



Peer network and social support and its influence on young people's experiences of growing up with HIV

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Author's declaration

I, Zivai Mupambireyi, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

As access to paediatric antiretroviral therapy (ART) continues to improve in sub-Saharan Africa, a relatively new and historically specific cohort of HIV-perinatally infected young people has emerged. They are now surviving into adolescence. These young people have complicated clinical needs which includes drug adherence and status disclosure. However, their ability to meet the clinical demands of HIV treatment, necessary to live long and healthy lives, are undermined by the challenges they face, not least, how they manage their HIV within their social lives outside of the clinic. Despite the emerging recognition that what happens outside the clinic significantly influences how young people conform to clinical guidance, there has, to date, been little exploration of the social lives and psychosocial needs of young people living with HIV outside of the clinical setting.

Adopting a bounded agency theoretical approach, this study sought to explore the interplay between experience of social support, including its absence, and young people's engagement with HIV treatment; with a particular focus on how young people manage their own HIV disclosure in both informal and formal peer networks. I draw on a longitudinal qualitative research study with HIV perinatally infected young people (11-13 years) participating in the AntiRetroviral Research fOr Watoto (ARROW) clinical trial in Harare, Zimbabwe. 26 young people were involved in up to three waves of in-depth interviews, 12 participated in focus groups discussions and 12 kept audio diaries. Additional interviews were held with 10 connected carers / significant others of the young people and five healthcare workers delivering clinical care to the young people in the study.

Findings challenge normative representations that young people are too young and immature to understand diagnosis and might recklessly disclose. Young people have a far more nuanced understanding of the social risks of HIV and the power that it has to alienate and change the way they are viewed and treated by their friends than the general belief. Disclosing status to friends is a thoughtful process and having considered the consequences, the majority of young people choose not to disclose. The findings demonstrate that young people are not passive beings but active agents as they are directly engaged with the decision to tell or not. However, their capacity to control disclosure is disrupted by multiple factors. The thesis also explored the role of support groups. Support groups were perceived as a safe social space for learning and acquiring HIV information. The study provided an example of how participatory research tools and audio diaries can be used to illicit data from young people in resource limited settings.

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List of Abbreviations

ACTGN	Adult Clinic Trials Group Network
AD	Audio diary
AIDS	Acquired immune deficiency syndrome
ARROW	AntiRetroviral Research fOr Watoto
ART	Antiretroviral therapy
ARV	Antiretroviral
CBO	Community Based Organizations
CBSG	Community Based Support Group
CeSHHAR	Centre for Sexual Health and HIV/AIDS Research
CPS	Child Protection Society
CRC	Clinical Research Centre
DART	Development of AntiRetroviral Therapy in Africa
EID	Early Infant Diagnosis test
FGD	Focus group discussions
HCW	Healthcare worker
HIV	Human Immunodeficiency Virus
HPTN	HIV Prevention Trial Network
IBD	Inflammatory Bowel Disease
IDI	In-depth interview
IMPAACT	International Paediatric Adolescence AIDS Clinical Trials
IRB	Institutional Review Board
JREC	Joint Parirenyatwa Hospital and College of Health Sciences Research Ethics Committee
LSHTM	London School of Hygiene and Tropical Medicine
MoHCC	Ministry of Health and Child Care

MoHCW	Ministry of Health and Child Welfare
MRCZ	Medical Research Council of Zimbabwe
NAC	National AIDS Council
NGO	Non-Governmental Organisations
PLHIV	People living with HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
PrEP	Pre-exposure prophylaxis
PSS	Psycho-social-support
SADC	Southern Africa Development Community
SSA	Sub-Saharan Africa
TB	Tuberculosis
TRSG	Trial-run support group
UCL	University College London
USA	United State of America
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	The United Nations Children’s Fund
UZCRC	University of Zimbabwe Clinical Research Centre
WHO	World Health Organization
YPLHIV	Young People Living with HIV

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CHAPTER 1: INTRODUCTION

1.1 Chapter overview

This study explored the role of peer networks and support for young people born with HIV in Zimbabwe, and investigated their influence on children's experiences of growing up with HIV. Given the importance of local context in understanding the experiences of these children, I began by providing a historical overview of the HIV epidemic in Sub-Saharan Africa, specifically Zimbabwe, highlighting the impacts of the epidemic on children. This chapter concludes by outlining the aims of this study and the organisation of the thesis.

1.2 Historical perspective of the epidemic

A significant feature of the HIV epidemic since the discovery of the Human Immunodeficiency Virus over three decades ago has been its dynamism. Worldwide, countries are at different stages and at different times with the epidemic being more advanced in some settings than others. In the late 80s and early 90s, when little was known about the disease, HIV was a terminal condition (Jackson and Service. 2002). This era was characterised by rapidly increasing numbers of sick people. In Sub-Saharan Africa, for example, mortality was high and the number of orphans and vulnerable young people living in households where economic resources were stretched was increasing (Chase and Aggleton 2001, Bauman, Foster et al. 2006, Abebe and Aase 2007). In 14 South and East African countries, HIV quickly became generalised from 1997 onwards (Ainsworth and Over 1997). However, in other regions, HIV remained concentrated within specific populations (Mumtaz, Riedner et al. 2014).

The mid 1990s onwards witnessed the transformation of HIV, when evidence of the effectiveness of antiretroviral therapy (ART) became available. Access to ART was rolled out although provision was uneven. In Sub-Saharan Africa, the region most impacted by the epidemic, ART was not widely available, while availability in high and middle income countries was scaled up (Van Damme, Kober et al. 2006). By 2002, people living in high income countries could easily access ART, while the majority of people in Africa and other low income countries had very limited access to publicly funded ART. In his closing address at the 14th International AIDS Conference in Barcelona, Spain, Nelson Mandela, advocated for the universal access to ART in low income countries (http://www.mandela.gov.za/mandela_speeches/2002/020712_aids.htm),

“We know that there are treatments available that restore the immune system, stop the opportunistic infections and return AIDS sufferers to good health for several years at least. We must find ways and means to make this treatment available to all who need

it regardless of whether they can pay for it, where they live or for any other reason why treatment may be denied". "

Although battling a persistent treatment gap between those receiving treatment and those in need of treatment, Sub-Saharan African countries have made significant strides in fulfilling Nelson Mandela's plea for universal access to ART (UNAIDS 2013). By June 2015, 10.7 million people out of the 15.8 million globally were receiving antiretroviral therapy in Sub-Saharan Africa (UNAIDS. 2015, Estill, Ford et al. 2016, Ford, Boulle et al. 2016). The universal accessibility of ART has made significant steps in transforming HIV from being a fatal disease to a manageable chronic condition in most parts of the world for the majority of those infected (Cook, Ciampa et al. 2011, Morey, Booth et al. 2014).

Due to the enormity of the scale of the epidemic and the clinical and social complexities associated with the condition, even when ART treatment became available, HIV remains a global crisis (Calligaro and Gray 2015). Crucially, although this has not received much attention until recently, the epidemic is not limited to adults but also affects young people in a myriad of ways (Ubesie 2012). Firstly, they are affected when their parents contract HIV and become sick; they start caring for their parents, increasingly taking on adult duties such as looking after younger siblings and are subject to household insecurity due to economic and social loss (Evans and Becker 2009, Evans 2010). Young people have the risks and responsibilities of being orphaned should their parents die (Gilborn 2002, Nsagha, Bissek et al. 2012, Boyes and Cluver 2013). An orphan is defined as a child who has 'lost one or both parents' (Skinner, Tshoko et al. 2006). Globally, it is estimated that around 17.8 million young people under the age of 18 years have been orphaned as a result of HIV (AVERT. 2014). Eight-five percent of these orphaned young people live in Sub-Saharan Africa (UNICEF 2013).

Secondly, despite huge advances in the prevention of mother to child transmission programmes, young people continue to be perinatally infected (Augusto 2012, Pegurri, Konings et al. 2015). The numbers are becoming considerably smaller than they might have been without antiretroviral therapy. However perinatally infected young people still make up substantial numbers. In 2013, there were an estimated 3.2 million young people under the age of 15 living with HIV and of these, 2.9 million were living in Sub-Saharan Africa (WHO UNICEF 2014).

1.3 HIV epidemic in Zimbabwe

Zimbabwe is a southern African country formerly colonised by Britain. When it gained its independence in 1980, it inherited a developed and predominantly stable economy. Between 2000-2009, Zimbabwe experienced an economic and infrastructure downturn (AEDI 2009). The economic situation was worsened by the unprecedented rise in inflation, a severe cholera

epidemic, high unemployment, political violence and recurrent drought (AEDI 2009, Mason 2009, Jones 2010, Duri, Stray-Pedersen et al. 2013). The socio-economic meltdown shattered the livelihoods of the majority of its urban and rural population, resulting in extreme poverty which led to a near-total collapse of the public health system (Meldrum 2008, Wakabi 2009, Mutasa-Apollo, Shiraishi et al. 2014).

The Government of Zimbabwe has received wide criticism from the international community for its corruption, human rights abuses, political and economic policies. All these factors have negatively impacted the HIV epidemic. However, recent reforms, particularly the adoption of the multi-currency and the cash budget systems in March 2009 have helped to restore macroeconomic stability and to support an emerging economic recovery (African Development Bank 2010). During the time of the study (2011-2013), although fairly stable, the Zimbabwean economy remained among the least competitive economies in the world, ranking 175 out of the 183 countries, with neighbouring countries such as South Africa and Botswana ranking 34 and 52 respectively (The World Bank and Corporation 2010). The failing economy affected the government's ability to fund public health delivery. There were serious drug shortages and high staff turnover among healthcare workers (DFID 2011). This significantly reduced the population's access to effective healthcare.

Zimbabwe has one of the world's most mature and sustained HIV epidemics globally (MoHCC 2013). Until 2003, Zimbabwe had the third highest adult HIV prevalence rate in the world of 33.7% after Botswana and Swaziland which reported prevalence of 38.8% and 33.8% respectively (UNAIDS 2002, Mapindu, Maposhere et al. 2004). Throughout the decade, deepening unemployment, poverty, food insecurity, the HIV and AIDS epidemic and a shortage of healthcare workers and essential drugs between 2005 and 2008 mutually exacerbated each other. However, declines in the HIV prevalence have been documented since early 2000s (Ojikutu, Makadzange et al. 2008, Halperin, Mugurungi et al. 2011) and adult HIV prevalence was estimated to be 14.0% in 2012 (Gregson, Nyamukapa et al. 2013, Eaton, Takavarasha et al. 2014, MoHCC 2014, Mutasa-Apollo, Shiraishi et al. 2014). This decline has been attributed to a combination of factors, which include a reduction in sexual partners and increased condom use (Hallett, Gregson et al. 2009, Halperin, Mugurungi et al. 2011, Eaton, Takavarasha et al. 2014). The initial decline was reported before ART was widely rolled out in 2004, however it is possible that ART has contributed to the further decline (Ojikutu, Makadzange et al. 2008).

In 2013, Zimbabwe adopted and implemented the World Health Organization's (WHO) new approach- Option B+ within its 2013 antiretroviral (ARV) consolidated guidelines (MoHCW 2013). The new approach recommended the provision of lifelong treatment to all HIV-positive

pregnant and breastfeeding women regardless of CD4 count (MoHCW 2013). This has resulted in important gains towards eliminating perinatal HIV infections with decreasing numbers of young people born with HIV (Kieffer, Mattingly et al. 2014, Dzangare, Takarinda et al. 2016). The cohort of prenatally infected young people is unlikely to grow in size if such treatment is sustained through provision of option B+, with fewer cases of perinatal infections recorded each year. Additionally, those young people born HIV infected are now being diagnosed very early and are initiated on treatment straightaway so they will not only survive but survive without sequelae than previously. Before ART was available, more than a half died by the age of 2 years (Nathoo, Rusakaniko et al. 2012).

In 2013, it was estimated that 170,717 young people in Zimbabwe were HIV infected, of whom 114,356 were in need of ART. As of November 2015 there were 121, 111 young people (0-14 years) living with HIV and in need of ART. However, these estimates on child prevalence should be treated cautiously as they are based on available data that could have underestimated prevalence due to insufficient data inputs.

1.4 Paediatric ART coverage

Global statics are beginning to show significant strides in improving paediatric ART coverage (WHO 2016). In the past (2001-2009), the lack of child friendly easy-to-use paediatric formulations and the high costs of some antiretroviral medicine has hindered efforts to deliver appropriate clinical care to HIV positive young people (Dionisio, Gass et al. 2007, Waning, Diedrichsen et al. 2010). Once developed and licensed, there were also delays in rolling out these paediatric formulations in low income settings (UNAIDS and UNICEF 2005). In Sub-Saharan Africa, further initiation delays were caused by the lack of paediatric expertise and experience to deliver the necessary clinical care (UNICEF and WHO 2004). However between 2012 and 2015, sub-Sahara African countries increased their commitment and accelerated efforts to improve ART services for young people and adolescents.

Zimbabwe is a case in point, at the inception of this study in 2011 there were 39,825 young people on ART in Zimbabwe representing 41% coverage (MoHCW 2012, UNAIDS 2016). By December 2014 there were 55,061 (55% coverage) HIV infected young people on treatment. In 2015 around 80% of young people living with HIV accessed antiretroviral therapy (MoHCC 2016, UNAIDS 2016). The table below adapted from the UNAIDS country fact sheet shows a steady increase in the percentages of paediatric coverage from 2009 to 2015 among young people aged 0-14 years living in Zimbabwe (UNAIDS 2016).

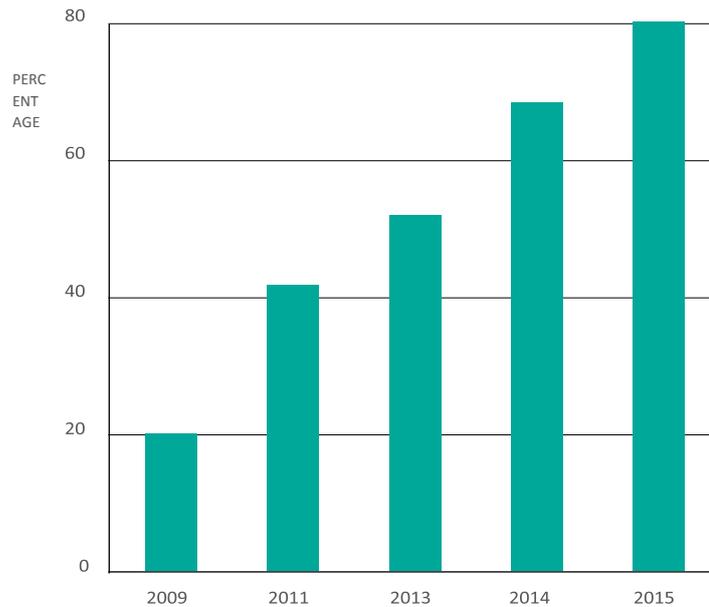


Figure 1.1: ART coverage among young people in Zimbabwe (UNAIDS Global plan fact sheet Zimbabwe 2016)

This improved access and coverage has been attributed to two initiatives. Firstly the recent decentralisation of paediatric HIV care to primary health care facilities. Secondly, the development and implementation of the Accelerated Action Plan for Pediatric and Adolescent ART (Zimbabwe 2016). The plan aims to scale up identification of HIV-exposed and infected infants, young people and adolescents, using a combination of facility and community based approaches.

Although the increase in paediatric ART coverage is impressive, there still remains a challenge with late diagnosis (EGPAF 2015, Zimbabwe 2016). In 2015 only 54% of HIV exposed infants received an early infant diagnosis tests (EID) (EGPAF 2015). Late diagnosis and ART initiation results to a minority of infected young people presenting with advanced disease, leading to high numbers of complex clinical cases amongst this cohort (Ferrand, Desai et al. 2012, Kranzer, Meghji et al. 2014). It is hoped that the trend for late paediatric diagnosis and ART initiation will be redressed over the coming years, as Zimbabwe adopted and responded to the newly issued WHO 2013 first consolidated ART prevention and treatment guidelines (UNAIDS 2015).

Although the prevalence of children not on ART has reduced there are still children not accessing treatment (estimated to be at 20%). The 2013 WHO guidelines stipulated that adolescents testing HIV positive but not symptomatic be initiated on cotrimoxazole pending the CD4 count results (WHO 2013). This is also presumed to change as Zimbabwe is moving towards treating all children below 15 years regardless of CD4 count (Doherty 2015). This

approach is believed to close the 20% gap and increase the overall number of children accessing ART.

1.5 Why focus on this cohort

The existing cohort of young people perinatally-infected with HIV can therefore increasingly be considered a discrete group of infected young people who reflect the changing epidemiological and clinical characteristics of the HIV population worldwide. Some of the changing clinical characteristics includes lower mortality rates and immune status improvement (CD4 cell count increase) and clinical recovery through reduced opportunistic infections (Kabue, Buck et al. 2012, Collins, Judd et al. 2014, Walter, Molfino et al. 2015). Having been born with HIV, their childhood is likely to have been characterised by frequent illness and hospitalization, and some may have significant cognitive and physical impairments (Bernays, Jarrett et al. 2014, Lowenthal, Bakeera-Kitaka et al. 2014). In addition, these perinatally infected children, have faced orphaning, HIV-related stigma and poor psychological health and will have to navigate through life while managing their HIV treatment (Biadgilign, Deribew et al. 2009, Calabrese, Martin et al. 2012). It is likely that they will have specific clinical and social needs that differ significantly from their HIV negative peers whose immune systems have matured and HIV positive adults who already reached adulthood prior to infection.

Regardless of the complexities of the social challenges facing them, this cohort has received little attention especially in resource limited settings. Of the 80% of young people that are successfully accessing ART in Zimbabwe as of December 2015 (MoHCC 2016, UNAIDS 2016), very little is known about their HIV and ART experiences outside the clinic setting. Attention has been primarily focused on their clinical care, resulting in significant neglect for the pressing and complex psychosocial needs of this unique historically specific cohort. Very little is known about how they are managing, and what it means to grow from birth with HIV. As they are growing into adolescence, they face an increasing array of social challenges, including coming to terms with their emerging sexuality in the context of having a life threatening, sexually transmissible infection (Lowenthal, Bakeera-Kitaka et al. 2014). They live with considerable uncertainty: for how long will they survive, what are the medical side effects of taking ART for life and what will their lives with HIV be like? (Michaud, Suris et al. 2010).

It is important to find out from these young people themselves what it is like for them to be born and to grow up with HIV taking ART for life and the challenges faced by carers, given their pivotal role in facilitating access to care. These challenges are likely to affect their clinical outcomes. Understanding these experiences is crucial in informing interventions that seek to improve and support their quality of life so that growing up with HIV involves more than just

survival. This study focuses on young people living with HIV and on ART aged 11 to 13 years, who were participating in a clinic trial in Harare.

This age group is particularly interesting to focus on because they have recently been disclosed to and have not yet become a focus of attention for sexual health interventions. We know surprisingly little about children's experiences post disclosure and how they manage with the knowledge of their HIV status.

1.6 Defining children

This thesis adopted the UNICEF(2013) definition of young people as any persons aged 18 years or under. The United Nations defines young people as men and women aged 10 to 24 years (Dick, Ferguson et al. 2006). This thesis focussed on those aged 11-13 years, and I have chosen to use the term young people to describe them throughout this thesis.

1.7 Aims and objectives

1.7.1 Study aim

The aim of the study was to explore the influence of peer support and informal social networks on young people aged 11-13 years' experiences of growing up with HIV and taking ART and to understand what facilitated and or hindered children's access to social support networks.

1.7. 2 Study objectives

The objectives of this study fell into two categories, that is those that are specific to the research question and those that focus on the methodological learning involved in doing research with children.

Primary objectives:

- To explore how young people are managing HIV disclosure in informal peer networks
- To understand the barriers that young people living with HIV face in accessing peer social support
- To examine young people's involvement in formal peer networks support, exploring factors which facilitate or hinder their participation.

Secondary objectives:

- To assess the potential benefits of using longitudinal interviews to explore HIV experiences among young people.
- To assess the feasibility of using audio diaries with young people (11-13 years) in resource stretched settings.

Contribution:

- To be able to inform policy, health professionals and all those who work with HIV infected young people about the support needs of young children.

- To contribute to academic literature on the qualitative methodological tools that can be used to access children's narratives and on the conceptualization of childhood and management of chronic illness in resource stretched settings.

1.8 Thesis structure

This thesis is organized into 9 chapters. In chapter 1, I briefly describe the paediatric HIV epidemic in Zimbabwe and outline the impact of the epidemic on children. The aim and objectives of this study are also outlined.

