, which result from a lack of trust and open dialogue about health service funding limitations. These damage the clinical relationship through the optics of impropriety, as opposed to actual theft or corruption. For those who do access clinic services, treatment provision in terms of HIV testing protocols lack privacy and carry the risk of HIV stigma, as does simply attending the clinic in the first place, due to its associations with HIV care in a highly stigmatized social environment. Although HCWs were seen by adult carers as being generally positive and trying to provide decent quality care, services are not inclusive or welcoming, and are not family- or child-friendly. Underserved groups such as adolescents or men are also excluded by programming which focuses mainly on women and very young children.

Ultimately, this strained health service relational context, combines with the material context of a chronically under-supported health system, to reinforce the negative SRs that the clinic is an unsafe place of HIV stigma, where there is little social trust but much social fear, and where little can be done for HIV-positive adults let alone children. The result of these factors combining is an unsafe social space, which unwittingly acts to exclude more positive SRs of children and HIV from emerging, in

what is essentially the only real social space in this community where they could potentially emerge. Underlying this is a chaotic social history which makes it hard to build or rebuild relationships, resulting from years of fractured social cohesion, low social capital, and a lack of social trust in a social environment constantly bombarded by violence, anarchy, destitution, and death. In order to begin to improve HIV care access and adherence for children, these long-standing social deficits must be addressed, before the anxiety and fear over HIV stigma can be lessened enough to facilitate a broader social dialogue over children and HIV, which could result in more positive and inclusive SRs being developed by stakeholders.

9.4.2: The need for social cohesion, social capital, and social trust
Given these underlying tensions within this community, it is difficult to see any further progress or improvement of the HIV care situation for children at this time, without the development of improved social cohesion, social capital, and social trust to counter the widespread HIV stigma and negative SRs which limit children's treatment possibilities.

The impact of a lack of social cohesion on children regarding HIV care access and adherence is that of the more socially prominent local adult stakeholders, the HCWs and adult carers, being unable to connect in a way that will challenge or change the current social status quo which is stigmatizing and excluding to children, particularly in terms of HIV services based out of the local clinic. As seen in the data findings, adult carers appear to prioritize the maintenance of a positive social identity and social status by rejecting connections with HIV services, at the expense of the children in their care. HCWs cause further barriers by inadvertently engaging in care practices which exacerbate these fears of stigma, but do not feel capable of taking on an increased practice role which would provide HIV outreach services and attempt to connect with carers and children outside of the stigmatized space of the local clinic. Adding to this lack of cohesion are SRs of HIV-positive children which further sow discord and difficulty, as they are seen as socially dividing and threatening to the positive social identities of the adult carers and HCWs in power.

To circumvent this, and to start to build social cohesion leading to an improved social situation for children regarding HIV, the adult stakeholder groups here would

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first need to develop ways of connecting and communicating outside of the stigmatized social space of the clinic, in order to facilitate a more open communication flow, and to generate more inclusive and less stigmatizing SRs and messaging about children and HIV. In addition, the creation or changing of social identities to positive ones which are inclusive, and can make space for HIV-positive children to exist with less or little threat to adults in society, would help in this regard. The creation of a changed social context at the clinic, where potential service users are welcomed in a non-stigmatizing, private and safe practice environment which is supportive of children with HIV and underserved groups, could also help to improve children's HIV care access and adherence.

In terms of a lack of social capital impacting negatively on children and HIV, as discussed in Chapter 4, Putnam (2000, p. 23) makes a distinction between social conditions where people are "getting by," or merely surviving in a society where there is little reciprocity and social support, and "getting ahead," where people have positive social connections and networks, and are able to advance themselves and others through increased opportunities and mutual aid. In this community at present, "getting by" is the only option, and a tenuous one at that. According to stakeholders, there is a lack of social networks and support organizations which can not only assist them in times of crisis, but also celebrate with them in times of happiness. This is further exacerbated by a complex social history of conflict and anarchy during the 1960s-1980s, where more formal sources of support were either strained or broken due to the impact of politics and the struggle for power and control of Uganda (Mutibwa, 1992; Kyemba, 1977). As a result, adult carers here feel unable to unite with others and speak out against more powerful forces in society, including the HCWs in the health system, despite HCWs also being caught in difficult situations not of their own making and beyond their control.

In order to build social capital, however, this presents an opportunity for adult carers and HCWs to connect and talk about the difficulties faced by both regarding health services and children's HIV care provision. Both stakeholder groups recognize the need for improved and increased community services, with better connections between people as a way of facilitating this. Again, outreach services hold the potential to start this process, but the need for funding and supporting resources

remains. Children and schools also have the potential to be engaged as sources of social capital, as the shared experience of having children in school can bring together families for whom the school becomes a key social space. As works made by the participating children capture the need for an improved HIV educational curriculum, the facilitation of broader connections between local health services, the local primary schools, and children's carers, could be a starting point for the building of social capital directly related to children and HIV. Bringing HIV outside of the local clinic and into other community spaces could not only help to lessen HIV stigma there, but could also help to create a more open SR of HIV generally, by providing further alternate social spaces for its discussion.

Turning to the perceived lack of social trust in the community, children felt this most deeply, as they referred to a fearful, unsafe world full of HIV risk, where few people are helpful or seem to care about others, particularly children suffering with HIV. The SRs discussed by them portray a lived experience where there is no wider social solidarity or trust in humanity, with feelings that nothing positive will ever happen, and fatalism over a future filled with potential HIV infection and resulting suffering. Given that the children who participated were 12 years old, the potential loss of hope in the future and fatalism towards HIV infection is troubling, as it may carry with it a risk for engaging in health-damaging behaviours, such as risky sex, and a rejection of the use of health services in the future. Although all stakeholder groups did acknowledge a lack of trust within society, the complete disavowal of trust in society by children is perhaps the most troubling of all the groups in terms of long-term life impacts.

To change this, building social trust could involve efforts to improve social relationships both at home in the family and in wider society, and could develop as an offshoot of improved social cohesion and social capital. Schools could be a potential place to work on social trust amongst children, however, as recent research in Zimbabwe suggests, this may not be an immediately feasible option (Campbell, et al., 2014). Building social trust is complicated and difficult, with many countries internationally facing this challenge, particularly after experiencing protracted social conflict such as civil wars, natural disasters, disease outbreaks, or complex emergencies combining several of these components (Keen, 2008). To

date, there has been no one ideal way to address the building or rebuilding of social trust after such crises. However, attempts must be made, and suggest a need to delve deeper into Uganda's social past, to uncover, discuss and acknowledge the previous conflict, before social healing can begin and relationships can be renegotiated. This, however, may be the most difficult challenge of all for the stakeholders in this community.