Chapter 2 provides a critical review of the psychosocial issues that HIV infected young people have to grapple with, with particular focus on the issues known to affect those in resource limited settings. These psychosocial issues range from those relating to being disclosed to, disclosing to others, and adherence to drugs, coping with stigma and discrimination, and managing peer relationship.

Chapter 3 presents results from a literature review I conducted to explore the use of audio diaries with young people.

Chapter 4 presents the theoretical framework that informs this study. The chapter begins by discussing Giddens's structuration theory and how agency became a core issue in childhood studies. The concept of bounded agency is described before outlining how childhood is conceptualised globally, regionally and in Zimbabwe. The chapter concludes by discussing how core theories of stigma and resilience are likely to shape our understanding of the lived experiences of growing up with HIV in young people and the place that they have in informing the analysis.

Chapter 5 outlines the methods, epistemological standpoint and research design for this thesis. The process of data collection, data organisation and analytical approaches are presented. Throughout the chapter, I pay particular attention to how researcher reflexivity, ethical and broader social considerations have shaped the conduct of this research with children. Ethical approval and broader social considerations in researching young people are also discussed.

Chapter 6 looks at the role of informal peer networks. Perceptions and understanding of friendship and the significance that they play in children's social worlds are presented. Focus is placed on how young people negotiate and manage HIV within these peer networks.

Chapter 7 explores young people's experiences and perceptions of formal peer support networks and considers the facilitators and barriers to their success, including through children's own access to them.

Chapter 8 addresses the methodological objectives of this study. I present how repeat in-depth interviews and innovative research tools can be used to provide spaces for young people to express themselves. Results from piloting the use of audio diaries are presented and discussed.

The discussion chapter, chapter 9, drew together and synthesized the findings and the theoretical framework. The chapter concluded by reflecting on the implications of the study and recommendations for future policy, intervention design and ongoing research

CHAPTER 2: YOUNG PEOPLE AND HIV

2.1 Chapter overview

This chapter serves to frame the research findings presented in chapter 5-7 by reviewing the lived experiences of young people growing up with HIV while being on antiretroviral treatment. For this literature review, searches were conducted in the electronic Scopus database, as this is the largest interdisciplinary (including clinical and social sciences) database of peer reviewed journals, appropriate to the psychosocial focus of this thesis. Multiple searches were conducted using some of the following search terms: HIV, HIV/AIDS, children, adolescent, paediatric, adherence, drugs, Antiretroviral Therapy, disclosure, stigma, social support, caregiver, carer, healthcare worker, Zimbabwe, sub-Saharan Africa, resource limited settings. Publications were eligible if they were in English and published before May 2016. References of selected papers were also reviewed and included if deemed relevant. Previously acquired documents were also included where appropriate.

This review focuses on sub-Saharan Africa as this is where the majority (>90%) of HIV infected young people live and where this research was done (Luzuriaga and Mofenson 2016). In a few exceptional cases, studies done in other settings, which were relevant to this thesis were included to provide a global comparison and to complement the literature gap in sub-Saharan Africa and this has been highlighted. This was to some extent challenging as the majority of the studies I located had been conducted in resource rich settings even though this is not where the burden of the disease is. HIV research covering both young people and young people up to the age of 24 years has been considered for review, and included as relevant to the objectives of this study.

HIV infected young people residing in resource limited settings, on lifelong ART, face multiple challenges related to their diagnosis, health and treatment as well as the social context of their lives. Children's long-term health outcomes are greatly shaped by the structural factors and social dynamics present within their different care environments. These factors not only influence their disclosure and adherence experiences but also define their sense of self, their peer relationships, how they relate to other significant people in their communities, and how they visualise their future lives. I will first discuss what is known about children's experiences of disclosure and their responses to disclosure. I will also discuss facilitators and barriers of drug adherence, stigma and peer social support as these experiences form the social landscapes that mediate and influence children's experiences of growing up with HIV.

2.2 Disclosure

HIV status disclosure is a central feature of the paediatric HIV experience and has significant implications for families and public health (Mahloko and Madiba 2012). Disclosure is taken in

this study to mean both the young people knowing about their status and young people telling other people about own their status (Vreeman, Gramelspacher et al. 2013, Kidia, Mupambireyi et al. 2014). Knowing one's HIV status is considered an important step in the HIV/AIDS response as well-being critical in terms of accessing HIV treatment, care and support services (Kidia, Mupambireyi et al. 2014). As a way of stepping up the HIV response the UNAIDS launched a fast track strategy to end the AIDS epidemic by 2030 called the 90-90-90 targets (UNAIDS 2014, UNAIDS 2016). This means that 90% of people living with HIV know their status, 90% of people who know their HIV status are accessing treatment and 90% of people on treatment have suppressed viral load

The 90-90-90 targets have also been set for young people and young people. They are aimed at stepping up paediatric status disclosure and ART coverage. However, for most young people, access precedes disclosure; the majority of HIV infected young people in sub-Saharan Africa have accessed treatment long before they are disclosed to (Bikaako-Kajura, Luyirika et al. 2006). Non-disclosure of HIV status to infected, tested young people hinders their access to social support services for example, participation in support groups is ordinarily confined to young people who are aware of their HIV status. Given the low rate of disclosure to HIV infected young people there is an urgent need to address the specific barriers to status disclosure (discussed below) as this also has implications on achieving the global 90-90-90 targets (Abrams and Strasser 2015, Davies and Pinto 2015).

In the context of paediatric ART, studies have focused on the potential benefits and disadvantages of adults disclosing to HIV infected children, especially on the most appropriate age to disclose, the psychological effects of disclosure on young people and the challenges that carers face in disclosing to young people (Domek 2010, Alemu, Berhanu et al. 2013, Vreeman, Gramelspacher et al. 2013, O'Malley, Beima-Sofie et al. 2015). Globally, children's disclosure of their own status to other young people has not been well studied save for a few studies in resource rich settings (Sherman, Bonanno et al. 2000, Calabrese, Martin et al. 2012, Hogwood, Campbell et al. 2013).

As young people progress into adolescence, clinical and research attention will no longer be on parents/carers disclosing to young people but on decisions around young people's self-disclosure of HIV to others, including their peers (Hogwood, Campbell et al. 2013). The social expectation will be that they have already been told and so the disclosure moves to a different stage which focuses on how young people disclose to others.

HIV status disclosure in young people is described as a complex stressful psychosocial process for the parent/carer and healthcare workers. HIV infected young people often face multiple structural challenges regarding their HIV status disclosure. Carers are often reluctant

to disclose or opt to delay disclosure for reasons discussed below (Mellins, Brackis-Cott et al. 2002). Young people often face challenges associated with learning about their own HIV positive status, as well as in coming to terms with the diagnosis and the decision to disclose their status to family and friends (Jaspan, Li et al. 2009, Arrive´, Dicko et al. 2012). In this section, I focus on what is known about the disclosure process and the challenges that lead to non-disclosure by parents/carers.

2.2.1 Non-disclosure and delayed disclosure

Many studies conducted in Sub-Saharan Africa show that a significant number of perinatally HIV-infected young people below the age of 14 have been tested but are unaware of their HIV status (Mutumba, Musiime et al. , Biadgilign, Deribew et al. 2011, Arrive´, Dicko et al. 2012, Kidia, Mupambireyi et al. 2014, Lowenthal, Jibril et al. 2014). The few studies that have looked at the disclosure prevalence among HIV infected young people in sub-Saharan Africa has estimated it to be between 24-30 percent; disclosure prevalence is higher in older compared to younger age groups (Bikaako-Kajura, Luyirika et al. 2006, Vaz, Maman et al. 2011). It was presumed this would change with the introduction of the 2011 WHO Guideline on HIV disclosure counselling for young people up to 12 years. The guidelines stipulated that young people 12 years and above should be told of their HIV positive status, younger young people should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure (WHO 2011, MoHCW 2012). However, studies that were conducted after the 2011 guidelines were issued found that many young people were not disclosed to until they were much older (Midtbø, Shirima et al. 2012, Kidia, Mupambireyi et al. 2014). Despite the guidelines publication, little work was done in terms of training and support to ensure that the guidelines were implemented on the ground. Paediatric HIV status disclosure remained very low in resource stretched settings (John-Stewart, Wariua et al. 2013, Kidia, Mupambireyi et al. 2014, Lowenthal, Jibril et al. 2014, Vreeman, Scanlon et al. 2014).

An integral aspect of the new WHO 2013 guidelines is that disclosure should be done by carers with the support and encouragement of healthcare workers (Sahay 2013 , Madiba and Mokgatle 2015). There is, however, documented evidence of reluctance on the carers part to disclose HIV status to their young people for various reasons and this tends to manifest itself in delayed or postponed disclosure, with young people being disclosed to at an older age (Alemu, Berhanu et al. 2013, Kiwanuka, Mulogo et al. 2014).

Studies into why disclosure is delayed showed that carers considered young people to be too young or not sufficiently mature to understand and cope with diagnosis (Lesch, Swartz et al. 2007, Heeren, Jemmott et al. 2012, Midtbø, Shirima et al. 2012, Mburu, Hodgson et al. 2014, Atwiine, Kiwanuka et al. 2015). Carers worried that young people would impulsively disclose to other people and risk suffering social rejection (Madiba and Mokwena 2012, Mahloko and

Madiba 2012). Although carers cited young people being too young to comprehend their diagnosis, some studies found that non-disclosure and secrecy continued even when young people appeared ready and mature to fully comprehend their diagnosis (Kidia, Mupambireyi et al. 2014, Mattes 2014). Despite the common narratives from carers the circumstances do not change with children's maturity or age as carers tend not to fully explain HIV to children.

Carers' worry about the capacity of young people to fully understand their own diagnosis has often been linked to their own reluctance to disclose (Kidia, Mupambireyi et al. 2014, Mandalazi, Bandawe et al. 2014, George and Lambert 2015). The relational aspects of the HIV diagnosis that is specific to perinatal infection is that it is an inherited disease, with the implication that if the child is vertically infected, the mother must by definition be infected too. This can make it particularly difficult for carers to disclose an HIV diagnosis to the child as they are not only disclosing the child's status but also their own. The extent to which they have adjusted and are accepting of their own diagnosis is likely to influence their willingness to disclose the child's status to them. Carers in particular, felt guilty that they had been the cause of a potentially terminal condition for their own child (George and Lambert 2015). Both biological and non-biological carers have commonly been found to adopt non-disclosure as a strategy of protecting their own and or relatives' images (Kidia, Mupambireyi et al. 2014).

2.2.2 Deception and Secrecy

One of the dilemmas that carers commonly face in delaying disclosure is how to manage questions that young people ask – young people are curious and keen to know about why they are taking treatment and the reasons for the countless clinic visits when they are not sick (Bernays, Seeley et al. 2015). In order to successfully avoid or delay disclosure, carers often misinform young people, often as a strategy to postpone having to reveal the true cause of their condition (Hejoaka 2009, Kajubi, Whyte et al. 2014). Many studies found that carers deceived young people by giving false diagnosis, for example, citing chest pain, malaria, tuberculosis (TB) and cholera as a way of evading disclosure (Kajubi, Bagger et al. 2014, Kenu, Obo-Akwa et al. 2014, Lowenthal, Jibril et al. 2014, Mattes 2014). Some carers kept the status a secret from the child and other household members (Hejoaka 2009, Kidia, Mupambireyi et al. 2014) This often started when young people were very young and this diagnosis is then perpetuated.

However, as they grow older and more mature, this mode of deception and secrecy become less effective as young people tend to ask questions regarding their illness and doubt the veracity of their carers' explanations. For example, why they needed to continue taking treatment despite their apparent recovery. The secrecy and deception may have at first seemed necessary when children were very young, but may become increasingly difficult to

disentangle from or navigate if the carer still feels that they are unable to handle the information appropriately (Mattes 2014).

Deception and secrecy are key acts of stigma as they associates the diagnosis with shame (Daniel 2015). Secrecy and deception are disruptive to the idea that HIV is commensurate with other chronic illnesses by showing that it cannot be spoken about or conceptualised in the same way (Funck-Brentano 1995, Hejoaka 2009). The secrecy implies that despite being a chronic condition, HIV is still exceptionally different from the other manageable chronic diseases (Philbin 2013). The secrecy and silence that surround HIV greatly influence how young people approach the management of their HIV as well as their construction of HIV and identities around growing up with HIV. Shrouding the diagnosis in secrecy and giving false diagnosis serves to increase internalized stigma, low self-esteem and lack of confidence; this goes against efforts to 'normalize' HIV (Michaud, Suris et al. 2009, Mattes 2014). Internalized stigma has been found to particularly damage young people's self-esteem, giving them a negative sense of self-worth (Close and Rigamonti 2015). Internalizing stigma regarding their diagnosis is more likely to result in depression (Tsai, Bangsberg et al. 2013) and young people might engage in denial and may fear disclosing their status to others and feel shameful regarding their condition (Close and Rigamonti 2015).

2.2.3 Accidental and deductive disclosure

The disclosure process is commonly submerged in obfuscation and a significant number of young people accidentally learnt about their diagnosis through overhearing carers or healthcare workers talking about the illness and exposure to HIV/AIDS related information in their care environments (Mburu, Hodgson et al. 2014, Mburu, Ram et al. 2014). A study conducted in Zimbabwe found out how some adolescents discovered their diagnosis through inferences from the casual talks in the HIV clinic that they attended (Kidia, Mupambireyi et al. 2014). Accidental and deductive disclosure may lead to maladjustment. It increases the risk of misinformation, confusion and means that young people are more likely to cope with the knowledge of their diagnosis in an unsupportive environment. In Botswana, young people who unintentionally became aware of their positive status were more commonly traumatised and distressed (Lowenthal, Jibril et al. 2014).

Besides causing trauma and distress, deductive disclosure limits the opportunity for young people to seek clarity or get more HIV information and social support at an early stage after they learn of their diagnosis (Madiba and Mokwena 2012, Kidia, Mupambireyi et al. 2014). Crucially, deductive disclosure may disrupt or strain the carer/parent-child relationship and increase their distrust of adults. Young people may feel unable to confide in the carers or feel a need to conceal that they are aware of their diagnosis. Learning about one's HIV positive

status through deductive rather than open talk implies that the condition is serious and highly shameful.

Having highlighted the consequences associated with delayed or non-disclosure, I will go on to discuss the dilemmas that young people face after being disclosed to. In cases where young people have been disclosed to (normally from around 12 years), I have found that disclosure tends to be a one-off event rather than a process as recommended by clinicians and WHO 2011 guidelines (WHO 2011).

2.2.4 Disclosure as an event

The most recent WHO global disclosure guidelines and the local Zimbabwean guidelines stipulate that disclosure must be taken as an ongoing process corresponding with the child's age and understanding (WHO 2011). In the ideal scenario, it is envisaged that, paediatric disclosure must involve multiple discussions that match the young people's cognitive development (Lesch, Swartz et al. 2007). Phased disclosure gives young people room to absorb the information gradually. Healthcare workers are also expected to play a part in the ongoing disclosure process through providing accurate information in response to questions and facilitating a developing understanding of the impact of HIV infection (Lesch, Swartz et al. 2007, Kidia, Mupambireyi et al. 2014). If treated as a process that explores the young people's concerns and ensures that they understand their illness, disclosure can promote trust and improve child's capacity to adjust, cope and manage growing up with HIV (Mellins, Brackis-Cott et al. 2002, Wiener, Mellins et al. 2007, Arrive´, Dicko et al. 2012, O'Malley, Beima-Sofie et al. 2015).

In practice though, studies have shown that disclosure normally occurs as a one-time event (Vaz, Eng et al. 2010, Lowenthal, Jibril et al. 2014, Mburu, Hodgson et al. 2014). Any subsequent discussions focus more on drugs than HIV (Vaz, Eng et al. 2010, Kajubi, Bagger et al. 2014). A recent study in Zimbabwe unravelled some of the negative implications of disclosure being a one-off event, where there is no further discussion regarding the status (Kidia, Mupambireyi et al. 2014). Interviewed young people cited failing to understand what HIV/AIDS was when they were disclosed to. Most of the young people reported relying on more experienced peers in support groups to fully understand their diagnosis (Kidia, Mupambireyi et al. 2014).

An ethnography study conducted in Tanzania reported a general lack of understanding that accompanies disclosure, when it is approached as a one-off event (Mattes 2014). Young people had to fill in the information gaps on their own (Mattes 2014). This often led to confusion or misunderstanding, compromising how young people manage and cope with HIV. In the same study, healthcare workers failed to engage with questions and concerns of young people

as they were too busy (Mattes 2014). This left the young people to “put pieces together” on their own (Mattes 2014). In the same study, young people cited being less able to seek additional information or to ask follow up questions from their carers after the ‘event’ of disclosure (Mattes 2014:31).

Similar observations were noted in Uganda where, even after disclosure, young people did not fully understand what AIDS meant (Kajubi, Bagger et al. 2014). Kajubi argued that drugs talk for example, good drug adherence, dominated the disclosure discussions regardless of age and carers were known to avoid talking more broadly about HIV (Kajubi, Bagger et al. 2014, Kajubi, Whyte et al. 2014). Two large, longitudinal qualitative studies with HIV young people living with HIV (YPLHIV) in five different countries (resource rich and poor settings) have shown similar findings where young people failed to ask carers and or healthcare workers questions regarding their status (Bernays, Papparini et al. 2015). In the same multi country study, young people who had access to the internet ended up researching on their own (Bernays, Papparini et al. 2015).

2.2.5 Lack of autonomy over disclosure

The discussion above illustrates that there is a reasonable amount known about the experience of disclosure to young people or at least the effects of it being done as a one-off event. What is not fully known is how young people engage with the decision to disclose to others. Many studies have looked at how carers manage disclosure to young people but within this empirical context, we know least about young people’s attitudes and experiences of disclosing to others. In this section, I now turn to how young people living with HIV share their own status with other people.

The majority of studies in both resource rich and poor settings have found that young people’s ability to share their status remains heavily controlled by carers and other family members (Lesch, Swartz et al. 2007, Vaz, Corneli et al. 2008, Daniel 2011, Mburu, Ram et al. 2014). In Switzerland, a resource rich setting, carers were found to be more insistent on non-disclosure and this over-rode the young people’s decision to disclose (Michaud, Suris et al. 2009). Studies in Sub-Saharan Africa also reported similar findings where young people were compelled to keep their status a secret because of the anticipated stigmatisation and discrimination for themselves and their families associated with an HIV infection (Hejoaka 2009, Midtbø, Shirima et al. 2012, Kajubi, Bagger et al. 2014).

In most cases, following disclosure, young people kept their diagnosis secret as their carers and society had taught them (Daniel, Malinga Apila et al. 2007, Daniel 2015). In as much as keeping the secret protects young people and their families from stigma and discrimination, it also prevents young people from receiving clarification, validation and support, making it

extremely difficult for them to ask for help from outsiders and friends (Daniel 2015). This has been linked to social isolation, low self-esteem and limited opportunities for social and emotional support (Abramowitz, Koenig et al. 2009, Persson and Newman 2012). In the long run, it may threaten their psychological growth and interfere with their ability to adapt, cope and build resilience to manage growing up with HIV.

Despite the pressure that young people are under to keep their own status a secret, a number of studies illustrate that they often have little control over who gets told, with adults often disclosing their status without the child's permission (Siu, Bakeera-Kitaka et al. 2012, Mburu, Hodgson et al. 2014, Mburu, Ram et al. 2014). A study conducted in Uganda found that HIV infected young people felt powerless regarding status disclosure (Siu, Bakeera-Kitaka et al. 2012). The study found that young people wanted to be consulted and to be in control of when, how and who to disclose to but they felt that this power was taken from them by their carers (Siu, Bakeera-Kitaka et al. 2012). Similar findings were reported in Zambia where adults were found to be in control of the disclosure process (Mburu, Ram et al. 2014). Mburu (2014) noted negative outcomes resulting from adults usurping disclosure autonomy from young people, which included emotional distress and feeling of powerlessness. The study recommended that HIV infected young people be empowered and given more autonomy over their own status disclosure (Mburu, Ram et al. 2014).

2. 2.6 Young people unwilling to disclose HIV status

A few studies from both resource rich and poor settings have shown that some young people who have been disclosed to are unwilling to disclose their status to other people (Michaud, Suris et al. 2009, Calabrese, Martin et al. 2012, Hogwood, Campbell et al. 2013, Mavhu, Berwick et al. 2013, Daniel 2015). Young people interviewed in these studies cited anticipation of stigma and negative attitudes as inhibiting disclosure. The literature has shown that every stage of disclosure emphasises the hidden and shameful nature of the diagnosis (Calabrese, Martin et al. 2012, Hogwood, Campbell et al. 2013). Young people have been taught to anticipate that disclosure will be negative. Through learning by hearing adult conversations and seeing how HIV is socially constructed as a shameful condition in their homes and communities and by their peers, young people are taught to anticipate stigma (Hogwood, Campbell et al. 2013).

It is not necessarily in the failure to disclose that young people learn of stigma but they are socialised to assume that they will be stigmatised well before they even make the decision to disclose their status. Some learnt that HIV is a stigmatised disease even before they were told of their own HIV status. Young people's experience of being told at the point of disclosure that they must keep their status a secret and seeing how their carers handled the knowledge

as highly stigmatising meant that young people learnt about stigma and discrimination without directly experiencing it. In Zimbabwe, some adolescents chose not to disclose their status to very close relatives which included siblings for fear of ill-treatment and rejection (Mavhu, Berwick et al. 2013). A study conducted in Botswana and Tanzania showed that fear of stigma and discrimination plus poor knowledge about transmission were the most cited reasons for non-disclosure to friends and other non-family members (Midtbø, Shirima et al. 2012).

This section has highlighted the persistent challenges regarding paediatric HIV disclosure. Noticeable in the majority of studies reviewed was the lack of social spaces at home and in the clinic for young people to ask questions about their diagnosis and to express and discuss their lived experiences. Additionally, the literature has focused more on the adult/child interactions as well as the formalised support networks while little has been done to explore child informal peer to peer interaction. Unanswered questions include - do they? Why would they? With what effect? What is known is that they face the dilemma of when and whom to disclose their status to (Siu, Bakeera-Kitaka et al. 2012). Additionally, little research has been done to date to explore the role of social peer networks in providing platforms for young people to discuss their experiences of growing up with HIV and to attain HIV information. More so, scant research has explored how young people are responding to the normalisation of HIV (Mattes 2014).

Given the complex issues involved in paediatric HIV disclosure discussed above and the demonstrated lack of insight into young people's decision-making process regarding their own disclosure, there is clear need for research, examining young people's experiences of disclosure to others. The paucity of literature on the decision-making process young people face around their own disclosure and its effect on their experiences is a major limitation in terms of understanding both their lived experiences of growing up with HIV and in designing interventions that respond to young people's unmet needs. This is the particular focus of this study.

The next section looks at young people's drugs adherence which is another key area in paediatric HIV treatment and care.

2.3 Adherence

In the context of paediatric HIV care, adherence is defined as "taking drugs in all the prescribed doses at the right time, in the right doses and in the right ways" (Amberbir, Woldemichael et al. 2008:2). WHO guidelines recommend at least 95% adherence to ART to prevent treatment failure (Hardon A, Davey S et al. 2006, Mitiku, Abdosh et al. 2013, Weaver, Pane et al. 2014). In a similar way to disclosure discussed above, adherence to drugs is dependent on a number of social and relational factors that either hinder or promote good adherence.

Achieving excellent adherence to ART has been identified as critical to the effectiveness of HIV treatment (Ketema and Shewangizaw Weret 2015, Nyogea, Mtenga et al. 2015, Zegeye and Sendo 2015). Research has shown that ART has the potential to reduce mortality and improve physical health; however this requires high levels of drug adherence (Harries et al. 2010). Poor retention and adherence to ART leads to virological resistance and ultimately to treatment failure (Bangsberg, Hecht et al. 2000, Patterson, Swindells et al. 2000). Second-line therapy is prohibitively expensive for Zimbabwe and many other low and middle income countries, and third-line therapy is currently not widely available (UNAIDS 2012).

Despite fear of poor retention in care and poor drugs adherence for young people in resource stretched settings, a number of studies (quantitative and qualitative) have shown that young people are able to achieve high levels of adherence (Campbell, Skovdal et al. 2012, Kim, Gerver et al. 2014, Vreeman, Nyandiko et al. 2014). A recent systematic review on adherence levels among adolescents and young adults (aged 12-24 years) globally found that more than 70% of young adults in Africa and Asia were adherent to therapy as compared to those in Europe and North America, who were at 50-60% (Kim, Gerver et al. 2014). The method of adherence measurement varied across studies and included self-report, pharmacological measurement or having an undetectable viral load. (Kim, Gerver et al. 2014).

Although adherence in Africa is reported to be high, there are a few studies that have highlighted suboptimal adherence among young people and adolescents (Nachega, Hislop et al. 2009, Skovdal, Campbell et al. 2011, Gross, Bandason et al. 2014). Non-adherence was largely influenced by the child's socioeconomic environment, stigma, carer characteristics and disclosure of HIV status (Vreeman, Wiehe et al. 2008, Biadgilign, Deribew et al. 2009, Haberer and Mellins 2009). Other scholars have identified a number of child specific factors that affect drugs adherence which include psychosocial function, neurodevelopment, developmental stage (Haberer and Mellins 2009, Lowenthal, Bakeera-Kitaka et al. 2014). Age is a key factor in adherence to many conditions. A number of studies have pointed out that adherence becomes worse as young people enter adolescence, as they start to want to control their own lives coupled with decreased parental supervision (Agwu and Fairlie 2013, Nabukeera-Barungi, Elyanu et al. 2015).

Social factors that hinder adherence and research methods that allow young people to openly talk about adherence slippages have not been given adequate attention (Campbell, Skovdal et al. 2012). Below, I discuss a few social factors relevant to the Zimbabwean context that have been cited as promoting and/or impeding adherence and their reporting of it among young people in Sub-Saharan Africa.

2.3.1 Facilitators to good adherence

It has been shown that the child's social and economic environments influence their drugs adherence (Vreeman, Nyandiko et al. 2009, Skovdal, Campbell et al. 2011). A review of emerging social challenges in perinatally infected young people in Sub-Saharan Africa found that good adherence was strongly associated with young people's knowledge of HIV status and the extent of their social support (Lowenthal, Bakeera-Kitaka et al. 2014, Cluver, Hodes et al. 2015, Nzota, Matovu et al. 2015). Studies in Sub-Saharan Africa have found that receiving support and encouragement from peers (in most cases peers who were also living with HIV), belief in value of treatment, and the desire to live (Ware, Idoko et al. 2009) significantly influenced good adherence. The review and ethnographic study referred to earlier (Ware, Idoko et al. 2009, Lowenthal, Bakeera-Kitaka et al. 2014), were conducted in resource stretched settings, with high HIV prevalence and widespread stigma hence the results are of particular relevance to Zimbabwean context which has a similar environment.

2.3.2 Barriers to good adherence

Several factors has been highlighted to affect drug adherence among young people living with HIV and these include structural barriers, carer and adolescent related barriers.

Structural barriers

Structural barriers of poverty and stigma have been seen to hamper adherence (Reda and Biadgilign 2012, Bernays, Jarrett et al. 2014, Lowenthal, Bakeera-Kitaka et al. 2014). Many HIV-infected young people live in poverty and face food scarcity, both of which have been associated with poor adherence in developing settings (Bikaako-Kajura, Luyirika et al. 2006, Fetzer, Mupenda et al. 2011, Young, Wheeler et al. 2014). Although developments in current drugs regimens mean that taking drugs with food is less critical than in the recent past, most carers still think that young people need to eat before taking drugs and studies have shown that carers may consequently delay or skip doses when food is scarce (Biadgilign, Deribew et al. 2009, Campbell, Skovdal et al. 2012). However, these missed doses are likely to have a profound effect on the efficacy of the treatment. Clinical literature on ART currently indicates that if drugs are not taken routinely at around the same time every day, HIV may become resistant to the therapy, causing it to stop working (Amberbir, Woldemichael et al. 2008, Weigel, Makwiza et al. 2009).

Adherence is widely understood to be hampered by stigma and discrimination (Simoni, Montgomery et al. 2007, Reda and Biadgilign 2012, Nabukeera-Barungi, Elyanu et al. 2015). Fear of being seen taking HIV drugs and taking drugs in secret and not wanting friends and other undisclosed relatives to know exacerbates non-adherence (Reda and Biadgilign 2012, Bernays, Jarrett et al. 2014). A study in Kenya found that carers would delay or skip giving

young people drugs if they were in the presence of other undisclosed people (Vreeman, Nyandiko et al. 2010). The need to keep the child's status a secret superseded the need to maintain good adherence. This however is not limited to young people, several studies have shown that adults also hide, delay or stop taking their ARVs in an effort to keep their status a secret from undisclosed relatives (Melchior, Nemes et al. 2007, Linda 2013, Colombini, Mutemwa et al. 2014). The only key difference with young people is the lack of relative autonomy in taking their medication.

Carer related barriers

Characteristics that are particular to carers have also been noted to contribute to how adherent a child becomes (Skovdal, Campbell et al. 2011, Hudelson and Cluver 2015). The majority of young people depend on adult carers for support in taking their medication. Skovdal et al. (2011) explored the experiences of orphaned young people living with grandparents and found that some carers did not fully understand how the drugs were supposed to be taken and often did not dispense them as recommended. Similarly, other studies have reported that elderly carers encountered problems in calculating dosages, as well as in seeing markings on syringes that they used to administer ART solutions (Haberer and Mellins 2009, Nahirya-Ntege, Cook et al. 2012) compromising good adherence as some young people ended up getting something other than the recommended dosage. In the long run, this will result in treatment failure and drug resistance or drug toxicities if consistent under/over dosage is given.

In other studies young people described the living conditions at home being a hindrance to good adherence for example, mistreatment and abuse especially from non-biological carers and other HIV negative relatives/siblings (Reda and Biadgilign 2012, Nabukeera-Barungi, Elyanu et al. 2015). Relationships are portrayed as having a significant influence on a child's adherence behaviour and broadly on their experiences of growing up with HIV.

Adolescence related barriers

A growing literature points to non-adherence being a characteristic of adolescent stage and this is not exclusive to HIV but noted across chronic conditions during adolescence (Taddeo, Egedy et al. 2008, Nabukeera-Barungi, Elyanu et al. 2015). The need to preserve a positive self-image, identity and peer pressure were identified as barriers to adherence. Fear that the physical changes arising from drug toxicity might make their peers suspicious of their health status has been shown to limit drug adherence among HIV positive adolescents. An example is the facial and buttock wasting due to the abnormal distribution of fat in the body caused by some of the ARVs (Piloya, Bakeera-Kitaka et al. 2012) Such physical changes if noticed or

commented on by their peers could lead young people to stop taking their treatment (Nabukeera-Barungi, Elyanu et al. 2015).

It is also evident from the literature that challenges emerge once young people take on full responsibility for taking their treatment on their own (Martin, Elliott-DeSorbo et al. 2007, Naar-King, Montepiedra et al. 2009, Buchanan, Montepiedra et al. 2012). This is of particular interest as this thesis looked at young people aged 11-13 years who are beginning to assume higher levels of control and responsibilities on taking treatment. Some young people transition to take full responsibility for their own drugs before they are mature or old enough to fully appreciate the importance of taking drugs (Nichols, Montepiedra et al. 2012). Lack of adult supervision and support even among adolescents has been shown to compromise adherence (Fetzer, Mupenda et al. 2011, Bernays, Jarrett et al. 2014). Although the process by which a child transitions towards autonomous treatment taking has been noted to bring about adherence challenges, studies looking at this transition are still sparse. This gap also impacts on the support needs as it is still unknown what kind of support young people require during and after the transition from mediated to autonomous treatment taking.

Although the literature has explored many of the factors which hinder and or facilitate adherence, there is still little understanding about how peer support networks may influence young people's adherence to ART. There is very limited research which explores, from the child's perspective, what may motivate them to take their drugs and what they perceive to be structural, cultural and social barriers that hinder them from adhering well. It is important to find out from young people what support they require in order to improve adherence.

In the next section I discuss stigma as it significantly undermines status disclosure and treatment adherence as discussed above.

2.4 Stigma

HIV related stigma remains a key social and public health issue in Zimbabwe (Duffy 2005, Campbell, Skovdal et al. 2011). Whilst the rationale and form stigma takes is shaped by the local, historical context, it remains a dominant feature of the experience of being HIV positive. For many years, HIV related stigma has been described as the chief structural barrier in the HIV testing and treatment continuum (Mukolo, Blevins et al. 2013). I will start by outlining the definition of stigma. Later in this section I will give the stigma dimensions (instrumental, symbolic and resources based) before and after the universal access to ART.

2.4.1 Defining stigma

Stigma has been defined by Goffman in his book and seminal essay as:

“...an attribute that is significantly discrediting, which in the eyes of society, serves to reduce the person who possess it”(Goffman 1963: 13).

Scambler interpreted Goffman’s definition, to mean that stigmatised individuals offend against the ‘norms of identity’ or ‘being’ and this implies an ontological deficit (Scambler and Paoli 2008). This connotes that normalcy is lost when one is diagnosed with a discrediting condition, for example, HIV or epilepsy. Stigma therefore alters the identity of the person by the condition that is thought to be socially undesirable and the person is seen as possessing a defect that is beyond their capability to rectify (Scambler and Paoli 2008). This often leads to individuals being morally judged and labelled for deviating from what is regarded as normal (Swendeman, Rotheram-Borus et al. 2006, Scambler 2007). Deacon and Campbell summarised it as a multi-dimensional social process, constantly changing, dependent on cultural and environmental contexts, but capable of being resisted in certain circumstances (Campbell, Foulis et al. 2005, Deacon and Stephney 2006). This thesis aligns with the Deacon and Campbell’s thinking and argues that stigma is content specific and not static.

Although HIV-related stigma has been prevalent for decades, it is not static. As the HIV epidemic matures, so the social construction of HIV evolves, which prompts changes in the form and nature of stigma. In the following sections, I discuss three main dimensions of HIV stigma before the advent of antiretroviral therapy and how the availability of ART has altered and shaped newer forms of stigma. Towards the end of the section, I discuss young people’s experience of stigma and how these forms of stigma impact on young people.

2.4.2 Stigma dimensions before universal access to antiretroviral therapy.

Jonathan Mann described HIV/AIDS as three global epidemics: first- the AIDS initial infection which is silent and asymptomatic, second- the acknowledgement of the infection though having limited knowledge regarding the infection, third- “epidemic of the social, cultural, economic and political responses to AIDS” (Mann 1987:131). I focused on the third epidemic which was largely the public response to HIV/AIDS. This focus was limited to resource stretched settings which bear the highest burden in terms of numbers affected by HIV.

This third epidemic as described by Mann has evolved from the time when HIV was characterised by fear of contracting an incurable and terminal infection (Mann 1987). This fear was not just limited to HIV’s association with death but also its association with sex and illicit behaviours (Mann 1987, Duffy 2005). During this period, HIV infected people were viewed as presenting a real material risk or threat to uninfected individuals. This fear, arising from a fear of contagion, allows individuals to distance themselves from infected people, resulting in ‘instrumental stigma’ (Herek and Capitanio 1998, Stein 2003).

Instrumental stigma produces the “distancing risk” (Stein 2003 , Deacon, Stephney et al. 2005) where people actually discriminate HIV-infected people. Research in many Sub-Saharan African countries has found high levels of instrumental stigma (Roura, Urassa et al. 2009, Maughan-Brown 2010). In South Africa, individuals whose status was not known shunned HIV infected people by refusing to visit ailing relatives or shake hands (normal form of greeting) or associate with them (Maughan-Brown 2004, Campbell, Foulis et al. 2005, Campbell, Nair et al. 2007). Similar findings were reported in Zimbabwe where most people were running away from infected people, refusing to nurse, associate or share anything with people known to have AIDS (Duffy 2005).

The second dimension was the moral and value-based judgements, blaming individuals for contracting HIV (Herek and Capitanio 1998, Gonzalez-Rivera and Bauermeister 2007). This has been described in the literature as **symbolic stigma** where individuals are considered to be morally responsible for contracting the infection through their immoral and irresponsible behaviour, for example, promiscuity, homosexuality and intravenous drug use (Campbell, Foulis et al. 2005, Winskell, Hill et al. 2011). Campbell reported symbolic stigma in her South African research, where both the very act of sex and sexual relations were regarded as shameful and taboo topics (Campbell, Foulis et al. 2005). She found that symbolic stigma often hindered people from disclosing their status, thereby limiting their ability to access care and other support services (Campbell, Foulis et al. 2005).

Symbolic stigma is prevalent in Zimbabwe; HIV is strongly linked with prostitution to the extent that the terms are interchangeable (Duffy 2005). The social construction of HIV as a shameful condition resulted in boundaries between ‘us’ the morally upright, normal, uninfected people, and ‘them’, the ‘other’, immoral, deviant and infected people (Ogden & Nyblade, 2005). This strategy has been widely used in Sub-Saharan African countries as a response to the HIV epidemic before the roll out of ART (Joffe, 1999; Parker & Aggleton, 2003).

Churches were cited within the literature as some of the perpetrators of symbolic stigma, given the traditional intolerance of the church to behaviours such as premarital sex, prostitution and infidelity (Ogden and Nyblade 2005, Parker and Birdsall 2005). A study in Tanzania found that religion played a key role in shaping people’s attitudes. People who viewed HIV as a punishment from God were more likely to show negative attitudes towards people living with HIV (PLHIV). However, this was context specific as in other contexts there were encouraging messages from the churches to care for PLHIV (Campbell, Skovdal et al. 2011).

A study conducted by Campbell in Zimbabwe, before universal access to HIV treatment and care found that symbolic stigma hindered people from disclosing their status and this limited their ability to access care and other support services (Campbell and Deacon 2006, Campbell, Nair et al. 2007). Fear of receiving bad treatment and possible rejection meant that HIV-infected individuals did not disclose their status to relatives and healthcare workers (Letamo 2009). The silence and secrecy limited opportunities for seeking and accessing support. Although several studies have shown that many adults use silence, secrecy and pretence as a coping mechanism (Funck-Brentano 1995, Hejoaka 2009, Daniel 2015), little is known about the social and psychological effects of silence and secrecy on young people. Some people with HIV are consequently viewed as innocent victims for example people who got infected through blood transfusion (Herek and Capitanio 1998) and young people who are infected vertically. I will discuss how young people are looked at in more detail below.

Apart from fear of infection and moral reproach, PLHIV were also resented because of their sick role which caused reduced productivity and their reliance on state services to support them (Maughan-Brown 2004, Campbell, Foulis et al. 2005). This third dimension of stigma was described as '**resource based stigma**'. At household level, the cost (financial and physical) of caring for a sick relative was in most cases related to higher levels of stress, exhaustion as well as diminishing resources, for example, family savings (Campbell, Foulis et al. 2005). Hopelessness of supporting a dying person whose care compromised the well-being of others was also another driver of HIV stigma at household level (Campbell, Skovdal et al. 2011).

At national level, the increasing number of people needing treatment and rising cost of HIV/AIDS treatment and care drains heavily on the scarce resources, leading health professionals to stigmatise PLHIV (Campbell, Foulis et al. 2005). Similarly, hopelessness among healthcare workers through watching patients die, and being unable to diagnose and manage HIV/AIDS related illnesses caused them to stigmatise patients (Bond, Chase et al. 2002). A number of studies have reported nurses insulting and scolding patients, being hostile as well as being abusive (Guma 2011, Saki, Mohammad Khan Kermanshahi et al. 2015). The frustration that comes with heavy workload compounded by understaffing has led many nurses to stigmatise patients. Duffy (2005) also found that healthcare workers also stigmatised HIV/AIDS patients by isolating and treating them differently from other patients. Such stigma can instil fear in the patients which often leads to non-attendance at the health facilities (Guma 2011).

Varying combinations of fear of infection, implications of perceived moral defectiveness and anger at the perceived disproportionate drain on resources make HIV/AIDS a very powerful

and laden symbol, often marking PLHIV and their families as social outcasts (Parker and Birdsall 2005).

2.4.3 Young people and stigma before ART

Before the roll out of antiretroviral therapy, young people infected with HIV were mostly associated with death as they tended to die very early in their infancy (Lallemant, Lallemant-Le-Coeur et al. 1989, WHO 2006). However, as highlighted in chapter 1, around one third lived into adolescence even without treatment (Ferrand, Lowe et al. 2010, Pegurri, Konings et al. 2015). While much of the stigma experienced by adults may have had some effect and implication for young people too, it is unlikely to have been exactly the same because of the high and early mortality (Deacon and Stephney 2006). There has been little understanding of children's experience of stigma before the roll out of ART and how it was theorised mainly because of the small numbers of young people who survived and the limited understanding of the possibility of young people being infected with HIV. During the early days, HIV was conceptualised as an adult disease. There was, at the time, limited understanding regarding perinatal transmission and definitive diagnosis of HIV in infants was not possible then (Lallemant, Lallemant-Le-Coeur et al. 1989).