9.5: Possible future scenarios based on these findings

To summarize the findings explored in this chapter, influenced by Bauer & Gaskell's (1999, 2008) Toblerone model of SRT, two possible future scenarios for children's HIV care access and adherence in this community, and in Uganda as a whole, can be extrapolated from the SRs, social identities, and social contexts seen by study participants.

9.5.1: Positive scenario

In the more positive scenario, the community is able to come together and work on increasing and supporting social cohesion, social capital, and social trust amongst its stakeholder groups. This leads to both increased and improved health and HIV service provision by HCWs, as well as additional supportive social services being advocated, sourced, and funded for children living with HIV and their families, by HCWs, adult carers and children. This also helps to develop more positive SRs about HIV generally, as well as specifically for children living with HIV, including movement towards seeing HIV as a non-stigmatized, chronic, treatable illness. Over time, this could lead the community to gradually become more open and tolerant of HIV overall, and possibly even using it to draw light onto underlying long-standing social issues which both fuel and are fueled by HIV infection, such as poverty and gender discrimination.

The implications of this could be that the community starts to heal itself from decades of social anarchy and suffering, and that wider social conditions become more supportive and help individuals and families to not just survive, but to thrive. As Kabarole district and wider Ugandan society takes notice of this, news of the positive works and benefits resulting in this community spread, and other communities facing similar issues also begin to make these social changes. Over

time, this could lead to a nation beginning to heal itself from a tragic past, to which it is no longer bound.

9.5.2: Negative scenario

In the more negative scenario possible, nothing is done and the social status quo in terms of HIV stigma and low use of children's HIV services remains, or begins to get worse with further regressive national legislation surrounding HIV care provision. Unfortunately, during the final writing of this thesis in May 2014, this has just occurred, with the Ugandan parliament approving an "HIV Prevention and Control Act," where HIV transmission has now been criminalized, including fines or jail terms of up to 10 years for wilfully passing on HIV, and where HCWs are now able to disclose a client's HIV status without or even against their consent (IRIN, 2014b; Human Rights Watch, 2014; BBC, 2014b). Unfortunately, human rights and health services advocates predict that this bill will have a negative impact on HIV in Uganda, by increasing HIV stigma even further, and decreasing HIV service usage, as fear and paranoia could become even more associated with HIV (ibid). For the participants of this study, particularly the adult carers who do not bring their children in for health services, the likelihood of continued poor or worsening service access for children with HIV appears likely. HIV-positive children will remain invisible and with unmet health care needs in the near future, and society will continue to be an unsafe, fearful place for children and adults alike.

9.5.3: Most likely scenario

Unfortunately, the implications of the passing of these highly regressive and stigmatizing laws in Uganda (IRIN, 2014a, 2014b; Human Rights Watch, 2014; BBC, 2014a, 2014b) are disheartening, and will most likely result in the negative scenario becoming the future lived reality for children and adults in this community. This could lead to continued or worsening suffering for children with HIV, with HIV care access rates remaining low, or more likely, decreasing even further, and with children's ART medication going to waste. Worryingly, there could also be broader negative impacts for HIV care for adults, as society remains or becomes even more stigmatizing to HIV-positive people, and where any hope of social cohesion and social trust is shredded, as communities become entrenched in fear, anxiety, shame, and guilt over HIV infection. Social capital will likely not have a chance to

develop, and the gap between stakeholder groups will continue to be wide and difficult, if not now impossible to bridge. HCWs could now be seen as tacit enforcers of this legislation, to be feared and avoided at all costs, with already poor trust relationships with community members damaged even further. Entrenched HIV stigma against women will likely worsen due to this legislation, as male privilege may allow them to exempt themselves from HIV testing regardless of the letter of the law (Human Rights Watch, 2014).

The long-term implications for children's HIV care access and adherence appear bleak, with children's ART programming in Uganda likely to fail as a result. Given that international donor funding to Uganda has recently been cut and withdrawn by some countries, due to the regressive "anti-homosexuality bill" previously passed in 2014, the risk of future cuts to HIV funding and programming in Uganda are increasing in light of this recent, even more draconian legislation (AVERT, 2014a; BBC 2014a). This could result in the worsening of health service provision, possibly with reduced ART service provision as a result of decreased funding. The implications of such service cuts are disturbing, as Uganda could even revert back to the "bad old days" of HIV before ART availability, and see deaths from HIV increase yet again.

Conclusion

It is important to recognize that whilst ART is not a magic bullet in itself as hoped for at the start of the ART era (Castro & Farmer, 2005), neither is health services programming, for as is seen here, even if you build it, people may still not come. Health services never exist in a vacuum but are heavily influenced by underlying social factors which mediate their uptake and use by the public. The use of the SRT Toblerone model (Bauer & Gaskell, 1999, 2008) captures how, despite the biomedical ideal of ART advancing society towards a better lived experience for HIV-positive adults and children, in fact this is not the case at all, as long-standing historical and current SRs and lived experiences frame and limit the current and possible future use of ART. In this regard, social context is constraining the potential of ART to change lives, by combining with social identities and SRs to limit perceived options for service users, and increase the gap between what is possible and what is probable for children's HIV care access and adherence.

Underlying all of this is a lack of social cohesion, social capital, and social trust which prevent open discussion and debate which could move forward the children's HIV access agenda. Before the constraining SRs, social identities, and social context can be addressed, there is first a need to build up a greater sense of social cohesion, social capital, and trust in both the health system and in society, in order to create the social conditions and connections which will support open dialogue and communication about children and HIV. Decreasing social stigma over HIV will be a large part of this, and can emerge from the development of safe social spaces and increased social cohesion, social capital, and trust. In the longer term, facilitated Community Conversations (Campbell, et al., 2013b; Ellis, 2000) show promise as a tool to help facilitate the joint creation of SRs which would be more inclusive of children and HIV. However, the need for increasing social cohesion, social capital and trust underlie such an intervention, for without them, there is no safe social environment in which HIV stigma can be challenged in a way that will not entrench it further. In this regard, this community, as well as Uganda at large, must first heal its deep social wounds of the past, before they can move any further towards the HIV reduction and treatment goals of "Getting to Zero" (UNAIDS, 2010a) by increasing children's access and adherence to HIV care services.