The few young people who survived were most likely to be spared from symbolic stigma. The symbolic stigma approach implies that those who were infected by HIV through blood transfusions, young people who were perinatally infected or through non-behaviour based routes were distinguished from the 'guilty' and cast as the 'innocent victims' of HIV. Whilst the discourse has moved away from these polarised identities, there are still many unaddressed questions about the specific experiences of young people growing up with HIV. It is not clear whether or not this label of innocent victims commonly applied to perinatally infected young people in paediatric care still exists, if so why are young people being told to keep quiet about their status? Could also this be because a child's HIV status implicates the parents or is it more rooted in cultural belief where HIV is seen as a symbol of bad luck (Parsons 2012). Why is there so much fear and often experiences of stigma and discrimination once they disclose their HIV status? Stigma appears not to simply go away because young people acquired infection in a non-behavioural way (Parsons 2012). If these exemptions do exist, how lasting are they? As young people transition into youth, will they still be perceived as "innocent" young people or is this likely to change over time?

The few studies that described stigma among young people before antiretroviral therapy noted young people experienced stigma in two ways. Firstly, young people experienced courtesy stigma because of their link with HIV infected parents (Kheswa 2014). In this case, stigma was transferred from parents to surviving young people (Evans 2005). Secondly, young people

experienced stigma through being seen as a burden or strain on limited resources (Clay, Bond et al. 2003) and risked being denied access to school and healthcare as there was still fear of contagion. They also risked being constantly passed from one carer to the other (Evans 2005) as the extended family members took turns to care for AIDS orphans.

Adults were found to be the perpetrators of the stigma experienced by young people (Clay, Bond et al. 2003). In Zambia, one study found that young people were taught and/or instructed by their parents not to play or interact with young people whose parents were known or suspected to have HIV including young people suspected of having HIV (Clay, Bond et al. 2003). In as much as young people might want to maintain their friendship with young people whose status is known or young people whose parents are HIV infected, societal pressure and punishment might deter them from keeping these friendships (Clay, Bond et al. 2003).

This section reviewed stigma dimension before the roll out of ART. I now turn to the anticipation of stigma reduction in light of the roll out of ART.

2.4.4 Anticipation of stigma reduction

It was anticipated that HIV related stigma would reduce over time as people acquired more information on the transmission routes and as HIV became less of a death sentence with the advent of ART (WHO 2003, Castro and Farmer 2005). It was argued that improved access to ART would enable PLHIV to regain their physical health and retain their economic and social roles, prompting reduction in the levels of stigma (Castro and Farmer 2005). Restoration of health was purported to bring restoration of social recognition (Campbell, Skovdal et al. 2011). I looked at how this has played out once ART became available and the impact it has had on the stigma affecting young people in particular.

2.4.5 Stigma in the era of ART

There have been mixed results of the assessment of the effectiveness of ART in reducing stigma. A few studies have shown a decrease in stigmatising attitudes since the successful roll out of ART. A comparative study of stigmatising attitudes before and after universal access to antiretroviral therapy in Botswana shows a significant reduction in stigmatising attitudes and discrimination and this has promoted status disclosure to family members and friends (Wolfe, Weiser et al. 2008). It was argued that universal access to ART has the potential to address some of the key structural barriers hindering PLHIV to access HIV treatment and care services (Wolfe, Weiser et al. 2008). It was hoped that universal treatment access would change public perceptions of the disease, normalizes life with HIV, and empower people living with HIV/AIDS to take an active role in resisting and combating stigma and discrimination (Wolfe, Weiser et al. 2008). However this has not necessarily turned out to have the desired outcome as the

normalisation of HIV continues to be questioned (Roura, Wringe et al. 2009, Mattes 2014, Moyer and Hardon 2014)

This has been supported by a number of studies in Southern Africa. In Zimbabwe it was found that with ART, PLHIV were able to rebuild their once spoiled identities and resisted identities that labelled them as the “devalued others” (Campbell, Skovdal et al. 2011). Treatment allowed for positive social and economic participation which led to the restoration of social value (Campbell, Skovdal et al. 2011). Despite the reclaimed social value, instrumental, symbolic and resource based stigma still persisted in the Zimbabwe (Campbell, Skovdal et al. 2011). In South Africa, the provision of ART opened new avenues for support through support groups (Zuch and Lurie 2012). PLHIV were able to form bonds and use support groups to reclaim their social status and resisted stigmatising identities (Campbell, Skovdal et al. 2011). However, the general trend has been the persistence of stigma not just in Zimbabwe but in many Sub-Saharan African settings (Maughan-Brown 2010, Mbonye, Nakamanya et al. 2013, Bond, Tesfamichael et al. 2014). There have been limitations to the efficacy of ART in transforming stigma.

The persistence of stigma in Zimbabwe has been attributed to two factors. Given the partial ART coverage at the time of the Campbell study (conducted in 2009), it is possible that many people at the time of the study were still dying from HIV due to limited access to ART (Campbell, Skovdal et al. 2011). However, it does show us that although ART played a key role in restoring lives, it did not automatically turn HIV into a non-stigmatised condition; hence the moral judgements persisted. Reframing social representations of HIV/AIDS from the moral-based judgements of immoral practices and discredited identities is a social process which takes time (Campbell, Skovdal et al. 2011). The strongly held beliefs regarding sexual transmission of HIV continues to shape community responses to HIV/AIDS in Zimbabwe to date. There is evidence that fear of infection is still key. However a study conducted in Malawi found that telling people that ART decreases the rate of HIV transmission to HIV negative partners reduces stigma between sexual partners considerably (Derksen, Muula et al. 2015).

Similarly, fear, shame and blame remained key structural drivers of HIV-related stigma in Tanzania and South Africa after the successful roll out of ART (Roura, Urassa et al. 2009, Maughan-Brown 2010). This persistence of stigma in that era of ART has led some scholars to strongly critique the normalisation characterisation of HIV (McGrath, Winchester et al. 2014, Moyer and Hardon 2014). Framing HIV as a manageable condition akin to other chronic conditions such as diabetes and cancer was believed to reduce stigma, promote disclosure and improve uptake of services (Roura, Wringe et al. 2009, McGrath, Winchester et al. 2014). However, the studies presented above showed that this rhetorical shift does not necessarily

translate into 'normal' lives for PLHIV as they continue to experience HIV-related stigma (Roura, Urassa et al. 2009, Philbin 2013, Mattes 2014). This suggests that the process of normalising HIV through ART is socially complex, slow and uneven (Bernays, Rhodes et al. 2010, Bernays, Seeley et al. 2015).

Although HIV-related stigma in the context of ART is well documented among adult populations, there is very little evidence on how ART has impacted on stigma in young people. A few studies have highlighted how ART in young people has brought in new forms of stigma. Although young people were not considered at fault for contracting the HIV infection in the same way as adults, they were still attributed responsibility not least for maintaining their own health. Young people were expected to maintain good adherence, regardless of the social obstacles they encountered (Bernays, Papparini et al. 2015).

Suboptimal adherence was punishable and has therefore brought in the adherence stigma (Bernays, Papparini et al. 2015), where young people who fail to adhere to the drugs as recommended by the healthcare workers are stigmatised by carers and other household members (Kawuma, Bernays et al. 2014). Young people were often blamed for non-compliance to medication. Carers were reported to be scolding and threatening young people who missed drugs and often referred to them as bad or irresponsible (Kawuma, Bernays et al. 2014, Bernays, Seeley et al. 2015). As discussed earlier, young people were regarded as not 'at fault' for acquiring HIV; they were however, regarded as responsible for their health by maintaining exemplary adherence (Bernays, Seeley et al. 2015).

Although the scolding and threatening is done as a way of encouraging young people to adhere, it may invoke negative feelings when drug slippages are seen as the child's fault (Kawuma, Bernays et al. 2014, Bernays, Papparini et al. 2015). Young people may conceal their non-adherence because they understand that they are failing to meet the expectations of their carers and healthcare workers (Kawuma, Bernays et al. 2014). However, this is not distinct or unique to young people but may be more pronounced in young people, given their bounded agency and limited power within the household and clinic. Young people are more likely to be subject to this adherence stigma as their carers are solely accountable for their non-adherence to clinicians. There is a need, therefore, to understand the various forms of stigma that are particular to young people in order to inform appropriate interventions to support them in managing their HIV and growing up well with HIV.

2.4.6 Felt and Enacted stigma

Stigma has become such a widely used term and so broadly applied that some critics have argued that it has lost its theoretical focus, especially in understanding the experiences of HIV (Mahajan, Sayles et al. 2008). As such, it makes sense to apply a focused conceptualisation

of stigma which delineates between felt and enacted stigma (Scambler 2004, Scambler and Paoli 2008). Felt stigma has been defined as the individual's own attitude about their condition and how they expect others will react on learning of it. It has also been referred to as self-stigmatization and as fear of being stigmatized and discriminated against (Scambler 2004).

Felt stigma has two layers to it (Scambler 2004), the first being the shame associated with having a socially unacceptable condition in this case, being HIV positive. The second layer is the relationship between the community's attitudes and how this becomes internalised by the individual (Scambler 1998, Scambler 2004). Felt stigma forces PLHIV to conceal their status to family members and friends. In contrast, enacted stigma is the actual unfair treatment from others as a result of one's diagnosis (Scambler 2004). In affecting how individuals imagine themselves and their social worth, as well as the likely and or actual response they will experience in their interactions and relationships with other people - stigma, both felt and enacted is likely to have a profound effect on social relations (Campbell, Foulis et al. 2005, Kheswa 2014)

Stigma has implications on the decision to disclose or not to disclose, on peer acceptance, as well as on the forms of support HIV-infected young people will receive from their peers. Understanding the impact of HIV stigma on support networks and how this influences young people's experiences of living with HIV is likely to play a significant role in informing support interventions that are relevant to the context and the specific needs of young people living with HIV. The conceptualisation of stigma is discussed in chapter 4, as it is a key concept which will be drawn on in investigating the experiences of young people living with HIV. The following section discusses what is known on childhood friendship and social support.

2.5 Childhood friendship

Friendship has been described as an important part of childhood which fosters social and emotional growth (Way and Greene 2006, Boer and Schmidt: 2012). Childhood friendships serve numerous functions including companionship, stimulation, physical support, and intimacy, and affection (Rubin 2004, Meyer 2011, Bagwell and Schmidt 2013). Each of these functions has a different degree of importance at different times during a child's development.

The few studies in resource rich settings that have looked at friendship in young people have argued that childhood friendship is crucial in identity formation and provides insights and information about the development of their sense of self (Meyer 2011, Boer and Schmidt: 2012, Bagwell and Schmidt 2013). It is through acceptance and participating in social networks and interacting with others that young people attain self-awareness (Rubin 2004, Tomé, de Matos et al. 2014). Through mixing, playing and sharing with others, young people learn to bond and trust other people who are not necessarily family members (Olsen, Parra et al. 2012,

Tomé, de Matos et al. 2014). Scholars have argued that the quality of friendship is more important than the number of friends or time one spends with friends (Tomé, de Matos et al. 2014). Accessing social support has been reported as having positive outcomes. For example, a study in Italy among 14-20 year olds (Ciairano, Rabaglietti et al. 2007) and a study among Africa American, 6th -10th grades (Meyer 2011) showed that young people who received support from their friends reported higher well-being than young people who reported having no social support.

2.6 Social support

As already outlined earlier, the remarkable clinical successes in keeping young people living with HIV alive have not adequately addressed some of the negative outcomes that commonly accompany the experiences of growing up with HIV. HIV-infected young people have been described as being at risk of depression, isolation and stigma (Lam, Naar-King et al. 2007, Mavhu, Berwick et al. 2013). For many young people, this continues to be a significant characteristic of living with HIV despite access to ART. The social aspects of growing up with HIV is woefully underappreciated and unaddressed. The explanation to this is threefold: lack of resources, ongoing emphasis on clinical outcomes and because of a concern about the complexity of the challenges to be faced. This is reflected in the increase in attention given to the funding and implementation of non-clinical interventions (Sopeña, Evangeli et al. 2010, Skovdal and Daniel 2012).

Due to the paucity of literature on social support for young people living with HIV, the section will start by giving a broader picture of the role of social support for young people living with chronic illnesses before specifically focussing on HIV. Social support for individuals living with chronic illness has been linked to positive health outcomes as it is perceived to reduce psychological distress such as depression or anxiety as well as promoting psychological adjustment to chronically stressful conditions (Casale, Wild et al. 2013). Social support in resource rich settings is consistently associated with positive outcomes in adult cancer patients; including better adjustment to cancer, coping, and quality of life and lower levels of depression (Trevino, Fasciano et al. 2013). Similar findings have been witnessed in studies with paediatric and adolescent cancer patients and survivors of childhood cancer in resource rich settings (Ishibashi 2001, Woodgate 2006). In these populations, greater social support is also associated with the development of healthy coping strategies and interpersonal relationships.

Although friendships have been found to play an important role in the health and well-being of young people with chronic illnesses such as cancer (Tomé, de Matos et al. 2014), little

research has been done about friendship particularly its role in HIV management in any setting across the world. The stigmatised and secretive nature of HIV as a condition even in the context of ART, might account for this gap in the literature. It is important to consider how friendship may shape or counter some of the deleterious effects of stigma.

As with other chronic diseases, research from HIV adult populations confirms that receiving social support from significant social network members can promote positive psychological adjustment in PLHIV (Oppong 2012). Moreover, a recent study amongst people living with HIV and AIDS in South Africa showed that individuals who were satisfied with the amount of support available to them tended to experience less psychological distress, a higher quality of life, and more self-esteem; whereas those who perceive that they have access to low levels of social support reported experiencing higher levels of distress (Casale, Wild et al. 2013). Access to social support was also associated with gender, and men tended to benefit more from it than women living with HIV (Oppong 2012). One explanation given for the gender difference was that women in the study did not want to give up on their caring responsibility hence unsolicited support might have been interpreted to mean that they were failing to satisfy their prescribed roles. Men on the other hand, are generally recipients of care hence they could have been grateful to receive care and support from relatives and friends (Oppong 2012).

The significance of having access to emotional social support in the lives of young people with HIV is now being recognised as likely to be a significant determinant in their psychosocial response to the experience of HIV and treatment outcomes in resource stretched settings (Gillard and Roark 2013). In resource rich settings, it was found that satisfaction with social support was directly associated with lower levels of depression among HIV-infected adolescents in 13 USA cities (Murphy, Moscicki et al. 2000).

Although social support is cited as being of paramount importance as it improves coping skills and self-esteem, which results in improved psychological wellbeing in young people, disclosure is expected (Menon, Glazebrook et al. 2007, Di Risio, Ballantyne et al. 2011, Mavhu, Berwick et al. 2013). Knowing one's HIV status is a requirement for accessing most of the psychosocial support services available in Zimbabwe (Mavhu, Berwick et al. 2013). This presents problems if disclosure of one's status is difficult, as may be the case for young people in particular circumstances (Gillard and Roark 2013). Sometimes being aware of one's HIV status does not necessarily mean being prepared to disclose to other regardless of the social spaces. This study sought to explore how young people manage to access and benefit from social support and whether, and in what ways, non-disclosure affects their experiences of living with HIV, including in relation to their well-being.

There are only a few studies which have focused on peer groups for HIV- infected young people in Sub-Saharan Africa (Menon, Glazebrook et al. 2007, Midtbø, Shirima et al. 2012, Mavhu, Berwick et al. 2013). These have highlighted peer groups' inherent value in providing HIV information and a social space to share, learn and mix with other HIV-infected children. Studies conducted in Tanzania and Botswana found support groups to be a valuable resource for HIV positive young people (Midtbø, Shirima et al. 2012). Young people who attended more formalised support groups gained HIV knowledge, reported reduced levels of stress and were said to benefit from receiving support from fellow members (Midtbø, Shirima et al. 2012).

A study in Zambia found that HIV-infected young people involved in a peer-support group appreciated meeting and talking to other young people who were HIV positive (Menon, Glazebrook et al. 2007). In the same study, young people valued the importance of meeting and talking to other HIV-infected young people in peer-support groups. Three young people were reported to have refused to participate in support groups but their reasons were not explained. The refusal to participate could point to some of the unexplored structural barriers that limit young people's access to support groups. Very few studies have looked at the barriers that limit young people's access and participation in these formalised support groups (Mupambireyi, Bernays et al. 2014).

Overall, there is a lack of a strong evidence base on the importance and relevance of social support in the Sub-Saharan African region which further points to the clinical emphasis in paediatric HIV management discussed in Chapter 1. This clinical emphasis which was bone out of the clinical urgency has resulted in little exploration of the social lives and psychosocial needs of young people living with HIV outside of the clinic settings. But as the clinical situation becomes less about life and death, there is need for more exploration of the social components of growing up with HIV to improve the quality of life of people. This focus on the social for example, how stigma may affect adherence is likely to also strengthen the clinical responses. The success of clinical interventions lies in understanding and addressing some of the social cultural and the wider social environment in which these young people are raised (Busza, Dauya et al. 2014). Due to the limited evidence in this region, I will draw lessons from resource rich settings in the ensuing discussion.

Research conducted in resource rich settings has demonstrated the value of peer-support groups for HIV positive young people. For example, a study in Paris, found that young people who were attending support groups were coping well with their HIV positive diagnosis (Funck-Brentano, Dalban et al. 2005). In Canada, it was found that support groups had beneficial effects on young people's acceptance and perceptions of their HIV infection (Di Risio,

Ballantyne et al. 2011). Peer-support groups were also crucial for sharing and learning as they provided a valuable platform where HIV-infected young people openly talked and shared experiences of living with HIV (Di Risio, Ballantyne et al. 2011). Although peer support groups are considered to be helpful, there is an assumption that these social networks or groups are available and accessible to HIV-infected young people. Earlier studies looked at the benefits but did not look at the challenges of accessing support groups from the young people's perspectives (Menon, Glazebrook et al. 2007, Peterson, Rintamaki et al. 2012). This study sought to describe the perceived benefits and overall challenges in accessing support groups faced by HIV perinatally infected young people in Zimbabwe.

Having discussed the role of social support generally, this PhD research adopted the definition of support given by Dennis who defined it as the:

"the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person" (Dennis 2003:329).

This definition falls within the social support model, which is defined as the process through which social relationships might promote health and well-being (Cohen 2004). Friends may have a greater understanding of an individual's situation than a member of their own family, and are capable of making one feel that he or she is cared for, loved, esteemed, and valued (Xia, Liu et al. 2012). Social support in this study includes both formal and informal forms of support. Formal-support is the support that young people receive through their interaction with other HIV infected young people and facilitators during or after attending support groups, as well as their exposure to support groups while informal is support received from peers in their sphere of influence. The term peer-support is used in this study to refer to young people who are both HIV-infected and those who share the same demographic characteristic i.e. playmates, classmates and age mates who may not necessarily be HIV-infected and this could be either formal or informal. Table 2.1 below, summaries the evidence and gaps identified through this review.

Topic	Evidence	Gaps
Disclosure	Carers delay disclosure considering young people to be too young to comprehend what HIV status is /means Disclosure is taken as an event rather than a process	How young people engage with the decision to disclose to others: <ul style="list-style-type: none"> · Do they disclose? · Why do they choose / chose not to disclose? · With what effect? young people's attitudes and experiences of disclosing to others
Adherence	Barriers and facilitators to adherence	Do peer support networks influence young people's adherence to ART
Stigma	Barrier to access to services including support services	How ART has impacted on stigma in HIV perinatally infected young people How lasting is the label of "innocent victims" commonly applied to HIV perinatally infected young people Does stigma go away because young people acquired HIV in a non-behavioural way
Social support	Role of social support in improving health outcomes	Implications of HIV on peer acceptance Role of friendship in HIV management Barriers and facilitators in accessing support services. What are the young people's perception of support services

Table 2.1 Summary of the evidence and gaps

2.7 Conclusion

This chapter has provided an overview of what current research illustrates about the experiences of young people living with HIV in Sub-Saharan Africa, in particular focusing on their experiences of disclosure and adherence experience as well as the forms of stigma which may shape their broader experiences. This chapter has also highlighted the perceived value of social support and the gaps that exist in the current literature on this topic and as such the areas that this study aims to contribute to. In the next chapter, I presents finding of the literature review on the use of audio diaries with young people.

3.0 Researching young people

The nature of social knowledge does not only extend to validity of qualitative inquiry but also to the capacity of different subjects to produce valid and credible social knowledge. There has been a global shift from positioning children as objects of research to being subjects of research (Christensen and James 2000). For a significant period of time, children's lives and experiences have been solely accessed through interpretations of adults (parents/carers and professionals) (Coad and Evans 2008). In Western countries, the exclusion of children as research participants was grounded in two dogmas: firstly the belief that data from children were unreliable and invalid (Evans and Becker 2009); secondly, the ethical concerns over children's vulnerability to exploitation by researchers (Kirk 2007).

Children were believed to be less capable of articulating their experiences than adults (Christensen and James 2000). Researchers who used adults as proxies argued that children were too immature to have an adequate understanding of their social worlds and as such were said not to be competent enough to talk about their experiences (Kirk 2007). Socialisation models tend to be guided by 'top-down' relationships of adults imposing their ideas on children, rather than viewing children as active agents in constructing their own representations of their lives and experiences (Thorne 1993).

3.1 Children as competent beings

Corsaro (2011) contends that children's accounts must be taken as valid in their own right as that is how they understand their world. He argues that children must be seen as social actors in the production of knowledge and meaning about being a child, and about their health especially in the context of HIV (Corsaro 2010). Therefore, excluding children in research is seen as a major weakness which down plays children's agency. It is argued that it's not appropriate to rely on and generalize research with adult population to children's experiences, as children understand their social worlds in their own terms which may be very different from adults (James and Prout 1997). With emphasis on children's agency, children perinatally infected with HIV should play a more active role and have a say in issues that affect them including on their treatment, care, disclosure, research and policy. Children must be seen as capable beings in their own rights who can speak on their own behalf about issues that concern them.

During the first decade of HIV literature on HIV in sub-Saharan Africa was not exceptional as it was largely unmindful of children's agency. Although there were many examples of children's interdependence rather than mere dependency on adults for care and support, the notion that

children are passive victims in need of adult care and support, predominated in studies looking at HIV-affected children. The focus however changed and researchers realised the importance of HIV infected and affected children's perspectives (Skovdal 2011, Evans and Becker 2009). Although there have been a call to use participatory research tools that aid children's story telling there have been very few reviews that have looked at the benefits of using these participatory tools with children.

In conducting the qualitative study, I constantly had to respond to questions about talking with children, which were raised by the clinical trial team and ethics reviewers. The main issue raised was the feasibility of obtaining 'useful and valid' data from 11-13 years olds using qualitative research methods. Firstly, the project principal investigator and myself gave a presentation to the trial team to explain and discuss the importance of qualitative studies nested within clinical trials and in particular the multi-site qualitative study in which this PhD thesis was nested. Discussions included the rationale behind the research design and the various methods that we were going to use to elicit children's stories. I responded in writing to the comments raised by the reviewers concerning the appropriateness of the intended age group, citing the arguments outlined earlier in previous chapter, as well as providing more detailed information on the research tools that I had planned to use for data collection (discussed later in this chapter). Of importance was the fact that the study was longitudinal, hence it was designed in a way that would nurture rapport and allow children time to develop trust and to feel comfortable talking to the researcher. But it was also underpinned by the principle that if we can provide an environment where children are comfortable to talk about their experiences, then by listening we create a valuable opportunity to learn from them (Evans and Becker 2009).

At household level, some carers felt that it was important for the carer to sit in on the interviews to help children respond to the questions. Most carers were not convinced that the 11-13 year olds were capable of articulating their experiences. I constantly had to assure them that suitable methods that were tailor-made to suit the young children would be used. Even though the concept of agency was subject to significant theoretical consideration, the agency of children and their capacity to participate in research was still considered to be bounded by relational and cultural factors specific to their contexts.

The challenges that I faced in securing access to children as participants at these various levels reflect the structures which bind the agency of children to articulate, as well as to shape, their experiences. There is remarkable neglect relating to children's agency both at national and household level. At the national level, ethics Institutional Review Boards (IRBs) still doubt the proficiency of young children to participate in research and most reviewers questioned why

the study intended to interview more children (n=26) than carers (n=10) and felt that it should be the other way round. More of these ethical dilemmas are discussed in detail later in this chapter under Ethics.

In the past, uncertainties balancing the value of participation with protection of children's rights have been a major stumbling block to securing ethical approval from IRBs in the global north. This has, however, been challenged by the new sociology of childhood which argues that studying children does not necessarily mean using different methods and ethical guidelines but requires rigorous application of the general methods that are used in adult studies (Christensen and James 2000, James and Prout 2010, Daley 2015). Although children are now being increasingly recognised as competent beings in research, there are important ways in which ethical issues and the actual conduct of research become more pronounced when dealing with children as participants. This is mostly to do with the children's understanding and experience of the world being different from that of many adults and because of children's communication skills and power relationships.

Globally, ethical considerations in conducting research with or about children have shifted significantly from a predominant focus on a protectionist discourse, which positioned children as vulnerable and requiring safeguarding by adults, to an emphasis on recognising children's agency and competency, and highlighting children's right to participate in research (Dockett and Perry 2011, Daley 2015). As such the research world is evolving and the reliance on children as participants is growing, although it is interesting that many researchers still encounter surprises from funders, ethic boards and other researchers that they are able to do research with children. This illustrates that this discourse still has influence, even if it does not predominate anymore.

Informed consent, for example, is complicated when enrolling children into research because children are deemed incompetent to give consent, they can only be deemed able to give assent (Dockett and Perry 2011, Bwakura-Dangarembizi, Musesengwa et al. 2012). Children's assent is only deemed sufficient if it is accompanied by adult consent (Dockett and Perry 2011). The ethical conduct of such research is also complicated by the fact that children are perceived to be less able to protect themselves than most adults. This makes protection from abuse a less straightforward process than is often assumed. All these challenging factors result in greater caution amongst ethics boards to approve research with young children.

In the African context, children's participation in research was, for a long time, considered unethical. However, this view is shifting (Bwakura-Dangarembizi, Musesengwa et al. 2012). This has been encouraged in part by the principle of children's rights to participation, which is enshrined in the United Nations Convention on the Rights of the Child (UNCRC) of 1998 article

12 (Dockett and Perry 2011). Although an increasing amount of paediatric clinical research is taking place in Africa, ethical principles guiding the research processes are still modelled along western laws of ethics mainly because of the principle of universalism. The Helsinki Declaration widely adopted by many countries, including Zimbabwe, was designed narrowly for a few countries. The challenge is that the principles arising from this framework are not necessarily tailored to suit African contexts.

An example is the requirement of a legally authorised representative to provide consent on behalf of a minor in cases where the child's parents are deceased. This is challenging as most of the foster care arrangements that take place in Africa are not legalised per se and although carers/guardians fulfil significant responsibilities in terms of caring for the child, this may not be formally recognised. Obtaining informed consent from guardians of orphaned children may be very difficult, considering the fluidity of care arrangements and the extended family support network in the African context, and is likely to be of particular pertinence when conducting research with children living with HIV.

Another example is the age that a child can be when they are deemed old enough to consent for themselves. This may differ across countries; some countries have put it at 16 while in other countries 18 (Wheeler 2006). For example, in the United Kingdom research with children and the ethical dilemmas of who needs to be consulted to give informed consent is shaped by legal precedent pertaining the British jurisdiction referred to as the Gillick ruling (Wheeler 2006, Fortin 2011). The Gillick ruling refers to a legal case which specifically looked at whether doctors should be able to give contraceptive advice or treatment to under 16 year olds. However, this ruling does not apply in Zimbabwe or other African countries where parental/guardian consent is required. In Zimbabwe any children below the age of 18 are deemed incompetent of giving consent with the exception of emancipated minors. The Medical Research Council (MRCZ) regards children below 18 years who are mothers themselves and children heading households as emancipated minors and are considered capable of consenting on their own (www.mrcz.org.zw).

Researching children requires the use of appropriate research methods which are sensitive to children's competencies and interests and allows children to be active participants (Punch 2002, Kirk 2007, Coad and Evans 2008). This does not rule out traditional approaches but these may need to be enhanced in order to afford children the maximum opportunity to express their views. Innovative research methods that are child-friendly have been suggested as a way of enhancing children's participation in research. This thesis seek proposes to use pilot the use of audio diaries in eliciting the experiences of children living with HIV.

3.2 Background to the literature review

This thesis seeks to be part of the growing body of literature that demonstrates that children are competent research participants whose accounts have their own validity (Kirk 2007, Dockett and Perry 2011). However researchers have to adopt appropriate research methods that aid young people's story telling. By conducting this review I want to first establish whether audio diaries have been used in research with young people and then explore the benefits of using the audio diaries with young people.

3.3 Objective of the literature review

To review published studies that have used audio diaries in capturing the experiences of young people.

3.3.1 Specific objectives

1. To determine whether audio diaries have been used to explore the experience of young people
2. To establish the benefits of using audio diaries as an innovative method with young people.

3.4 Methods for the literature review

3.4.1 Inclusion criteria

Publications were eligible for inclusion if they:

1. Reported qualitative findings on young people aged 24 years and below.
2. Used audio diaries entirely or in combination with other qualitative research methods.
3. Were published in English and in peer reviewed journals by December 2011.

3.4.2 Exclusion

Studies were excluded from the review if they did not primarily interview children (24 years and below) even though they report on the experience of young people. This review also excluded studies that were not published in English. Conference abstracts were excluded from this review as they rarely provide detailed results making it difficult to assess their eligibility in this review.

3.5 Search strategy

The review looked at studies published by December 2011. Studies published in peer-reviewed journals were retrieved from two electronic databases: Pubmed/Medline and Scopus using key word searches and Key Medical Subject Headings (MeSH) headings. Keywords

searches “children” or “child” or “adolescents” or “youth” or “young people” AND “audio diaries” as shown in table below. All studies identified during the database search were assessed for relevance to the review based on the information provided in the abstract and descriptor/MeSH terms. The review topic was split into two components (Children and audio diaries). I read relevant literature in order to identify all the synonyms for children and audio diaries. Free text searches were conducted for all the synonyms and then using the MeSH. I combined all the searches in each component using the Boolean operator “OR”. Lastly I conducted a final search with components joined together with the operator “AND” as shown in table 3.1 below.

Concept Children	Concept audio diaries
child*	Audio diar*
adolescen*	(MeSH specific to Scopus and PubMed)
young people	All the above were combined with operator “or”
Youth	
Teen*	
Minor	
MeSH specific to Scopus and PubMed	
All the above were combined with operator “OR”	
Results from concept 1 and concept 2 were brought together using the operator “AND”.	

Table 3.1: Search terms used

3.6 Assessment of quality of included studies

My colleague and I first assessed the independently then jointly. Quality of the studies was assessed by looking at the study design, participants’ characteristics, clear statement and aims, data collection methods described and appropriate report on ethical procedures and analysis adequately described.

3.7 Results of the systematic review

After duplicates were removed, there were 22 studies and only 5 met the inclusion criteria (figure 3.1 below). 15 studies were rejected as they did not interview young people while 2 studies did not use audio diaries. Figure 3.1 below, summarises the review process.

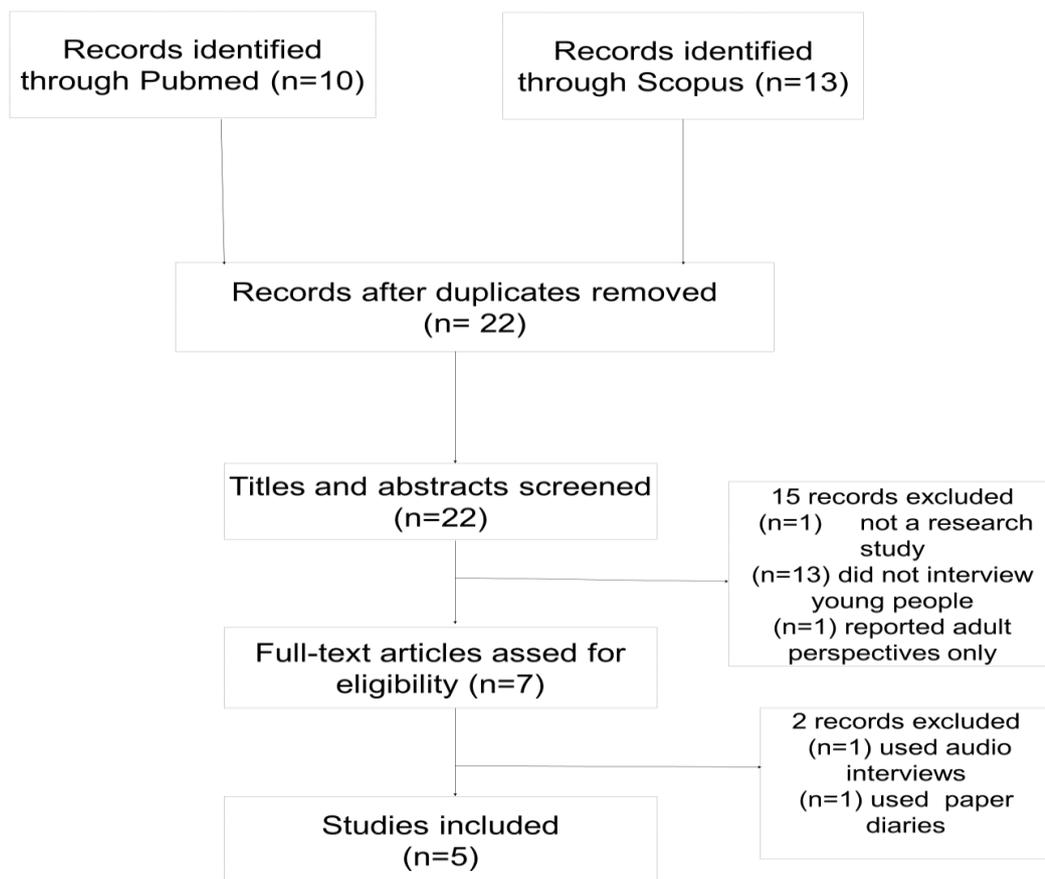


Figure 3.1: Study search process

3.7.1 Study design and characteristics of included studies

All the studies were predominantly longitudinal qualitative studies (4 of 5) with only 1 (study 1) being a once off study nested within a longitudinal study. All the five studies, used audio diaries and individual interviews. All the studies were conducted in resource rich settings (United Kingdom 3, USA 1 and Canada 1). There was a wide variation in the sample sizes of participants who actually used the audio diary method, ranging from 1 participant to 22 participants. The ages of participants ranged from 11 to 25 years old as shown in Table 3.2 below. All the studies were perceived to be of good quality as they reported on the study design, data analysis procedures and clearly stated their aims and objectives as shown in table 3.3.

Study number	Date published	Country	Authors ref	Age of participants	Study design	Number of participants who used audio diaries	Data collection methods
1	2007	USA	(Cunningham, Meyers et al. 2007)	14-19 year old females	Sub study to a longitudinal study	3	In-depth interviews and Audio diaries
2	2007	United Kingdom	(Nicholls 2007)	16 year old male	Longitudinal study	1	Audio diary and semi structured interviews
3	2009	United Kingdom	(Worth 2009)	16-25 year olds	Longitudinal study	22	Narrative Interviews and audio diaries
4	2010	Canada	(Tamminen and Holt 2010)	Mean age of 16 years	Longitudinal study	13	Audio diaries and interviews
5	2011	United Kingdom	(Sargeant and Gross 2011)	11-16 year olds	Longitudinal study	6	Interview and Audio diaries

Table 3.1: Characteristics of included studies

Study number and Author	1. Cunning (2007)	2. Nicholls (2007)	3. Worth (2009)
Paper reports findings from qualitative methods	Yes – mixed methods	Yes	Yes
Clear statement on aims/objectives	Yes- to explore the decision-making process for disclosure of STI diagnoses to sex partners among adolescent females in Baltimore City, MD	Yes- to examine the stress and coping experiences of an international golfer during a training program for coping	Yes- to examine the use of audio diaries as an innovative method for research with young people
Sampling strategy explained	Yes- participants were recruited from a longitudinal study to represent 14-19 year olds who had tested positive for chlamydia or gonorrhoea	Not discussed	Yes- participants were recruited via phone or email following a longitudinal study to represent visually impaired young people
Data collection methods explained	Yes- semi structured interviews and audio diaries	Yes-audio diaries and interviews	Yes- audio diaries and narrative interviews
Mention of ethical considerations	Informed consent obtained and parental consent was not required	Parental consent was obtained	Assent obtained in the main longitudinal study
Theoretical approach mentioned	Grounded theory- identified emergent themes and relationships between themes	Phenomenological qualitative analysis- line by line coding	Thematic narrative analysis
Sufficient data presented to support the results	Yes-quotes provided	Yes- quotes included	Yes quotes included
Results section reflects on the use of audio diaries	No reflections on the audio diary in the results section	No reflections on the audio diary in the results section	Yes reflected on methodological value of using audio diaries
Quality rating	Good	Good	Good

Table 3.2: Quality assessment of included studies

Study number and Author	4. Tamminen and Holt (2010)	5. Sargeant and Gross (2011)
Paper reports findings from qualitative methods	Yes	Yes
Clear statement on aims/objectives	Yes- to examine how female adolescents athletes attempted to cope with stress over the course of a season	Yes- to identify how and in what ways young people achieve a balance between the demands of an inflammatory bowel disease (IBD) and developing independence as they mature
Sampling strategy explained	Yes- purposively selected a basketball team with a reputation of performance excellence	Yes- recruited from clinic records to represent young people diagnosed with IBD
Data collection methods explained	Yes- interviews and audio diaries	Yes- interviews and audio diaries
Mention of ethical considerations	Parental consent and assent was obtained	Parental consent and assent was obtained
Theoretical approach mentioned	Inductive content analysis and content analysis	Positioning theory
Sufficient data presented to support the results	Yes- quotes included	Yes- quotes included
Results section reflects on the use of audio diaries	No reflections on the audio diary in the results section	Yes- reflected on methodological value of using audio diaries
Quality rating	Good	Good

Table 3.3 continued

3. 7.2 Using audio diaries with young people

In the included studies, young people were able to use the audio diaries to capture their varying experiences. However, a common thread in four of the five studies was the use of guide or prompt sheets as optional strategies to aid young people in using the audio diary methods, with the exception of one study (study 1). In three studies (study 2, 4 and 6) the prompts were in the form of questions related to the issue under study while in study 3 the prompts were broad topics. In all the four studies, the prompts were however optional and young people were told that they were not limited to questions or topics outlined on the prompts sheets but that they were free to choose the context and focus of their diaries. A few participants were reported to have ignored the prompt questions and topics and were highly flexible in the content they chose to record.

In all the studies, audio diaries were accompanied by follow-up interviews and debriefing sessions in which the researcher sought clarity and detailed descriptions of issues raised in the diaries. In two of the studies (3 and 5) young people became more confident in using the method as they continued to record files and continued to use the method. In one of the studies (study 3), the first recordings were short and did not have detailed description regarding young people's experiences, but became longer and more detailed with subsequent recordings. This highlights the importance of investing in time for young people to gain confidence in using the method as well as the importance of supporting young people with guidelines for example on how to use the recorders and what issues to record.

3.7.3 The benefits of using audio diaries with young people

Only two of the five studies reviewed (study 3 and 5), reflected on the audio diary method in the findings section. In these two studies young people had control of the method as they decided when, where and what to record. In study 3 young people were able to edit and erase files they were not prepared to share and again emphasising the control that young people had when using the audio diary method in this study. The two studies (study 3 and 5) that reflected on the methodological value of using audio diaries also cited that the method was less intimidating to participants and lessened the pressure resulting from physical presence of the interviewer. Children were able to record the diaries in the comfort of their homes at their own convenience. The young people adapted the audio diaries to suit their own schedules making audio diaries fit in with their lives. In the same studies, young people were reported to having enjoyed keeping the audio diaries and were able to fully engage with the method.

The audio diary was described as a novel method that can capture ongoing processes of young people's everyday lives, which is often difficult with face- to face interviews. Most of the cited quotes captured young people's emotions and feelings in real time. For example, in study

3 one of the participants recorded her diary when she had just returned from a Maths exam. In the diary she shared her frustrations and anger at the unfairness of the exam as some of the diagrams were inaccessible to visually impaired people.