Appendix 1: Ethics Permissions from the LSE

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Institute of
Social Psychology

Uganda National Council for Science and Technology.
Plot 6 Kimera Road, Ntinda.
P. O. Box 6884,
Kampala - UGANDA.
Tel: +256 414 705500
E-mail: info@uncst.go.ug

March 07, 2011

To: The Executive Secretary, UNCST
Re: Ethics Approval for Ms. Sara Belton, UNCST File #HS 720

Dear Sir or Madam,

Please be advised that Ms. Sara Katharina Josefa Belton (LSE I███████) is a full-time MPhil/PhD student at the Institute of Social Psychology, London School of Economics and Political Science. To facilitate the collection of research data for her degree, she is planning to undertake fieldwork in Uganda from May to September, 2011.

Ms. Belton has met all of our Ethics Requirements as assessed by the Institute of Social Psychology at the London School of Economics and Political Science, and has been granted approval to pursue her fieldwork in Uganda, pending your review.

For further information in this regard, please direct your enquiries to Ms. Linda Duffy, PhD Programme Administrator, Institute of Social Psychology, London School of Economics and Political Science, Tel: +44 207 955 7700, Email: l.m.duffy@lse.ac.uk.

Sincerely,

Dr. A. J. Wells
Professor & Ethics Coordinator,
Institute of Social Psychology
London School of Economics and Political Science

The London School of Economics is a
School of the University of London. It
is a charity and is incorporated in
England as a company limited by
guarantee under the Companies Acts
(Reg. No 70527).

TO WHOM IT MAY CONCERN

LSE Id Number: ▮▮▮▮▮▮

This is to certify that Sara Katharina Josefa Belton, date of birth ▮▮▮▮▮▮▮ has been registered at this School since 01 October 2010 as an MPhil/PhD research student preparing for a degree in Psychology.

Ms. Belton is registered for the 2010/1 session as a full-time student, and her expected end date is 30 September 2014.

The School has approved Ms. Belton to undertake a period of fieldwork for the Summer term of the 2010/1 academic session. This fieldwork will take place in Uganda.

23 February 2011

for Academic Registrar

Appendix 2: Study Approval from UNCST

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS 720   30/05/2011

Ms. Sara Josefa Belton
Makerere University School of Public Health
P.O Box 7072
Kampala

Dear Ms. Belton,

RE: APPROVAL OF PROTOCOL AMENDMENT AND CONTINUATION, "AN EXAMINATION OF THE BARRIERS T OPEDIATRIC HIV/AIDS TESTING AND HAART TREATMENT IN KABAROLE DISTRICT, UGANDA, VERSION 16 MARCH 2011".

This is to inform you that on April 08, 2011, Uganda National Council for Science and Technology (UNCST) reviewed and approved the amendments made to the above study to facilitate more in-depth investigation of earlier research findings. The UNCST has taken note of change in institutional affiliation and other administrative modalities with regard to your research project.

The UNCST has granted your request for approval to continue with the study. The approval will expire on April 08, 2012. If however, it is necessary to continue with the study beyond the expiry date, a request for continuation should be made to the Executive Secretary, UNCST.

Yours sincerely,

For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE   *COMMUNICATION*

Plot 6 Kimera Road, Ntinda   TEL.: (256) 414 705500
P. O. Box 6884   FAX: (256) 414-234579

Appendix 3: Research Permit from UNCST

Appendix 4: Study Permission from Kabarole District Local Government

THE REPUBLIC OF UGANDA

KABAROLE DISTRICT LOCAL GOVERNMENT

Telegram...............
Tel: 0483-422866.

E-mail

Your Ref:..............
Our Ref EDUC/161/1

Office of the District Education Officer
Kabarole
P. O. Box 38,
FORT- PORTAL

Date: 6th June, 2011

The Head teacher,
▮▮▮▮▮ Primary School.

Re: **PERMISSION**

This is to permit the bearer, Sara Belton, a PhD student/researcher who wishes to carryout he research activity in your school.

Please accord her the necessary support to carry out her research using pupils of your school as her respondents.

Thank you for your co-operation

DISTRICT EDUCATION OFFICER
KABAROLE

DISTRICT EDUCATION OFFICER, KABAROLE.

Appendix 5: Topic Guide Questions

Questions to be asked in Interviews and Focus Groups will focus on, but not be limited to, the following areas as appropriate, as per the empirical and theoretical reviews and in-field findings.

General health, HIV and ART:
- What helps people to access health care?
- What keeps people from accessing health care?
- Tell us about how you access health care. What is involved?
- Describe the HIV services available to you locally. Is ART available to you here?
- From where do people hear about HIV? About ART?
- How do men and women use health services? What about adults and children?

Children
- Do people talk about HIV and children? What do they say?
- Are there services that would help children with HIV available locally?
- Tell us what the life of a child with HIV would be like here.
- Do people talk about HIV to children? Do children learn about HIV? Where?
- What would happen if a neighbor's child was found to be HIV positive?

PMTCT
- Are PMTCT services available locally? How would they be accessed?
- Is it easy or difficult for women to access PMTCT here? Why?
- What do women say about PMTCT? What do men say about PMTCT?
- How would your spouse react if you talked or asked about PMTCT?

Caregivers
- Describe a day in the life of a person who cares for someone living with HIV.
- What are the local challenges to caring for people with HIV?
- How are people who are caregivers seen by the community? Are services available to them?

Health Care Workers
- What made you decide to work in health care?
- Do you feel supported in your job? Are there difficulties you face with your job?
- Describe how a client would get an HIV test here. How is ART accessed here?
- Describe how children access health care. What about HIV services?
- Are there policies that help you in your practice? What would help to make your job easier?

Appendix 6: Information Letter & Consent Form (Adults)

Study Information Letter

<u>Title of Research Study:</u> Facilitating access to HIV testing and treatment in children in Kabarole District, Uganda.

Principal Investigator: Sara Belton, London School of Economics (LSE), United Kingdom, s.k.belton@lse.ac.uk.

Supervisor: Dr. Catherine Campbell, London School of Economics (LSE), United Kingdom, c.campbell@lse.ac.uk.

Hello,

My name is Sara Belton and I am a MPhil/PhD student in psychology at the LSE in the United Kingdom. I have come to Fort Portal to learn more about HIV/AIDS testing and antiretroviral treatment in children. I would like to find out what people think and believe about children being tested for HIV, receiving drugs for treatment, and what difficulties may occur in getting tested and treated for HIV. I will be working with adults and children in this study.

<u>Procedures</u>: You are being asked to participate in a research study that asks people questions about HIV/AIDS and highly active antiretroviral (HAART or ART) drugs and their use in children.

Participating in this study will involve either:
  a) Answering questions in a personal interview that will be tape recorded and transcribed. A research assistant and I will meet with you to complete the interview, which will take anywhere from 30 to 90 minutes. All information will be kept confidential and your name will not appear in the transcript in any way; or
  b) Joining a group discussion lead by me and my research assistant who will ask the group similar questions to the interview. There will be other people who have been asked to participate there, and the discussion will last for 60 to 90 minutes. The discussion will be held in a private location and tape recorded, but you will not be identified on tape. All participants will be asked to keep what is said in the discussion confidential.

<u>Possible Benefits</u>: By participating, you may improve your understanding of the problems preventing children from receiving health care and treatment for HIV/AIDS.

<u>Possible Risks:</u> Talking about HIV testing and drug treatment in children may make some people uncomfortable. At any time, you may choose not to answer questions. You may also choose not to continue with the interview or group discussion. In group discussions, I cannot guarantee that other participants will keep what is said confidential, but they will be asked to sign an agreement to do so. In the event of

severe emotional distress, we can help refer you to your local health authorities for further assistance.

Confidentiality: To make sure your answers are kept confidential, we will:
1. Use a pseudonym or number code instead of your name, which only my research team, my supervisor, and I will be able to access. Your name will not be disclosed by us at any time, to anyone.
2. All participants will sign an agreement to keep all information confidential, including other study participants, my research team, my supervisor and I.
3. You are free to not answer any questions that make you feel uncomfortable. You can also withdraw from the study at any time with no penalty to you.
4. Any reports published as a result of this study will not identify you by name.
5. The information you provide will be retained by the researcher, on a password-protected computer, or in another secure storage format as required by the medium, and access will be restricted to the researcher.

The information collected by this study may be used in the future to answer related questions. If so, there may be an ethics board review as required, to ensure the information is used ethically and appropriately. If you have any questions or concerns, please contact me, Sara Belton, at s.k.belton@lse.ac.uk or at (Uganda mobile number). Or you may contact T.R., Project Contact in Kabarole district, at (Uganda mobile number).

Consent Form

Title of Project: Facilitating access to HIV testing and treatment for children in Kabarole District, Uganda.
Principal Investigator: Sara Belton, s.k.belton@lse.ac.uk   Phone Number: (Ugandan mobile number)
Supervisor: Catherine Campbell, c.campbell@lse.ac.uk   Phone Number: (UK mobile number)
_____

To be completed by the research participant:

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time,	☐	☐
without having to give a reason and without affecting your access to medical care?		
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study:	YES	☐	NO	☐
I agree that I am aged 18 years or older:	YES	☐	NO	☐
I agree that I am the primary caregiver of a child under age 15:	YES	☐	NO	☐
I agree that I am a currently employed nurse or midwife:	YES	☐	NO	☐
I agree that I am a current resident of Kabarole District:	YES	☐	NO	☐

Signature of Research Participant: _____
Printed Name of Participant: _____
Date: _____

Signature of Witness: _____
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: _____ Date: _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Concerns or questions about participant rights regarding this study can be forwarded to the PI's Supervisor at the London School of Economics, UK, at (UK mobile number); or in Uganda, can be directed to the PI as above or T.R. in Fort Portal, Uganda, at (Ugandan mobile number).

Study Information Letter

<u>Title of Research Study:</u> Facilitating access to HIV testing and treatment in children in Kabarole District, Uganda.

Principal Investigator: Sara Belton, London School of Economics (LSE), United Kingdom, s.k.belton@lse.ac.uk.

Supervisor: Dr. Catherine Campbell, London School of Economics (LSE), United Kingdom, c.campbell@lse.ac.uk.

Hello,

My name is Sara Belton and I am a MPhil/PhD student in psychology at the LSE in the United Kingdom. I have come to Fort Portal to learn more about HIV/AIDS testing and antiretroviral treatment in children. I would like to find out what people think and believe about children being tested for HIV, receiving drugs for treatment, and what difficulties may occur in getting tested and treated for HIV. I will be working with adults and children in this study.

<u>Procedures</u>: You are being asked to participate in a research study that asks people questions about HIV/AIDS and highly active antiretroviral (HAART or ART) drugs and their use in children.

Participating in this study will involve two parts:
  a) Drawing a picture with the provided materials to answer the request "Draw a picture and write a short accompanying story about a child who has affected by HIV/AIDS in any way". This activity should take about 20-30 minutes, and the picture will be kept by the researcher for analysis and study purposes. All information will be kept confidential and your name will not appear on it any way; and
  b) Writing a brief text with the provided materials to explain what has been drawn, which should take no longer than 20-30 minutes to complete. This material will also be kept by the researcher for analysis and study purposes. All information will be kept confidential and your name will not appear on it in any way.

<u>Possible Benefits</u>: By participating, you can explore what you think about children living with HIV/AIDS in Uganda. You may improve your understanding of what you believe about HIV/AIDS. You will have the opportunity to demonstrate what you know about HIV/AIDS in picture and story format.

<u>Possible Risks</u>: Talking about HIV/AIDS and children may make some people uncomfortable. At any time, you may choose not to continue with the activities. In the event of severe emotional distress, we can help refer you to your local health authorities for further assistance.

Confidentiality: To make sure the work produced is kept confidential, we will:
1. Use a pseudonym or number code instead of your name, which only my research team, my supervisor, and I will be able to access. No names will be disclosed by us at any time, to anyone.
2. All participants will sign an agreement to keep all information confidential, including other study participants, my research team, and me.
3. You are free to stop participating at any time if you feel uncomfortable. You can also withdraw from the study at any time without penalty.
4. Any reports published as a result of this study will not identify you by name.
5. The information you provide will be retained by the researcher, on a password-protected computer, or in another secure storage format as required by the medium, and access will be restricted to the researcher.

The information collected by this study may be used in the future to answer related questions. If so, there may be an ethics board review as required, to ensure the information is used ethically and appropriately. If you have any questions or concerns, please contact me, Sara Belton, at s.k.belton@lse.ac.uk or at (Uganda mobile number). Or you may contact T.R., Project Contact in Kabarole district, at (Uganda mobile number).

Consent Form

Title of Project: Facilitating access to HIV testing and treatment for children in Kabarole District, Uganda.

Principal Investigator: Sara Belton, s.k.belton@lse.ac.uk   Phone Number: (Ugandan mobile number)

Supervisor: Catherine Campbell, c.campbell@lse.ac.uk   Phone Number: (UK mobile number)

_____

To be completed by the research participant (child):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your access to medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your information?	☐	☐

Who explained this study to you? _____

Caregiver or Guardian:

I agree to have this child take part in this study:	YES	☐	NO	☐
I agree that I am aged 18 years or older:	YES	☐	NO	☐
I agree that I am a current resident of Kabarole District:	YES	☐	NO	☐

Signature of Caregiver/Guardian: _____

Printed Name of Caregiver/Guardian: _____

Date: _____

Participating Child:

I agree to take part in this study:	YES	☐	NO	☐
I agree that I am currently 12 years old:	YES	☐	NO	☐
I agree that I am a current resident of Kabarole District:	YES	☐	NO	☐

Signature of Research Participant (Child): _____

Printed Name of Child Participant: _____

Date: _____

Signature of Witness: _____

I believe that the people signing this form understand what is involved in the study and voluntarily agree to participate.