The audio diary method also facilitated a reflection process where young people reflected on their experiences. This prompted diarists to build on their previous recordings and detail how previous events were influencing their current experiences. For example, in study 5 which was exploring how young people were managing to live with IBD, one participant expressed her fears around traveling by air by reflecting on what had happened on a previous flight several months earlier, when she went for a holiday soon after her recovery from an operation. The event was linked to her upcoming holiday. The holiday narrative is cited an example of the value of using audio diaries as they capture rich detail that may not be directly linked to the condition but characterise the experiences of living with a particular condition.

3.7.4 Audio diary as an innovative method in resource stretched settings

Although the audio diary method has been used to explore experiences of young people, this review shows that by 2011, the method had not been used in resource stretched settings, nor was it widely used in resource rich setting. Only five studies were identified as having used the audio diary method in resource rich settings, meaning that audio diaries can still be considered an innovative research method especially when researching young people. Additionally the audio diaries have not been used to explore young people's experiences of HIV making this a novel method to explore with young people living with HIV in Zimbabwe.

3.8 Strength and limitations of this literature review.

The major strength of this review is that this is the only review to date that has evaluated the use of audio diaries with young people. Given the push for innovative methods that facilitate the process of conducting high quality, in-depth qualitative research with young people, audio diaries may be an important addition to the methods tool box. Audio diaries have been shown to prompt young people to reflect on their experiences, at the same time as providing scope for reflection of experiences in real time. This method can therefore provide a route to access young people's social worlds. One limitation of this review is that it relied on published studies alone and excluded unpublished literature. Although this is common in most reviews, it has the potential to bias the findings.

3.9 Conclusion

This review has shown that audio diaries can be used with young people, although they have not been used in resource stretched settings. Their greatest advantage is allowing young people the flexibility to choose when, where and what to record thereby giving them more control of the method than some more traditional qualitative methods such as face to face

interviews. Audio diaries are also good at prompting young people to reflect on their experiences, which may not necessary be directly related to the condition under study, but might have a bearing on their overall experiences. This review suggests that there is scope to explore the use of audio diaries with young people in resource stretched settings. It is clear that they also need to invest time in building the competence and confidence of young people in using the method.

CHAPTER 4: THEORETICAL FRAMEWORK

4.1 Chapter overview

This chapter discusses the macro and core theoretical concepts that frame this study. The overarching theme of bounded agency is influenced by Giddens's structuration theory. The structure-agency debate is largely framed around how individual actions are either enabled or constrained by social structures. The study particularly focuses on young people's agency, which has been characterised as largely bounded by intergenerational relations and the dynamics at play within their socioeconomic contexts. I give an overview of how childhood is conceptualized in different contexts, highlighting the main differences in the construction of childhood between the global north and south. I argue that normative constructions of how young people should be and should not be, broadly shape the lived experiences, perceptions and aspirations of children. Lastly, I discuss the stigma theory as it significantly influences our understanding of children's perception of themselves and their experience of and access to care and support.

4.2 Bounded Agency

Human action and structure are perceived to be intertwined. Individuals are socialized and become reliant on existing social structures but at the same time they change the social structures by their activities (Broger 2011). Social structures in this case are the institutions, rules and resources which determine the range of possibilities for action (McAnulla 2005, Hay 1995). The structuration theory argues that social structures are not fixed but can be changed and replaced or reproduced differently (Turner 1986, Parker 2000). Structuration theory recognises that agents are both knowledgeable and reflexive. This implies that individuals monitor their activities and others with their social contexts. Individuals have the capacity to reflect on their actions and intentions (Giddens 1984). The theory argues that actors can account for their actions.

Giddens's structuration theory, even with its own limitation of conflating structure and agency (Archer 1982), has been cited as influential in childhood studies (King 2007, Valentine 2011). Young people's agency is now a key theoretical development in the 'new sociology of childhood' (Qvortrup, Corsaro et al. 2009, Brady, Lowe et al. 2015). More recent studies have demonstrated children's competence and knowledge. Young people are seen as capable of acting, influencing structures and systems in their contexts. Although structural forces such as poverty, disease and adult dominance constrain young people, some young people still find ways of responding to such structures. An example has been their response to HIV/AIDS epidemic. Young people demonstrate their agency through their caring roles, domestic chores

and income generating activities as well as living with and managing a lifelong terminal infection as well as negotiating relationships with adults and other young people (Evans and Becker 2009, Skovdal and Ogutu 2009, Parsons 2012, Skovdal and Daniel 2012). Despite the constraints, young people express their agency through their resourcefulness in managing and sustaining households.

Young people's agency is described as a situated process, "shaped by the experiences of the past, the chances present in the current moment and the perceptions of possible futures" (Evans 2002 :248). Although young people should be seen as social actors whose societal concepts are constructed and negotiated within a social fabric, they are subjected to a number of boundaries which restrict and sometimes prevent the expression of their agency (Evans 2007, Hamilton and Adamson 2013, Bergnehr and Nelson 2015, Brady, Lowe et al. 2015). Stigma and discrimination discussed in the previous chapter, are some examples of the structural issues that largely shape young people's agency. HIV-infected young people have to constantly negotiate and find ways to evade stigma and discrimination.

One of the starting points is the inequitable access to information regarding their own HIV status. Carers are often the ones who decide when and how much information to disclose using their own discretion although they are also subject to wider structural conditions and social relationships, where other might disclose their child's status against their will. In other words, everyone to varying degrees has their agency bounded by the relationship and structural conditions. As discussed in Chapter 2, even after disclosure, discussion of HIV status remains largely controlled by adults and young people are expected to seek authorization to disclose their own HIV status (Mburu, Ram et al. 2014). Social norms and expectations about what would happen should people know contribute to the secrecy that shroud HIV status disclosure. The social norms form the social fabric in which children's agency is exercised, hence their experiences of growing up with HIV, are influenced by a number of factors, including those located beyond themselves (Brady, Lowe et al. 2015). Understanding these structural factors that bound children's agency and how the interaction of these structures and children's agency within this framework significantly influence how young people experience HIV and how they engage with support interventions.

Skovdal (2012, Skovdal and Ogutu 2013) alludes to the predominant discourse that views HIV-infected and affected young people as helpless, vulnerable and victims. Much of the paediatric HIV research in Sub-Saharan Africa is framed around illness and weakness, despite the majority of young people being relatively healthy and doing well on treatment (Skovdal and Ogutu 2013, Bernays, Seeley et al. 2015). Despite the increasing availability of ART, HIV is still viewed as imminent death and people living with HIV, especially children, are perceived

to be intrinsically fragile (Mburu, Ram et al. 2014). This has created representations of HIV positive young people as weak, sick and vulnerable (Bernays, Seeley et al. 2015). Such representations persistently deny and ignore the agency that young people exhibit in shaping their experiences. Such discourse contributes to the structures which constrain their agency in this fixed mould of weak and sickly.

As outlined above, although surrounded by many structural barriers which include adult and peer surveillance, HIV-infected and affected young people negotiate and find ways to express their agency (Skovdal and Daniel 2012). Young people are not simply passive objects but they make decisions and respond to the social world in which they live (Skovdal and Daniel 2012, Hamilton and Adamson 2013). There is a need to look for subtle manifestations of young people's agency instead of describing them inaccurately as operating without agency. Bourdillon (2000) argues that despite having limited autonomy, young people constantly negotiate and renegotiate their position with adults and other young people, as well as finding ways to work within rules and norms. This illustrates that it is not a question of young people versus adults, but also about negotiating with other individuals - in this study I describe how HIV infected young people negotiate with their peers.

Young people's health, wellbeing and agency are described as 'relational and embedded' (Watson, Emery et al. 2012, Bergnehr and Nelson 2015). For young people growing up with HIV and taking treatment, this interplay of structure and agency happens within a range of different care environments which include household, clinic, school, church, support group and within peer networks. This, therefore, highlights the need to examine the relational, institutional and symbolic influences of these different care environments on young people's uptake of HIV services. The young people's capabilities to manage their HIV status, treatment and developing coping mechanisms are largely rooted in the specific social and historical contexts in which they live.

Having highlighted the concept of bounded agency, the next section looks at how childhood is contextualised. The contextualization of young people has a significant bearing on their agency, for example, the position they occupy in the household determines, to some extent, their capacity to make decisions within and outside their households. Appreciation of social definitions of childhood is important because any society's perspective on the treatment of young people is largely dependent on how that society constructs childhood.

4.3 Contextualizing childhood

The experiences of childhood have remained very diverse world-wide and within communities and continue to be inevitably heavily shaped by social, economic and cultural factors (Frønes

1997). Sociologists (James and Prout 1997, Qvortrup, Corsaro et al. 2009) have been calling for some time for childhood to be regarded as a social construction that is context and time specific rather than a natural universal phenomenon (James, Jenks et al. 1998). The following section discusses the diversity in discourses on young people and childhoods between the global north and south.

Within western societies there is a predominant and widely held belief that childhood is a special protected period and that adults, government agencies and authorities are responsible for protecting young people until their smooth transition into adulthood (Evans and Becker 2009). 'Normal' childhood in the global north is characterised by being playful, work free, dependent, vulnerable and care receiving (Abebe 2007). The relationship between adults and young people is broadly considered to be that care is given in one direction rather than being based on mutual care and support or horizontal care within childhood. This notion portrays young people as weak, dependent and vulnerable beings that need adult protection until such a time as they reach adulthood (Abebe 2007, Morrow 2008, Montgomery 2009).

This is contrary to many global south contexts where young people's lives are dominated by work, which in the Western construction would be considered a supposedly "adult" preoccupation (Robson and Ansell 2000, Punch 2003, Abebe 2009, Brobbey 2011). In most African societies, young people are involved in numerous domestic and productive activities (Evans and Becker 2009, Chizororo 2010) and this work has its own socio cultural meaning. Young people's work must therefore be understood within its social, historical and cultural context (Brobbey 2011).

HIV and AIDS have redefined childhood in the global south with some young people becoming de-facto household heads caring for sick parents and looking after siblings (Robson, Ansell et al. 2006, Evans and Becker 2009). Under the western construction of childhood, such young people would be looked at as "abnormal, troubled and vulnerable to psychosocial distress and in need of adult care" (Bourdillon 2006, Abebe and Skovdal 2010).

Referring to young people in the global south as 'cared for dependants' or as having missed or been without childhood, might be misplaced as this ignores the significant contributions that they make through their caring roles and income generation (Abebe 2009). The portrayal that there is an absence of childhood privileges the norm of a particularly Westernised cultural expectation of childhood which may not be an appropriate characterisation for all settings in the global south (Abebe 2007). This notion of dependency and vulnerability ignores young people's agency and fails to appreciate cultural diversity in relation to young people and work (Bourdillon 2006). This highlights the shortcomings of decontextualizing young people by conceptualising them as a homogeneous global social category. Having said this I must point

out that many settings in the global south are changing to consider childhood in a way that is more commensurate with Westernised understandings (Twum-Danso Imoh and Ame 2012).

Despite the contribution that young people may make and the different notions of what it means to be a child, it is characterised by relational hierarchy (Evans and Becker 2009, Chizororo 2010). This hierarchy is not fixed but changes as young people grow, develop and respond to the circumstances of their personal social contexts (Brady, Lowe et al. 2015). As such it demands an understanding of how childhood is constructed and what is competing discourses may be influencing how it is considered.

4.3.1 Childhood in Zimbabwe

Having highlighted the diversity of childhood in different contexts, it is important to highlight how young people are conceptualized in Zimbabwe. Childhood in Zimbabwe is shaped by a hybrid range of influences, including modern legislation, economic conditions, traditional values and the influence of HIV/AIDS (Kesby, Gwanzura-Ottmoller et al. 2006). The majority of households are built around patrilineal and patri-local kinship systems and are shaped by patriarchal notions of authority in which young people occupy the lowest position in the gendered and generational hierarchy (Bourdillon 2000).

However, despite their socio-political marginalisation, young people are traditionally highly valued, including through their household contributions either as carers, and through income generation (Skovdal, Magutshwa-Zitha et al. 2013). In Zimbabwe, for example, young people are expected to make meaningful contributions to households either through engaging in income generating activities or through performing household chores including looking after young siblings (Bourdillon 2000, Chizororo 2010, Skovdal, Magutshwa-Zitha et al. 2013). Although young people are protected in terms of making sure that they are safe, they make significant daily contributions to the households they live in (Loewenson and Kerkhoven 1996, Cluver, Orkin et al. 2012, Parsons 2012).

Childhood is highly gendered for example the childhood of boys is often very different from that of girls even when living in the same household and or context. Although occupying the lowest positions in their communities, gender-based hierarchies and roles also exist between young people themselves. Young people of the same age are expected to perform different duties within the household with girls doing more domestic, household chores while boys perform outdoor duties such as cattle rearing (Gelfand 1975, Chizororo 2010). Young people's relations with each other are also shaped by these gendered hierarchies and roles, with boys tending to occupy a more senior position than girls. Within households, gender shapes divergent life courses and opportunities among young people, although not in the same way between rural and urban areas (Chizororo 2010). For example, girls in rural areas tend to

perform adult duties such as cooking well before their age mates in the urban areas. There is also hierarchy within gender which draws on other characteristics other than age and gender such as a higher status conferred by biological connection to the carer versus orphaning or health.

This section has highlighted that there are multiple notions of childhood throughout the world, and described how childhood is conceptualized in Zimbabwe. This global diversity cautions against generalising childhood. There is need to be attentive to the cultural and social contexts which shape contemporary notions of childhood within a community. Relevant to this study, young people's HIV experiences must be considered in the social, economic and cultural contexts in which they occur.

The conceptualisation of childhood is important in characterising young people's experiences of growing up with HIV in terms of the position they occupy within the household and how much freedom young people are permitted to have (Qvortrup et al 2011). The gendered and generational hierarchy in which young people occupy a subordinate position, constrains their ability to talk freely about their HIV status. Despite the subordinate position they occupy in the described generational order, young people manage to express their agency in a number of ways. The following section highlights how HIV stigma, as a societal disapproval of one's self, can have damaging consequences in peer networks and general wellbeing but also how they may be able to resist or engage in altering this social response.

4.4 Stigma

As discussed in Chapter 2, stigma practices can damage identities, lower self-esteem, and limit the possibilities of agency. In the preceding chapter, I discussed how stigma has been identified as the chief barrier to the uptake of antiretroviral drugs and adherence for young people living with HIV (Campbell, Skovdal et al. 2010, Campbell, Skovdal et al. 2012). In this section, I now focus on the interplay between stigma and agency. I then discuss the individual, macro and multi levels approaches, demonstrating how the multi-level approach aligns with the structure agency debate which informs this study. I discuss that even though social and environmental constraints limit agency, they also provide opportunities for young people to cope with adversity, enabling resilience (Skovdal and Daniel 2012).

4.4.1 Stigma and agency

Labelling, stereotyping, social distancing and loss of status that characterise stigma have been noted to be a result of the distribution of social, economic and political power (Link and Phelan 2001). The use of power in ascribing stigma limits the agency and wellbeing of the stigmatised individual. The stigmatised individuals are portrayed as helpless and passively accepting the norms that disqualify them from equal participation in social interaction (Link and Phelan

2001). Such internalization of negative values leads to self-hatred and shame and negative identities.

The question of agency though has been contested in recent literature, with studies illustrating the inherent dynamism of stigma experiences. This, however, does not mean that the stigmatised individual or group cannot contest stigma, and or develop ideological defence strategies to avoid or minimize discrediting attributes. For example, studies have shown that there have been cases where stigma and/or discrediting labels have been contested through activism (Campbell, Foulis et al. 2005). Schneider and Conrad in (Scambler and Hopkins 1990) in their study of people with epilepsy, argued that stigma becomes pertinent when the stigmatised person accepts societal devaluations of his or her condition. This implies that individuals have the capacity to choose to accept or resist a discrediting attribute. A relevant example where stigma and discrimination was heavily contested is the South Africa Treatment Action Campaign group (TAC), which advocated for improved access to drugs and equal access to opportunities for HIV-infected people. At the same time, they collectively challenged those who sought to discriminate against them. TAC developed a range of educational material including trademark the 'HIV positive' T-shirts which were used as a tool to break the silence, secrecy and shame that surrounded HIV (TAC 2010).

Although there is evidence of people acknowledging and openly talking about their status and not allowing negative association to define them, this may not be relevant to young people who experience stigma through internalised secrecy and silence (Hejoaka 2009, Kajubi, Bagger et al. 2014, Daniel 2015). Being constantly told not to tell anybody about their status as highlighted in Chapter 2, limits young people's power to contest meanings that are given to people living with HIV or how the meaning of a child living with HIV in the age of ART might be distinct from adults. Young people have specific ways of experiencing stigma either in the home or clinic through the perceived need to be silent and through non-adherence to medication (Kawuma, Bernays et al. 2014, Bernays, Papparini et al. 2015). The way they are told about their status reinforces stigma and at the same time limits their opportunities to resist it. Thus, the specificity of the relationships and circumstances that young people are living in, binds their agency to contest or resist stigma.

This highlights the dynamism of the conceptualisation and operation of stigma, as stigma experiences are not uniform and may not be fixed. This implies that stigma reduction interventions may need to be age specific and tailored for young people and be responsive to the different forms in which stigma is experienced. Much of the anti-stigma efforts are about returning to yourself before the HIV diagnosis which is not relevant to young people, considering how they experience stigma and that they have had a lifelong infection.

Table 4.1 below summarises the gaps identified in chapter 2 and the theory that will be used.

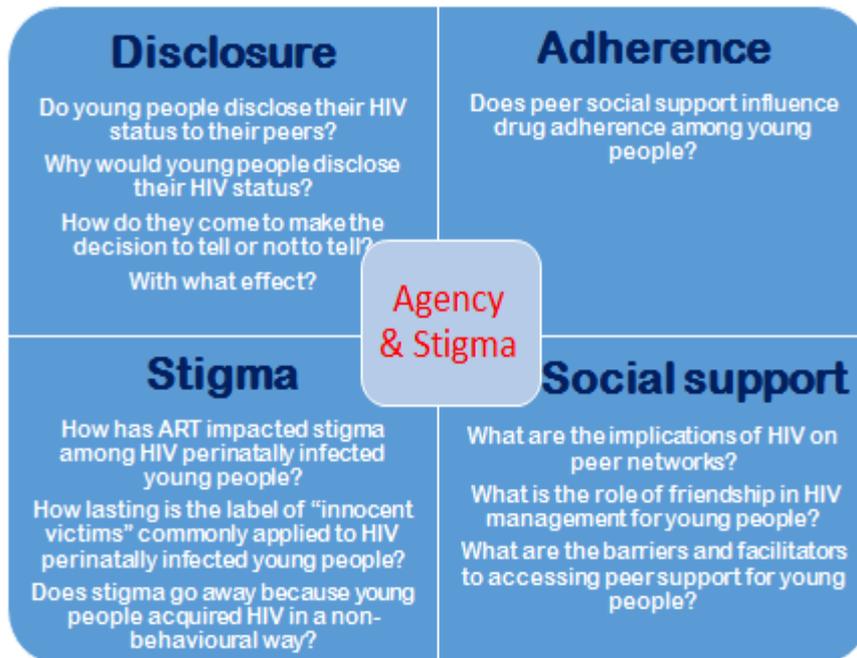


Table 4.1: Summary of evidence, questions and proposed theories

4.5 Conclusion

This chapter has discussed the theoretical concepts underpinning the methodological and empirical explorations of young people’s experiences of growing up with HIV on treatment, highlighting how access to social support is either enabled or constrained to varying extents by the social context in which they are brought up. I have highlighted how taking childhood as a global social category might misrepresent young people in the global south and undermine their agentic nature and significant contribution in the household they are raised in. The theoretical concept of bounded agency play an important role in framing the conceptual thinking that I apply in this thesis. Chapter 5, outlines the study design and study methodology. The chapter provide an account of how data for this thesis was collected, analysed.

5.1 Chapter overview

This chapter gives a description of the methods and study design used in this study. The chapter starts by highlighting the epistemological position that guides this study. I outline briefly how young people became involved in research as participants and the research design, including data collection methods used. In the following section I illustrate how the data analysis framework was applied, the steps that were taken in the analysis and how my reflections on this research study corresponded with my epistemological position.