Signature of Investigator or Designee: _____ Date: _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Concerns or questions about participant rights regarding this study can be forwarded to the PI's Supervisor at the London School of Economics, UK, at (UK mobile number); or in Uganda, can be directed to the PI as above or T.R. in Fort Portal, Uganda, at (Ugandan mobile number).

Appendix 8: Coding Frames Health Care Workers (Chapter 5)

Table 5.1: Global theme: Supply side opportunities & constraints

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
1A Tensions in health care system confuse children's carers and are working against one another (discussed in 5.1.1)	1A1 Traditional medicine vs modern medicine	-traditional herbal medicine -modern medicine -Western/clinic medicine	-patients choose which medical system to use -legitimate beliefs vs fraudulent practices	-competing providers makes service provision/choice difficult -choice based on access/cost not quality
	1A2 Tensions between local, government and NGO priorities & provisions	-lack of government leadership -lack of government accountability -unmet need for interventions -NGO assistance vital	-lack of government leadership & accountability leads to negative impact on health system	-poor support impacts negatively on care options provided -parents may be dissuaded from using clinic for children
1B Health care system resources limit what can be done for patients & children (5.1.2)	1B1 Challenges of service delivery & staffing	-short staffing -pedriatric services lacking -over-reliance on volunteers	-permanently understaffed -unlicensed workers may impact poorly on patient safety	-poor staffing levels prevent better HIV care
	1B2 Lack of financial & materiel resources	-funding shortfall -lack of essential supplies	-funding & priorities inappropriate or unsustainable	-resigned to the reality of poor funding & its negative impact on care
	1B3 Lack of institutional outreach-services reactive, not proactive	-sensitizing adults to children's needs -need improved outreach services	-sensitizing adult public to use health care services -opportunities for outreach -solutions to long-term	-adults not aware of children's health needs -no support to provide outreach services

				problems
1C Shortcomings of wider HIV educational responses (5.1.3)	1C1 Current media campaigns exclude children either as topics or audiences	-media HIV coverage excludes children -HIV seen as adult disease	-reorient media to include children and pediatric HIV	-need for public engagement & dialogue over children & HIV
	1C2 Not enough counseling services for families	-opportunities to do counseling -need for child-focused interventions	-counseling skills help families	-need for improved HIV counselling skills for children & families
1D Miracle of ART availability vs previous work without ART (5.1.4)	1D1 ART has greatly improved clinical practice outcomes	-death less frequent -confidence -drugs make patient physical appearance better -pre-ART clinical practice -ART saves lives	-people used to die & it was horrible -ART a positive force which helps their work -increased confidence in providing care	-ART has improved practice & confidence -ART helping those who access it

Table 5.2: Global theme: Demand side opportunities & constraints

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A Stigmatization of HIV/AIDS makes it difficult for children to access treatment (in 5.2.1)	2A1 Parents can't cope with the potential stigma & blame for their child's HIV	-blame parents -caregivers "give up" on children -HIV-positive children "hidden" away	-parental fear of blame leads to clinical absence of children from HIV treatment	-parents don't bring children in due to fear
	2A2 AIDS denial may be presenting as "ignorance" in the face of	-denial of children's HIV as coping -misbeliefs about	-denial as coping strategy against potential	-"ignorance" of children's HIV is the safer social option

	social stigma	children & HIV	social stigma & blame	
2B Genuine ignorance of HIV risk for children possible (5.2.2)	2B1 "Ignorance" of HIV & children may be genuine in the community	-HIV education adult-focused	-general lack of education about children & HIV	-need for dialogue about HIV & children
2C Representations of children negatively influence access to HIV services (5.2.3)	2C1 Community status of children: Competing roles & values may limit health care access	-sociocultural role of children -adult ambivalence towards caring for children -children dependent on adults for health care	-community roles & norms for children: children lack agency -children dependent on adults for health care access	-traditional social roles for children limit HIV service access
	2C2 Moral status of children: Seen as "good" and "innocent" related to HIV	-children are "good" -children are "innocent" -denial of child sexuality	-being "good" and "innocent" socially incompatible with being HIV-positive	-parents not children seen as to blame for HIV status
	2C3 Legal status of children: Should help facilitate health access but does not	-children's rights -traditional social status of children	-clash between "traditional" status of child & modern rights frameworks	-legal status of children precarious, rights not supported
	2C4 Socioeconomic status of children: Opportunity costs often too high to commit to a child's HIV treatment	-SES impact on families -costs of child rearing -costs of HIV treatment	-SES stressors can trigger child abuse and/or neglect -financial difficulties in treating children for HIV	-poor SES appears to prevent children's HIV service access

Table 5.3: Global theme: Implications of demand & supply constraints for professional identities

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Positive motivations for becoming a health worker (5.3.1)	3A1 Being a health worker has personal, financial & social benefits	-health care work a "calling" -well-paid job -reliable job	-rationale for job choice	-HCWs motivated to do their work
3B Positive Impact of ART on professional image and personal coping (5.3.2)	3B1 ART has improved personal outlook on the profession & practice	-ART gives us hope -ART helps us cope with the job	-ART has had a positive impact on us personally	-ART improved work conditions and morale of HCWs
3C Professional identity reframed as "heroic worker" (5.3.3)	3C1 Reframed a prior threatened professional identity to a positive identity	-heroism -self-esteem -respect -patient recognition	-"heroic worker" identity a result of ARTs in clinical practice	-positive identity can improve care provision
3D Remaining fears & anxieties about HIV practice (5.3.4)	3D1 Psychological anxieties related to dealing with clients	-problems with treating clients -clients "don't care" -counseling skills lacking for difficult situations	-clients difficult to deal with at times -client resistance to behavior change suggestions -lack of skills in counseling difficult clients	-acknowledge need for professional development in counselling & client skills
	3D2 Fears related to medical & social complexity of sick children	-children difficult to treat -children complex due to social issues	-fear of working with sick children -problems dealing with caregivers	-need for more training for complex clients especially families & children
	3D3 Workplace stress resulting from system problems	-external stress -coping with stress -stress affects services	-working conditions create stress -ways of coping with stress	-burnout remains a risk for HCWs

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Appendix 9: Coding Frames Adult Carers (Chapter 6)

Table 6.1: Global Theme: Perceived supply side constraints prevent demand opportunities to increase children's access

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
1A Public system access difficult for families due to high incidental costs but private & traditional systems not good either (see 6.1.1)	1A1 Private clinics easier to access/use but cost more than government clinic	-private clinics better supplied -private clinics easier to access but cost -pay on credit	-private clinic usage significant despite extra costs	-people paying to get faster, more "reliable" care services
	1A2 Need money to access care regardless of provider	-government clinic free -health care costs -transport costs	-incidental costs high to use government clinic	-government service still "costs" to use, in terms of time & effort
	1A3 Traditional medicine cheap & easy to access but not as effective	-traditional vs modern (Western) medicine -traditional medicine cheaper -traditional medicine not reliable	-traditional medicine seen as lower quality option but cheaper & easier to use	-people want best quality for least "cost" -convenience wins out over quality (if have to choose)
1B Drug supply irregular at clinic & has negative impact on care (6.1.2)	1B1 No/not enough drugs at government clinic	-no/few drugs at clinic -HCWs not giving out drugs/supplies	-poor logistics: drug provision & monitoring -public expectations vs provider capacity	-irregular drug supply in some areas taken to be the case in all areas
1C Mistrust of services due to perceived profiteering of HCWs (6.1.3)	1C1 Allegations of HCW profiteering	-some HCWs have side businesses -HCWs not good workers -HCWs unmotivated -no system accountability	-allegations may be real or just gossip -wages of HCWs not enough relative to personal & family needs	-mistrust damages provider-user rapport -public may not use clinic as a result of allegations

Table 6.2: Global Theme: HIV the main threat to a positive social identity, which results in health choices which negatively impact on children and families

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A High levels of HIV stigma remain in community (6.2.1)	2A1 High levels of HIV fear & stigma are widespread in society	-HIV stigma -fear of HIV -reluctance to test for HIV -"hiding" HIV	-not testing for HIV at local clinic for fear of being "outed" with HIV	-stigma & fear preventing HIV service uptake for adults & children
	2A2 Women bear the worst impacts of HIV stigma	-unintended impact of PMTCT -sociocultural norms "blame" women for HIV	-serious social consequences for being a HIV-positive woman	-won't bring kids in if will be "outed": too much risk
	2A3 Fear of HIV spreading in community by behavior of some HIV-positive people on ART	-HIV risk in community -fear of HIV spreading -Behaviour of HIV-positive people	-Fear over risk of ART drugs increasing HIV -Social/health "benefits" of ART drugs put others at risk	-Potential backlash against HIV-positive people & ART -continued stigma limits service use
2B Social role confusion due to ART use in community contributes to fear (6.2.2)	2B1 Can't physically tell anymore who is HIV-positive due to ART	-HIV-positive appearance improving -HIV treatment helping -HIV treatment hurting -HIV changing	-HIV treatment obscuring who has HIV -perceived "taking advantage" of ART effects	-fear at risk of HIV spread from people on ART -backlash against ART
2C Jealousy & "treatment envy" from increased HIV resources & attention on disease (6.2.3)	2C1 More resources for HIV than for other illnesses	-HIV programming -HIV resources	-Funding focus on HIV as opposed to other illnesses	-resentment at lack of funding for other problems
	2C2 HIV-positive people doing better than HIV-negative ones due to more clinical support & resources	-HIV support -HIV caregivers -HIV-positive get preferred treatment at govt clinic	-"Treatment Envy" as HIV-positive seen as being an "advantage" in getting care	-potential for backlash against HIV programming

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Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Denial of children's HIV risks links to a lack of dialogue on youth sexuality (6.3.1)	3A1 Adults "deny" children with HIV exist 3A2 Adult denial of youth sexuality	-children can't get HIV -HIV-positive children "hidden" -youth aren't sexual -youth not sexualized by choice -transactional sex	-children with HIV exist but "not here" -youth "not supposed to be sexual" in Ugandan society: taboo subject	-reluctance to acknowledge HIV risk for children -youth sexuality linked to HIV spread -transactional sex & sexual abuse/rape a "hidden" issue
3B Education about children's HIV risk is inadequate overall (6.3.2)	3B1 HIV education for children is inadequate for their needs	-HIV education school-based -no media on children and HIV -carers rarely teach children about HIV -carers can't talk about HIV to children	-HIV school curriculum at odds with local social norms -no at-home HIV discussion -no real media content on HIV & children	-HIV education needs of children not being met -carer HIV education needs also not being met
3C Battle between traditional ideals & modern realities of raising children in the HIV era (6.3.3)	3C1 Children are "good" but at risk for behaviours which could lead to HIV infection 3C2 Adults feel their parental authority is under threat, but remain in control	-children are "good" -some children do bad things -HIV risk for children -children's rights impact on family dynamics -children still dependent on adults -adults make big decisions for family	-most children are well-behaved -some children misbehave & partake in risky behaviours -adults guardians in charge of children's health care -society not set up to handle "emancipated minors" in health care	-children are seen as good if they obey their parents -some are involved in HIV risk behaviours -carers worry about "controlling" their children in the HIV era -adults hold economic power which you need to access care

Appendix 10: Coding Frames Children (Chapter 7)

Table 7.1: Health services are not effective in the fight against HIV

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
1A HIV/AIDS has negative impacts across society (see 7.1.1)	1A1 HIV is an illness with negative impacts across society	-HIV as illness -Negative impact of HIV on activities of daily life	-HIV seen as the negative reality of life in Uganda	-children live in the HIV era as their reality -suggests current need for A & A should also increase
1B Health system not effective in the fight against HIV/AIDS (7.1.2)	1B1 HIV services, including ART drugs, are difficult for people to access and use	-healthcare costs -opportunity costs -no/few drugs at health clinic	-people can't "afford" to access health system	-opportunity costs will need to be reduced to increase A & A
	1B2 Health system options do not help those with HIV	-traditional medicine bad -clinic medicine not working	-neither system works for people with HIV	-health services need to be improved to increase A & A
1C People manage HIV "at home" not at health clinics (7.1.3)	1C1 People cope with the effects of HIV by themselves "at home"	-HIV illness experienced "at home" -absence of medical/clinical imagery/stories -main settings for pictures the home setting	-children observe health care decisions of adults -adults don't use the health clinic	-people don't use the clinic for HIV needs, so A & A not increased -HIV-positive are cared for "at home," not in society or the clinic: unmet & unknown need