5.2 Epistemological position

This study was embedded within a biomedical clinical trial (a detailed description of the trial is provided in section 4.4) which was, by nature, positivist. The qualitative study operated independently of the trial, using the trial primarily as a recruitment tool. In the ARROW clinical trial, for example, the main focus was to find out whether anti-HIV drugs could be administered safely and effectively to young people without routine laboratory monitoring (Kekitiinwa, Cook et al. 2013). When the trial was implemented, the priority was on getting young people onto HIV treatment in the context of a resource limited setting. As the trial progressed, it became clear that clinical outcomes were significantly shaped by social factors and influences. A qualitative study was therefore developed and began towards the end of the main trial. However the remit of this qualitative study was not to explore the trial focus, but instead to explore participants' experience of treatment and growing up with HIV more broadly. As the qualitative study was exploring these broader themes, the trial intervention arms were not relevant to the design and conduct of the qualitative study and did not have a bearing on the recruitment. This PhD thesis draws from one element of this qualitative study- a focus on peer support and relationships.

The qualitative study responded to a lack of knowledge on the experiences of perinatally infected young people in managing their HIV treatment, health, status disclosure and their support needs during early adolescence. The study was designed to provide insight for both clinicians and policymakers into how young people were managing HIV outside the clinic setting. The qualitative study was exploratory in nature, hence the adoption of the interpretive epistemological position. The adoption of the interpretive approach in the social science sub study, which is a different epistemological position to the trial as a whole does not in any way conflict with the trial findings. It merely illustrates that there are two modes of social inquiry (clinical and social) aimed at answering different elements of any particular research question

(Malterud 2001). These epistemological positions have major bearings on the ethics, study design and sampling strategies as highlighted by Filstead when he stated that:

“Quantitative and qualitative methods are more than just differences between research strategies and data collection procedures. These approaches represent fundamentally different epistemological frameworks for conceptualising the nature of knowing, social reality and procedures for comprehending these phenomena” (Filstead 1979:45).

By outlining the epistemologies that support this study I hope to provide greater clarity around the assumptions I am making about social knowledge and what needs to be investigated in order to come to a better understanding of the experiences of HIV perinatally infected young children. This study needed to address substantively different research questions to the clinical trial. For example, I wanted to find out what young people were managing HIV status within their friendship networks, not necessarily the severity of the symptoms, which may be understood in fixed clinical measures. This, therefore, implies a specific assumption that reality is dynamic, contextual and socially constructed (Green and Thorogood 2009).

The specific questions I address within this thesis are:

1. Do young people living with HIV disclose their status to their peers?
2. How do they come to make the decision to tell or not to tell within informal peer networks?
3. What are some of the barriers that young people face in trying to access peer social support?
4. What are young people’s perception and experiences of formal peer support networks?

This study sought to access young people’s social worlds and be able to learn and capture their own interpretations, their shared meanings and lived experiences in their natural settings. The interpretivist paradigm acknowledges the importance of understanding people in terms of their own definition and within their own contexts and in their natural settings (Bever and Rhodes 2003, Bevir 2004). Young people construct meaning through talking and interacting with their peers, carers and the wider community in which they are engaged and my role was to understand young people’s interpretation of their informal and formal support experiences and how this interplays with their experiences of growing up with HIV.

5.3 ARROW clinical Trial

The Antiretroviral Research for Watoto (ARROW, ISRCTN24791884) was an open-label multi-site randomised five-year clinical trial (2008–2012) whose aim was to evaluate and monitor

first line antiretroviral therapy strategies in HIV-infected young people in Uganda and Zimbabwe (Kekitiinwa, Cook et al. 2013). This clinical trial was implemented in 2008 and completed in June 2012. The Zimbabwean site recruited 400 children aged 6 months to 14 years who were all treatment naïve at enrolment. The clinical trial provided the optimal care available, which was better than the standard of care offered within the country at the time outside the context of the trial (Bwakura-Dangarembizi, Musesengwa et al. 2012). The ARROW trial was implemented at a time when the national ART roll-out for children had only just started and was characterized by long waiting periods before initiation in a healthcare delivery system that was on the verge of collapse. The trial provided a full package of healthcare, meeting the healthcare and drugs costs for opportunistic infections and bus fare reimbursements during the clinic visits. The ARROW trial was also conducted in sites in Uganda and Zimbabwe through the same clinics that were hosting the DART trial.

In Zimbabwe the ARROW trial site was located in Harare, in the Clinical Research Centre (CRC) at the Parirenyatwa Annex Hospital which is Zimbabwe's premier referral hospital and one of the two teaching hospitals of the University of Zimbabwe. The CRC treated patients with HIV and related infectious diseases. The centre was set up for clinical research purposes and has participated in numerous trials including DART, ACTG HPTN (O52) and IMPAACT (P1060). Figure 5.1 below shows the map of Zimbabwe and images of the ARROW site.



Figure 5.1: Map of Zimbabwe and images of the ARROW clinic

5.4 The PhD research and my role

The longitudinal qualitative study was conducted among a sample of ARROW trial participants towards the end of the clinical trial (March 2011– June 2013) in four sites (3 in Uganda, 1 in Zimbabwe) as shown in the flow chart, figure 5.2 below.

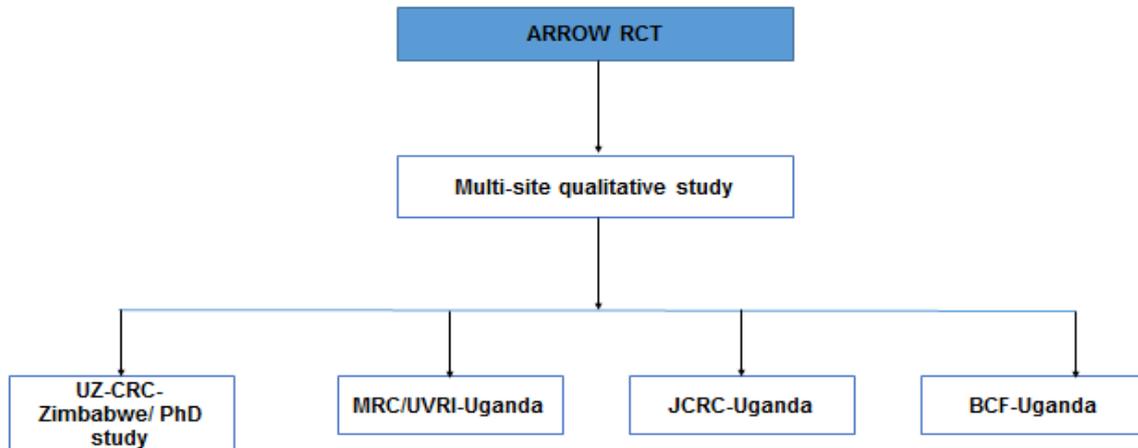


Figure 5.2: The Multi-site longitudinal study

The multisite longitudinal qualitative study did not focus on the trial interventions but explored the experiences of growing up with HIV and being on treatment. Although the four trial centres in Uganda and Zimbabwe were working together as part of a coherent programme, guided by the social science team, country teams defined the locally relevant focus of their study across the key areas of investigation, which included ART adherence, disclosure, sexual behaviour transitions and experience of informal and formal care and support. The Uganda teams for example, looked at adherence (Kawuma, Bernays et al. 2014) and disclosure experiences (Nakyambade, Bernays et al. 2013, Kabajaasi, Bernays et al. 2015).

The PhD study

Although this PhD study was nested within the multi-site longitudinal study, the work described in this thesis relates to my independent work. From the design and conceptualisation of the multi-site longitudinal study, the focus on peer social support networks was already conceived and agreed upon as a separate PhD focus. This thesis maintained a discrete analytical focus from the multi-site longitudinal qualitative study. I was responsible for developing topic guides that explored peer support networks. I made significant contributions to the design of data collection tools used from phase 1-5. The findings I presented in this thesis are drawn from the data that I collected and analysed from the Zimbabwean site.

I became part of the ARROW trial team through my work as a qualitative researcher with Centre for Sexual Health and HIV/AIDS Research (CeSHHAR) Zimbabwe, which is based in Harare. CeSHHAR Zimbabwe (<http://www.ceshhar.org.zw>) houses a number of HIV prevention and sexual health research and programmatic projects and had an ongoing collaboration with UZ-CRC which hosted the ARROW clinical trial discussed above. I was the

primary researcher for the qualitative study in Harare responsible for data collection, processing and analysis including write up. I had no other direct involvement in the trial.

5.5 Research participants

A total of twenty six young people were recruited. Twenty participants came from low income residential suburbs of Harare, initially, established for the urban poor during colonial times and characterised by densely packed housing. Five came from rural and farming communities out of Harare with the furthest child staying approximately 206 kilometres out of Harare. One came from a high income residential location even though she was staying with her grandmother who was working as a housemaid for a British couple living in Zimbabwe. The majority of participants came from Mbare residential suburb. Mbare is one of the oldest and most impoverished residential suburbs in Zimbabwe. It is over populated with between 10 to 16 people living in each one bedroomed flat, sharing the kitchen and the bathroom with other residents (see snapshots of Mbare residential area on figure 5.3 below). Most of the participants came from poor households and were looked after by unemployed carers who relied on hand-outs, illegal urban farming (usually in undesignated areas) and piece jobs.



Figure 5.3: Pictures of Mbare low income residential suburb

Thirteen young people were staying with biological parents, six were staying with grandparents and five with aunts/uncles while two (Sekai and Elias) were staying with non-biological

relatives. Non-biological foster families are very rare in sub-Saharan Africa. Informal care within the extended family network is the most common form of orphan care in the region (Frontiers. 2012, Grant and Yeatman 2012). Sekai was fostered following the death of both of her parents as well as her paternal grandmother. Her extended family was overwhelmed and could not cope with the huge number of orphans within the immediate and extended family. Her late grandmother's friend (who shared the same totem as her grandmother) offered to look after her. [A totem is natural object or animal that is believed by a particular society to have spiritual significance and that is adopted by it as an emblem]. Sekai's foster carer is referred to as her grandmother in this thesis.

Elias is another example of a maternal orphan who could not be absorbed within the extended family system. Born out of wedlock, and experiencing poor health, Elias was fostered as a result of a family crisis. Elias' maternal relatives refused to look after him when his mother was hospitalised forcing the mother to ask her former sexual partner whom she had another child with to care for Elias. This former partner agreed to do this and Elias was fostered by him following the hospitalisation and eventual death of his mother. This foster family is referred to in this thesis as Elias' stepparents.

5.6 Study Design

This study enrolled young people aged 11 to 13 years in order to explore the interim period post-disclosure, which in Zimbabwe is encouraged from the age of 8 years, and prior to them becoming a focus for HIV prevention and sexual health initiatives (Bernays, Seeley et al. 2015). The literature suggests there are two predominant areas of research among HIV infected young people at the moment, which are disclosure and sexual health concerns. This leaves an interim period when young people are between 11-14 years old, when they have already been disclosed to but are not yet considered to have sexual health concerns. This 'holding time' appears to have received relatively little attention and there is limited understanding or acknowledgement about the specific needs of young people at this time as well as understanding about what is happening during this period to shape their attitude towards ongoing disclosure in friendships. The period post-disclosure is potentially a critical phase in which young people know about their status but have very limited opportunities to discuss it. I wanted to explore the experiences of young people after they had been told of their status, in relation to accessing support, specifically peer support. I was interested in capturing their social support experiences as they move from supervised to becoming fully responsible for taking their treatment.

Ideally I would have liked to include younger children, immediately post disclosure to capture experiences immediately after learning about their status when they are even younger, but as

shown in chapter 2, disclosure tended not to be done earlier. Younger people were therefore unlikely to be aware of their status. Additionally, I was not confident that they would be willing to comfortably talk about it in the rare instances where they did know their HIV status. In my previous research (Campbell, Skovdal et al. 2010, Campbell, Skovdal et al. 2012, Campbell, Skovdal et al. 2012) I have worked with HIV-affected young people as young as six years using drawings and short stories. Although I never directly talked about HIV in the discussions, HIV came up often and I observed the discomfort and sadness it triggered. The discomfort was greatest among young people particularly young people aged 10 years and below.

I consider it to be fundamentally important to enable young people to have the opportunity to describe and depict their world. This, to some extent, safeguards against the normative tendency to rely exclusively upon adult presentations of childhood experience. However, this principle of inclusion also presents ethical dilemmas around how to balance protection and access: fairness both demands protection and opportunity for inclusion. In as much as children's opinions are "not simply reflective of their parents' ideas", and "if young people had greater access to a public voice through vehicles such as research, they would be able to contribute to the social structures that concern them" (Irwin and Johnson 2005:821), their welfare is equally important. After weighing the potential discomfort and potential benefits I decided to enrol young people aged 11-13 years. I discuss issues around disclosure for eligibility in greater details in the following section.

5.6.1 Sampling and recruitment

Young people aged 11 to 13 years were drawn from the 400 clinic trial sample and a total of 65 young people were identified as falling within this age category at the point of selection (August 2011). The sampling is illustrated in a flow chart (Fig 5.4) below.

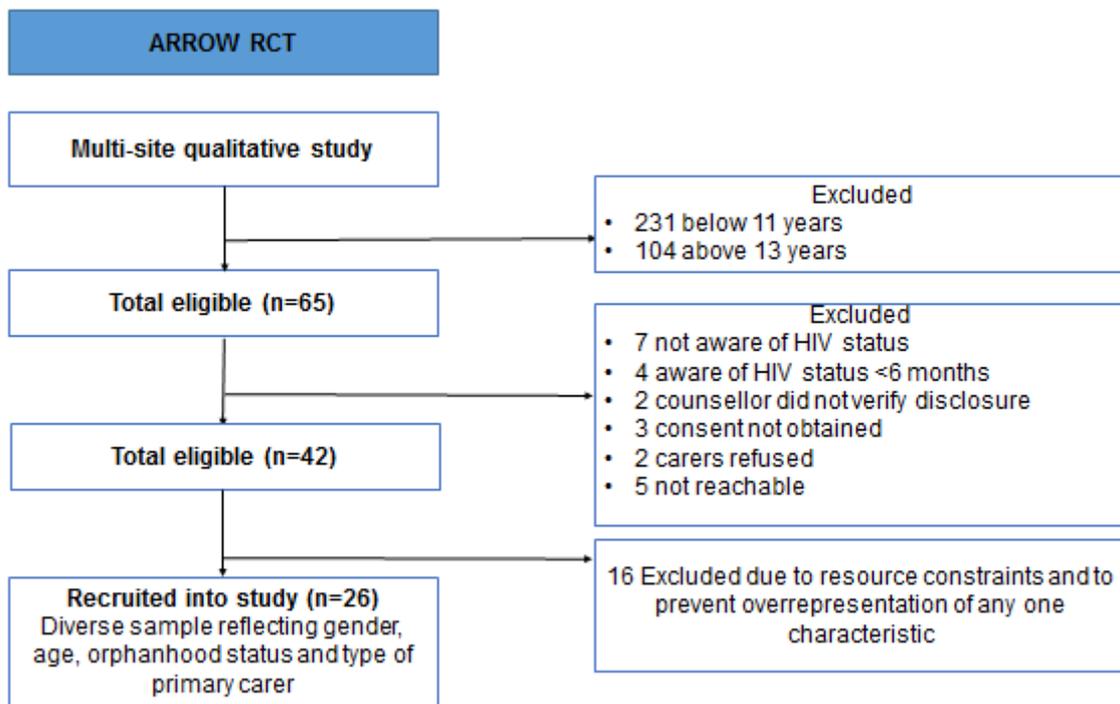


Figure 5.4: Sampling flow chart

The sampling criteria included age (8 participants aged 11 and 9 aged 12 and 9 aged 13 years), orphanhood status (22 orphans and 4 non-orphans), school repeats, type of primary carer and household environment. The sample included young people for example, who repeated school (11) and those who never repeated school (15) as they were presumed to have different experiences. The sampling information was obtained from the trial data pool and any missing information was obtained from the trial counsellors. 26 young people (14 girls and 12 boys) were recruited to participate in the study out of the 42 eligible for inclusion. Including all the 42 young people would not have been possible considering the time, resources and iterative nature of data collection, where all the interviews had to be transcribed and translated in order to inform individualised guides for subsequent in-depth interviews. Twenty six young people represented a significant proportion of total eligible young people.

My decision to recruit 26 young people at baseline was initially met with criticism from the clinical trial team who thought it was too small to produce ‘valid’ data. This reflects in part, the challenges of working within a clinical trial and with clinicians who are used to large sample sizes because of their quantitative orientation and emphasis on the value of statistical representativeness. For qualitative studies, and this study in particular, which focuses on in-depth exploration, 26 was large enough to ensure theme saturation and a broad coverage of perceptions of peer social support. It also enabled a sample size which covered the range of characteristics of this trial population within our specific age range of 11-13 years old. The fundamental objective of trials and qualitative research differ and different sample sizes and

approaches are needed to reflect the distinct research questions that each are addressing. This meant that there was constant dialogue on the qualitative research having its own criteria for assessing validity and reliability which is different from those considered in quantitative research.

5.6.2 Inclusion and exclusion criteria for participation

Young people were included in the study if they were aged between 11-13 years at enrolment. Secondly they were required to have known about their HIV status for a minimum of six months before being recruited to participate in the study. Disclosure status was verified with carers and the trial counsellors. Young people were excluded from the study if there were younger than 11 and older than 13 years. Secondly if there was no confirmation from the carer and the trial counsellors of status disclosure. Knowledge of HIV status was defined as knowing the disease by its name and understanding some of its ramifications. In order to avoid recruiting participants who were not disclosed to, I came up with a list of eligible participants and held a meeting with five trial staff members, who had direct contact with the young people and I verified whether a child was disclosed to or not. Additionally, I consulted the child's carers about whether their child was aware of their status.

It was important to double check status awareness to avoid enrolling young people who had been partially disclosed to. This information was also included in the information sheet and consent and assent forms. Only 2 young people were deemed ineligible as neither of the two counsellors could verify disclosure. Only once these checks had been satisfied did I approach the young people to invite them to participate in the study. This was not always a sufficient safeguarding process though and there were two young people who participated in the phase 1 interviews who despite the staged eligibility checks and consent / assent process turned out not to be confident that they knew their status during the interview. In these instances, the interview discussion focused on their experiences of the disease in general terms they were suffering from rather than the specifics of HIV and their perceptions of their different care environments.

Verifying disclosure status was done to avoid inadvertently disclosing the HIV status to those who were not aware of it. Furthermore, the study wanted to reduce the ethical dilemmas evoked by talking about HIV when young people were still going through the grieving process that comes immediately after disclosure of an HIV positive status. I presumed that young people needed time to understand and accept their diagnosis. Six months was deemed the minimum period for young people to adjust to the news and be able to talk about it without evoking sad or unpleasant memories or making them distressed. Responses post-disclosure

are complex and individualised and so whether six months was appropriate will be reflected on in Chapter 8.

Recruitment and data collection were done in five phases (four for young people and one for adults) and after each phase, data were analysed in order to inform recruitment and further data collection. Figure 5.5 below summarises the overall study design, which is explained in detail phase by phase below.

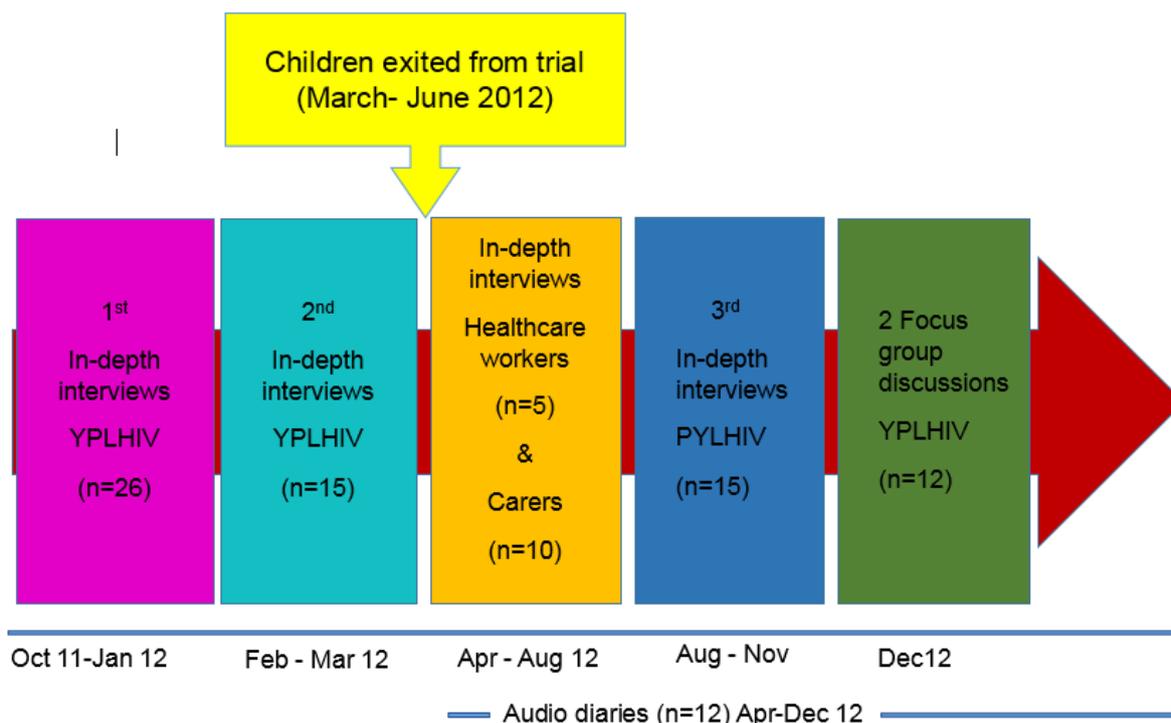


Figure 5.5: Diagrammatic illustration of the study design

Phase 1

26 individual in-depth interviews were held with young people in phase 1. Phase 1 focused on establishing rapport and understanding the circumstances of young people’s lives. It was agreed in the planning stages that words such as HIV or ARVs would not be used until the young people had introduced them. This was both for ethical reasons to avoid inadvertent disclosure should young people actually be unaware of their HIV status and to provide time and space for young people to become comfortable with the interview setting prior to any discussion of HIV. Phase 1 interviews were also used to broadly discuss the experiences of young people outside the HIV clinic, to map out various care environments and their significance in children’s lives. The key concepts explored included household contexts, schools, clinic, church and other social spaces that young people hang out such as the streets and soccer fields.