Table 7.2: HIV/AIDS continues to have terrible impacts on our society

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
2A HIV maims & kills people (7.2.1)	2A1 HIV/AIDS kills	-deaths from HIV -graves at	-idea of HIV=death -HIV killing	-HIV equated with death, little mention of

		home from HIV deaths	all/everyone	ART -risk A & A being seen as futile
	2A2 HIV-positive people are the walking dead	-HIV skeletons -People living with HIV -HIV physical appearance	-HIV-positive people are scary skeletons (both adults & children)	-pre-ART physical HIV signs & symptoms still in use -risk A & A being seen as futile
2B HIV & poverty inextricably linked in our society (7.2.2)	2B1 HIV exacerbates poverty and vice versa	-risk behaviours vs personal safety/wellbeing -HIV treatment -HIV resources & programming -lack of financial resources	-low SES leads to risky behaviours & HIV infection -HIV treatment & support expensive	-link between HIV risk & poverty not adequately addressed by services -A & A limited by finances & opportunity costs
2C Social contradictions about women, girls & HIV (7.2.3)	2C1 Negative impact of HIV on women & girls	-polygamy -faithfulness vs infidelity -rape or defilement risk for girls in community -females more at risk for HIV	-male norm to have multiple sexual partners -male privilege not questioned	-girls socially disadvantaged -girls have higher HIV risks than boys -girls may be less likely to access care
	2C2 Women are negatively associated with HIV infection	-sociocultural norms "blame women" for HIV -impact of PMTCT -prostitution	-women forced to bear the blame for HIV from society	-stigma may prevent girls from accessing HIV care -unintended consequences of PMTCT & HIV messages

Table 7.3: The world is an unsafe place for children due to HIV/AIDS and we are at risk

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to Access & Adherence
3A Children are not safe	3A1 Children are at risk for	-dependent children at risk for	-physical risk of HIV	-children at risk for HIV

from HIV anywhere (7.3.1)	HIV	HIV -child abuse in family -spread of HIV in family -polygamy spreads HIV -children can't get HIV -HIV-positive children "hidden"	infection -emotional risk from effects of HIV in family -dependency (care & financial support) creates HIV risk	but least likely to get care -adults not helping HIV-positive children -A & A not likely to increase on its own
	3A2 Nowhere and no one is safe from HIV	-avoiding HIV -behaviour of HIV-positive people -HIV risk in community -children are sexual/sexualized -adults aren't safe to be around	-society is not a safe place to be for children -nowhere is safe from HIV/AIDS risk	-adults & other children seen as sources of HIV -HIV too prevalent to be stopped by A & A
3B HIV has had a negative impact on children (7.3.2)	3B1 Childhood is negatively impacted by HIV	-childhood -family -impact of HIV on childhood negative -family caregiving	-HIV has disrupted our lives	-need high level of resources to cope well with HIV/AIDS -A & A not accessed without resources
	3B2 HIV causes suffering and loss for children	-children's suffering & loss from HIV -orphanhood -extended family affected by HIV	-families are destroyed by HIV/AIDS -HIV destabilizes families	-children affected by HIV suffer greatly -Families not accessing A & A well
3C The HIV education messages in schools do not resonate with children's lived reality (7.3.3)	3C1 HIV prevention messages do not resonate with children's lived reality	-HIV education -HIV prevention -some families & caregivers do talk about HIV to children -Christian religion	-HIV education doesn't reflect reality -HIV fueled by social factors not lack of knowledge	-school-based HIV education not reflecting children's lived HIV experiences -HIV education not helping A & A

Appendix 11: Coding Frames Clinical Ethnography (Chapter 8)

Table 8.1: Relational environment of the clinic is intimidating & unwelcoming to carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
1A HIV interventions carry risk of stigmatizing carers (8.1.1)	1A1 Legal requirements for HIV testing may fuel stigma for carers	-ANC HIV testing required -Ugandan law -Hiding HIV status	-Uganda requires HIV test at 1st ANC visit: women don't return	-high risk for loss to follow up of carers -may pass HIV to baby
1B A lack of privacy may reinforce stigma & intimidate carers (8.1.2)	1B1 Clinic layout does not provide private spaces for service provision	-privacy -lack of private spaces -out in the open -HIV day	-physical layout a problem in providing safe, private spaces -specific day for HIV clinic	-setting may hinder disclosure & service use
	1B2 Limited privacy in one-to-one care and counselling	-"one-to-one" -private counselling -private care	-role of privacy in HIV testing & counselling -HIV stigma	-privacy best for children's or family counselling
1C The clinic social environment is unwelcoming to children, youth & men (8.1.3)	1C1 Adult-centered services are not child- or family-friendly	-parents' committee -maternal health -not child friendly -mother-child interactions	-services geared towards adults needs as caretakers of children	-may be barrier for families to use services -clinic programming not child- or family-friendly
	1C2 Majority of programming for women & babies, none specific to underserved youth or men	-peer mothers programme -mainly women -few men -men don't use the clinic -few youth	-clinic services focus mainly on women -men & older children unintentionally excluded	-need for programming for school-age children -need to target youth & men more

Table 8.2: Procedural limitations result in long waits for carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
2A Clinic patient flow not well regulated & leads to poor service outcomes (8.2.1)	2A1 Inefficient patient management	-inefficiencies -priorities -patient flow	-poor service experience	-parents may not bring children at all
	2A2 Long waits for carers to be seen create backlogs for services	-waiting -huge numbers -"2 stage processing" -backlogs of patients	-clients wait all day to be seen -poor patient management & waiting creates a backlog	-too long for parents to wait -clients may leave without being seen by staff
2B Outreach programming suffers from a lack of staff (8.2.2)	2B1 Providing outreach services "loses" 1-2 staff members for the whole day	-outreach -"losing" staff to outreach -choose between clinic & outreach	-to provide outreach services, the clinic loses staff	-can't provide both outreach & in-clinic services at same time
2C Records system inadequate for work needs of HCWs (8.2.3)	2C1 Patient records system inadequate with inaccuracy risk which slows clinic work	-patient files -notebooks -clinic log book -paperwork -catching up	-risk losing or not accounting for patients & care provided -poor system of reporting & monitoring	- risk for service duplication or omission -parents may not wait with children -clients may not wait to use services

Table 8.3: Resource shortages discourage clinic usage by carers

Organizing Themes	Basic Themes	Codes	Related Issues	Relevance to access & adherence
3A Poor management & lack of staff impacts negatively on care given (8.3.1)	3A1 Not enough HCWs in clinic	-short staffed -town council funding	-too few staff for too many people	-low staffing leads to low quality care
	3A2 Staff members doing "double duty" at clinic	-"double duty" -working two areas at once	-staff move between areas, open/close accordingly	-staff can't fully run clinical areas for clients
	3A3 HCWs working erratic hours & not enough	-staff come late -staff leave early -staff disappear	-staff presence not reliable & constant -staff burnout & disillusionment	-negative perceptions of HCWs -clients won't bring children
3B Supplies are received "irregularly" which hampers care efforts (8.3.2)	3B1 Not enough supplies to regularly provide good care to children	-no supplies -no drugs -immunization days	-chronic supply shortage impacts on children's care	-care seen as unreliable & not good
	3B2 HCWs prioritize interventions due to supply shortages	-priorities -interventions -shortages	-not enough supplies for all client needs	-clinic not able to provide for children reliably
	3B3 Profiteering or corruption risk observed	-government corruption -profiteering -in charge officer's clinic	-perceptions of staff corruption -shortages blamed on staff alone	-clients may not use services if seen as corrupt

Appendix 12: Transcript Extract IDI

(IDI #6)

I: Now, can you explain to me the life of HIV-positive patients? What does their day look like? How do you see their lifestyle?

R: Do you know what?

I: Umm?

R: What has brought the problem, okay, I have some members in my groups, but, sometimes I am disappointed and discouraged with the assistance which they give them. Now, you find a person on ART, umm, then when the patient's health improves, or when they start looking good, they regain their normal position, now you find, like a woman getting married. You find a man or the woman's husband died of HIV/AIDS, but after getting treatment, time [passes] and she gets what? Married.

I: [Interjects] She gets married?

R: Whereby you find her delivering children. Yet she had children before, so she starts losing strength.

I: Umm…she becomes weak…

R: Then, after knowing that the second husband had died, she leaves the home. She changes position, goes to another place, and gets married again. Instead of her knowing that, I am becoming more weak when delivering, or when I continue conceiving, she can't stop conceiving for fear of being recognized that she is HIV positive. And in most cases, such people, most of the women, they normally get transfers. When they lose someone, the husband from this place, that lady will shift from this place to another place where she's not known.

I: And get a new husband?

R: Yeah. Umm.

I: Now, do you think women are the only ones who do that? Is it done by only women?

R: Even men, even men. In most cases, like these women, men, having money, those ones with money, you find a man operating a business here, you find him marrying another wife, and when you have money, people will not suspect, women will not suspect you to be having HIV/AIDS. Because most of the women, they want money, yeah. They don't even… if they tell that person that so-and-so is HIV-positive, she will have to refuse. She's after money…Eh, "I will die when I have enjoyed life." Umm.

Appendix 13: Transcript Extract FG

I: When you hear about the word Silimu- HIV/AIDS- how do you feel?

R4: I feel very bad.

I: You feel very bad?

R4: Mmmm .

I: What do you mean?

R4: Eh, these days, somebody with Silimu cannot be recognized. You cannot identify that such and such is infected with AIDS. Because somebody having HIV these days is the one who has a good skin because of the drugs they have brought-these tablets I was seeing on the shelf.

I: What do others think about that?

R5: A person with HIV/AIDS- when you try to identify him/her is too difficult, only that we have to promote prevention.

I: Anyone else?

R3: Now the word Silimu- Silimu came as a disease. When you receive good treatment, you can look after your children, you do your normal activities when you have received good treatment, and you can do all these things. But when you don't care about your life and you move recklessly and you [think] that, as long as I have been infected with Silimu I am going to die, there you will not do anything; you will just die.

I: How about you [participant 2]? When you hear people talking about Silimu, Silimu, Silimu, how do you feel, what do you think?

R2: When I hear about this disease which came, I feel bad because me as an old man, I can prevent myself [from being infected]. But my sons and daughters- will [they] prevent themselves [from being infected]? I feel worried.

I: What makes you feel worried about it? About them suffering from this disease?

R2: I feel bad, because I know that the disease came and it has no medicine and cannot be cured and it comes to kill somebody.

I: [Participant 1], what do you think?

R: To add on this, in my opinion this disease came, but in my opinion prevention should be paramount. I am seeing there in the villages people with this disease. Those who are receiving drugs are okay, but those who refuse to come here [to the clinic] end up dying.

(Draw-and-write #U38)

Picture:

Story Transcript (on reverse):

"A man and his wife died of HIV, those are their graves. They left behind four children with their grandmother. One day, they sat down with their grandmother on the mat and they discussed ways of avoiding getting AIDS. She told them, that 'AIDS killed your father, that is the grave.'" (Participant U38, male)

Appendix 15: Transcript Extract Field Notes

(Observation Session #3)

(1110)

The numbers of people are slowly increasing, and now there is the in-charge, the nurse who runs the lab, and a nurse who runs the dispensary here in attendance. The in-charge is sitting, talking with a patient in his office, and the lab lady has just finished doing a test on an older gentleman who is being helped out of the lab by a younger man- possibly a relative or son? In the main clinic area of the compound there are now about 15 pairs of adults and children, mostly mothers with their toddlers in attendance. Most of the children look less than 1-2 years old. Some look fairly healthy and robust, but others appear very small and less healthy- possibly even malnourished? About 5 pairs of adults with children are in the general clinic building waiting to be seen. The kids are a bit vocal and restless lately, fidgeting. At the moment no one is using the dispensary. Traffic on the main road- both cars and people- is picking up a bit.

(1125)

The midwife (nursing sister) has arrived and is in her office getting things set up for today.

(1135)

A large white pickup truck pulls up and a man and a woman get out and are greeted by the in-charge. According to [the RA], the woman is a clerk from Muchwa who works in records there at the District Health Office, she knows her. The ID badge of the man says he's from Baylor-Uganda. They go into the side room and talk with the HCWs.

(1140)

In-charge, the man from Baylor, and lady from Muchwa are meeting in the office and looking over some clinic record books. Looks like they've receiving an update, as they are going through records, from what I can see. The midwife is talking in the back with a client and her kids. The lab is ongoing, the lab lady is writing down something in one of her clinic record books, and the men who had come out of her office prior, are resting in the shade nearby, possibly waiting on results. To me it looks like the older man has malaria, he looks really played out, tired and "floppy"- the previous times I've seen malaria, it seems to do that to people when in the acute stage. It doesn't appear to be proceeding like the HIV tests do, he doesn't appear stressed or nervous, but really tired like he's acutely ill. Maybe that's conjecture, but the clinical picture looks that way to me. If I were working here, I'd check him for malaria.

About 10 pairs of moms and babes now waiting in and around the main building, and about 20 total adults and kids are waiting to be seen in the general clinic area, now being attended to by the nurse who usually does the dispensary, as the in-charge is still in the meeting…

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