Age			
11 years old	12 years	13 years	
8	9	9	
Place of residence			
Urban high density	Low density	Rural areas	Farms
20	1	3	2
Orphanhood status			
Non-orphans	Paternal orphans	Maternal orphans	Double orphans
4	6	4	12
Changed households			
Not changed	Changed once	2 times	+3 times
7	8	7	4

Table 5.1: Socio-demographic characteristics of young people

The Zimbabwean site, however, went beyond these domains to explore the role of informal and formal support in the different care environments as well as perceptions of peer support. This study sought to gain a deeper understanding of how young people perceived formal or informal peer support and how support influenced their experiences of growing up with HIV and taking ART. This was explored alongside other dimensions such as involvement in HIV social support, HIV talk and care environments. To enable exploration of varying household contexts, young people were purposively selected. Above is a detailed table (5.1) summarising the key characteristics of the young people who participated in the study.

Purposive sampling is when the researcher uses their own judgement to ensure that the recruited sample maximises the chances that the questions that the researcher is aiming to explore are likely to be met. Purposive sampling is often criticized for being a non-probability sampling technique (McCrae and Purssell 2016). However, with the emphasis on the interpretation and hypothesis generation appropriate to the qualitative study design, this study never sought to measure or quantify young people's experiences, therefore the bias and

sampling errors associated with purposive sampling are less important. The sample selected to participate in this study was not representative of the population but were selected on the basis of their wide range of experience.

Phase two

In phase 2, which followed preliminary analysis of phase 1 interviews, a reduced sample of 15 young people (8 girls and 7 boys) were selected for interview from the 26 interviewed in phase 1. Reducing the number of participants in the follow up phases from 26 to 15 was a deliberate strategy to ensure that the participants involved had a wide range of experiences, relevant to answering the research question, but also limited the scale of the data collection so that detailed analyses could be conducted. In the follow up sample there were 8 girls and 7 boys, they were evenly spread across the age ranges with 4 participants aged 11 and 6 aged 12 and 5 aged 13 years. Of this sample of 15 young people, 6 were double orphans, 6 paternal orphans, 2 maternal orphans and 1 non-orphan. This reflected the diversity and characteristics captured in the larger baseline sample.

I adopted a theoretical sampling strategy to identify this refined follow-up sample informed by the findings of phase 1 interviews. Theoretical sampling is defined as interviewing directed by evolving themes rather than focusing on predetermined populations (Draucker, Martsof et al. 2007, McCrae and Pursell 2016). Support group exposure and consistency in support group attendance and disclosure to friends were considered important issues in shaping experiences of peer support among other things.

Two of the 15 HIV positive young people who took part in follow-up interviews had never attended any support group. These two were included as a way of widening the range of support group experiences. It was assumed that not attending support groups would have a significant impact on how young people conceptualize their care and support needs. I therefore explored how these two HIV positive young people (plus their carers) perceived support groups (i.e. whether they thought they were important at all, whether or not they felt they were missing out by not attending support groups). Importantly, most young people had attended support groups through the trial. Trial participants had better access to support groups than other young people outside the trial (those in the general population). My interests were in understanding the social processes that shaped the decision to disclose or not disclose their status to their peers as well as their engagement with formal support networks.

Phase 2 specifically focused on young people's experiences of being disclosed to as well as their experience of and attitudes towards disclosing to others, their HIV knowledge as well as their treatment experience and adherence, across the different care environments (identified

in phase 1). Despite the inclusion criteria for the study being only those who had been disclosed to for over six months and the verifying of this information with counsellors and carers, there were a few participants enrolled who seemed unaware of their status in phase 1. Although the majority were aware that they were living with HIV and were taking their drugs to control it, they still had low levels of knowledge around what HIV was, what their drugs did and did not do (i.e. not heal nor cure).

Phase 1 data shows that young people did not openly talk about HIV. I was interested in knowing how they learn to fear HIV, if it was so silenced, and what helped them to cope with the multiple, intersecting challenges that they faced. This prompted me to want to explore the participant's disclosure experiences and the type of support available to young people after disclosure. Phase 2 also explored the role of formal and informal support networks for adherence.

The topic guide for phase 2 (see appendix A) was informed by the preliminary analysis of the baseline phase data. Individualised guides tailored to suit the different characteristics and circumstances of the fifteen participants were developed, including adapting our questions in line with their own confidence, or lack of, to talk about HIV. Phase 2 interviews were scheduled to be relatively well spaced out to allow time to personalise the follow-up guide so that they drew on the detail of each individual's phase 1 account. During the phase 1 interviews, I successfully managed to build a trusting relationship with the participants. Good rapport created in the baseline interviews made it easier to conduct richer phase 2 interviews.

Phase three

While young people need to be understood as active subjects in research, it is important to note that how they make decisions and are influenced by particular sociocultural contexts in which they have been brought up. Their experience is significantly shaped by their relationships with their carers and significant others in their lives. The importance of involving adults alongside young people was emphasised by Prout when he stated that "young people's own meaning-making activities, with and alongside adults and other young people is a key to understanding how they respond to their social circumstances" (Christensen and James 2000 :XI). I was interested in these multiple perspectives in order to understand young people's perspectives around peer social support, hence adults were also interviewed.

Adult accounts were not about verifying young people's accounts, but provided an additional perspective of young people's support networks. I took this as an opportunity for triangulation, not necessarily looking for corroboration as this would suggest that I was prioritising 'one true'

account over another, but instead I focused on analysing these multiple perspectives for what they might tell us about how particular events may be experienced and perceived differently.

Although I explained and assured the young people that their confidentiality would be maintained throughout the data collection process, phase 4 interviews were used to reflect and inform them about the purpose of healthcare worker and carer interviews; specifically that they were intended to gain an additional insight and not to authenticate the accounts of the child participants. Young people noted in phase 4 interviews that their carers did not appear to have learnt anything that had been said during earlier interviews.

Healthcare workers

Between April and May 2012, five health-care workers (3 females and 2 males) were interviewed individually in a private room at the ARROW clinic. The ARROW trial team comprised 20 members of staff who ranged from professionals to non-professionals. Five (3 females, 2 males) healthcare workers were sampled to participate in the study. Of the ten professional staff, only five were selected to participate in the in-depth interviews. Five were excluded as they had limited contact with trial participants. Five professionals who had direct daily contact with the trial participants were recruited. Direct contact with participants was important as the data was required to be able to inform my understanding of children's experiences from the point of view of healthcare workers.

I was interested in exploring how those delivering care in the clinic consider that a child's everyday life within their household and communities influences their capacity to live with HIV, for example, how it influences children's ability to take treatment or influences their fears and anxiety around disclosure. Data from phase 1 and 2 (children's interview data) suggested that there was some variation in how young people were disclosed to. The existing literature and the data from this study suggest that how disclosure was conducted influences how young people approach the management of their HIV.

Despite guidelines suggesting that disclosure is conducted as a process, children's accounts suggested that they remembered disclosure as a one off discussion, and that their HIV was commonly not referred to again. It was important to interview healthcare workers in order to understand how they considered this process had happened and how HIV was talked about during and after disclosure. Disclosure was an important milestone for trial participants as it opened doors for accessing social support. For example, only those young people who were aware of their status were invited to attend the trial-run support group.

I sought to foster a transparent and positive working relationship with the health-care workers from the first day of the study. They came to feel comfortable with me, sharing their opinions.

While they discussed information with me, they were also aware and respected the boundaries of confidentiality to which I was beholden as a requirement for the research. The ARROW trial team held Monday meetings to give updates, discuss challenges and difficult cases. Although I was not based at the clinic, I attended almost all of these meetings and spent considerable time at the clinic talking to the nurse counsellors and doctors, setting up appointments and seeking consent and assent from the participants and their carers. Spending most of my time at the clinic was helpful in understanding the environment and context in which HIV care was delivered and also for meeting hard to reach carers who rarely came to the clinic.

The clinic offered a very relaxed and friendly environment. On most weekdays it was busy in the morning and quiet in the afternoon, freeing up time in the afternoons for informal discussions amongst staff. This enabled me to observe the clinic operations and to have access to contextual information about the participants and other young people attending the clinic who were not necessarily included in the sample. These afternoon discussions and observations informed my sampling approach.

Carers

Ten carers (9 females and 1 male) linked to the young people who participated in all the three phases were interviewed between June and August 2012. In two exceptional cases, two carers were interviewed from one household. In the first case, the child had confided that she had strong friendship ties with a tenant 24 years older than her and that she was a considerable source of support to her. I was keen to find out more about their friendship as it was very unusual in the Zimbabwean setting for a school going child to become close friends with a married woman. Most parents discouraged such friendships as they feared that their young people might be influenced or exposed to communication that might not be appropriate for their ages. In this particular case, I ended up interviewing the aunt who was the primary carer and the tenant/ friend to get a full picture of the nature of their relationship and the roles these different relationships played in the girl's life. In the second case, the child had a strong bond with his maternal grandmother and confided more in his grandmother than his mother and so I interviewed both the mother and the grandmother. The key sampling dimensions included gender, carer/ child relationship and household information obtained during phase 1 interviews. The socio-demographic characteristics of most carers were obtained from the trial records with a few exceptions whose information were collected during the phase 2 consenting process. Table 5.2 below shows some of the reasons for inclusion in the carer sample. The carer interviews explored family dynamics and social support in different care environments.

Carer	Gender	Age	Relationship	HIV status	Reason for inclusion
1	Female	51	Mother	Positive	Child has lot of support at home
2	Female	69	Maternal grandmother	Negative	Child has a strong bond with granny, disclosed status to friends
3	Female	66	Extended family	Negative	Stays with granny's sister in law and has a comprehensive adherence routine
4	Female	42	Mother	Positive	Abrupt disclosure, family dynamics affecting adherence & social life
5	Female	68	Maternal grandmother	Negative	Child's strong faith/ conviction that she is healed of HIV, poor adherence
6	Female	47	Not related	Negative (husband positive)	Stays with non-relatives, large household (13 members in a one bedroomed flat)
7	Male	46	Father	Positive	Child's referral of all personal questions to her father
8	Female	45	Paternal aunt	Not known	Child pretend not to have HIV, doesn't want other household members to know her status
9	Female	37	Friend	Negative	Child has an unusual strong friendship with tenant, significant age difference between child and friend (24years)
10	Female	43	Paternal aunt	Not known	Stays with a rigid unsupportive aunt, poor adherence

Table 5.2: Reasons for inclusion in the carer sample

The carer interviews were used to explore the relationship between the carer and the child and to understand how they came to be carers. Data from phase 1, 2 and healthcare workers indicated that young people who stayed with non-biological carers received less care compared to those who stayed with their parents. As such I over-sampled the non-biological carers in selecting ten of the fifteen carers connected to the young people in the study. This enabled me to further explore family dynamics and access carers' perspective of their caring responsibilities, for example, whether it was considered a burden, and why they had come to be in the situation of carer. After hearing the young people and the healthcare workers' perspectives on how disclosure has been done, I also wanted to find out how carers reported the disclosure experience and explore their perceptions and the risks of social support. Carers, to some extent, determine children's access to social support hence their views were important.

Baseline data showed that there was very little discussion of HIV within the home. What was discussed appeared to be limited to reminders about drug taking. I wanted to explore whether, and in what circumstances HIV was discussed within the home with the child and why carers tended to not discuss HIV. In the rare cases where HIV was talked about in a relatively open way within the household, I wanted to find out what relational and contextual circumstances were enabling this to happen and to capture carers' opinions on the effects of this more open talk. Furthermore, I was interested in understanding more about how space and time was managed within the household.

Phase four

Phase 4, which was the last wave of individual in-depth interviews with the children, was done with the same young people who participated in phase two. Phase 4 interviews were done after adult interviews and when the young people were exited from the trial and so were receiving their care from other healthcare facilities. Initially I had planned to conduct the interviews in the different clinics the young people were attending; however, securing private, quiet rooms with minimum distractions in these clinics proved to be difficult. The majority of public clinics that offer HIV treatment and care lack adequate infrastructure to accommodate this recently decentralised service. I did not want the setting to affect the quality of the data that was collected. In consultation with the carers, it was agreed to have all the interviews at the ARROW clinic.

This phase was largely informed by the analysis of data from preceding waves of data collection. The aim of phase 4 interviews was to capture transition from the clinical trial into public clinics and children's experiences and perceptions of the care they were receiving in the public facilities. Capturing the changes in HIV care and treatment including access and

changes in drugs was deemed important in characterising the experiences of living with HIV. Trial exit marked a significant change in access to HIV care and support for all participants. This phase also explored barriers in accessing social support.

One key aim of phase 4 interviews was to try and get advice on what could be done to help support children, whom I regarded as the experts on their own experiences. This meant that some of the questions explored what young people had been through and what they thought and felt about their situations.

Phase five

Two focus group discussions (FGDs) were held with twelve young people (n=7 girls; n=5 boys). The focus group discussions served two specific purposes. Firstly, they were used to tap into the group dynamic as they discussed the facilitators and barriers to accessing social support. During the focus group discussions, young people were asked the question: "what challenges do you think HIV positive people face when it comes to disclosing their status". After the discussion I summed up all the challenges and asked the young people to rank them according to what they perceived to be the most difficult challenge to deal with or address and who they thought could help them and what they thought could be done to address the challenges.

Secondly, FGDs served to discuss with the young people what was coming out of the study, and to inform the dissemination plan. My goal was to disseminate the results to target different users including HIV-infected young people and carers, hence I wanted information on how best to disseminate the findings to other young people, what form the results should take and what methods should be used to reach other young people.

The first focus group comprised two girls and three boys while the second focus group discussion had five girls and two boys. The rationale for mixing the gender was because the issues that were being explored were not gender specific or sensitive and were issues that were affecting both boys and girls in a more or less a similar way. Mixing the gender was believed to yield fruitful discussion. The focus group consisted of young people who had participated in the baseline interviews only (n=2), as well as those who had been followed up (n=10). Ideally, all 15 young people who had been followed up were scheduled to participate in the focus group discussions but five did not participate. Three were said to be on school holiday out of Harare and one came in the afternoon and arrived after the discussion had been completed. One participant was not comfortable to talk about his personal experiences in a group setting. Two young people who had participated in the phase1 only were selected in the FGD sample on the basis that they had never been exposed to community or trial-run support groups. They were considered to give an additional reflection of support group non attendees.

There was a deliberate strategy behind the composition of each focus group discussion. The first focus group discussion comprised five young people, all of whom had been followed up and participated in all three phases of interviews. All the young people had consistently attended the trial-run support group and were active members of community support groups except for two who had stopped attending community support groups. It is important to note that even though all the young people were participating in the trial, the trial intervention was not considered to have any bearing on their social experiences. Most of the young people were receiving similar care for example it was the same setting, similar appointment schedules and the only difference was their social characteristics.

More generally, it is likely there will have been differences between the experiences of the participants in this study who were all trial participants and those not participating in the trial. Just by being in the clinical trial they are likely to have experienced better clinical care. However, young people's exposure and lack of exposure to community-based support groups was anticipated to bring some differences in their experiences. Additionally the different social characteristics for example, type of carer were presumed to have an impact on their experiences. For example experiences of young people who were staying with biological carers could have been different from the experiences of young people who were staying with non-biological carers who ill-treated them and those who were constantly moving households. This first focus group discussion specifically explored the perceived benefits of attending support groups as well as the challenges young people faced in accessing and attending the support groups among other thematic areas.

The second focus group discussion comprised seven young people, five had been followed up and participated in all the three phases of interviews while two had only participated in phase 1. All the young people were no longer attending community support groups at the time the focus group discussion was convened and two had never been to support groups. This was more or less a homogenous group and the discussions focused on the reasons for not attending support groups and the benefits of attending among other areas of investigation. There are two types of support groups referred to in this study (trial-run and community based). Details of these two types of support groups are provided in Chapter 8.

5.7 Ethical considerations

This study was part of the main ARROW sub study funded by the Medical Research Council (MRC) UK through the London School of Hygiene and Tropical Medicine (LSHTM). Ethical approval was granted by the LSHTM Ethics Committee (5896). As the grant was hosted at the LSHTM, ethical approvals were also sought from their ethics review board. University College London (UCL) ethics was waived as the study was approved by LSHTM

<http://ethics.grad.ucl.ac.uk/forms/ucl-research-ethics.pdf>). In addition to obtaining the LSHTM approval, I sought and was granted ethical approval from two key bodies in Zimbabwe. The Joint Parirenyatwa Hospital and College of Health Sciences Research Ethics Committee (JREC) regulates and reviews research protocols of institutions affiliated to the University of Zimbabwe College Of Health Sciences (<http://www.jrec.uz.ac.zw>). The JREC approval is required for submission to the Medical Research Council of Zimbabwe (MRCZ). After obtaining the JREC approval, I sought approval from the MRCZ. MRCZ is the national ethics governing board established in 1974 under the Research Act of 1959 to provide health researchers and institutions conducting health research with independent ethical advice on research and to oversee the protection of human research participants. I was then offered the MRCZ approval (A/1616).

5.7.1 Informed consent and assent

The Nuremberg code and the Helsinki declaration are the pivotal documents that have made significant impact on medical research ethics, especially on how informed consent is used (Haggerty 2004). The Nuremberg code was drafted by a tribunal after harmful research experiments done by Nazi physicians and investigators (Ghooi 2011). The Declaration of Helsinki adopted in June 1964 and have been revised for the seventh time in 2013 (Ndebele 2013, World Medical 2013), outlines the ethical principles for health research which include respect for the individual, their right to self-determination and the right to make informed decisions (Maria da Gloria and de Chesnay 2015). These two foundational documents emphasise the need for voluntary consent of research participants. This implies that research participants are given necessary information to read, reflect and weigh up the risks and benefits of taking part and make an informed decisions regarding their participation (Williamson, Goodenough et al. 2005, Morrow 2012).

Although the Nuremberg code and the Declaration of Helsinki were the first widely recognized documents to deal explicitly with the issue of informed consent and experimentation on human subjects, they fall short on the enrolment of minors who are incapable of giving consent (Macklin 1999). The international ethical guidelines for biomedical research involving human subjects was the first document to legally allow proxy consent from legally recognised representatives of individuals deemed incapable of giving consent (Macklin 1999). In Zimbabwe, there are no laws dedicated to research involving minors (young people); however, the MRCZ considers all the young people under the age of 18 years legally incompetent to give consent with the exception of emancipated minors (those with young people) hence, parental/legal guardian informed consent was required.

All the young people who participated in this study were minors (below 18 years) and the consent / assent procedures strictly adhered to the considerations relating to young people contained in the principles of Good Clinical Practice. All the carers and young people were given necessary, accurate information on the study, its purpose, procedure and duration, including known risks and benefits. The information was enshrined in two different information sheets (young people and adult) and also in the consent and assent forms, written in standard simplified English or Shona (local language).

I understood informed consent to be an ongoing process of sharing information and addressing questions and concerns, rather than a mere signing of the consent form. I started the consenting process by introducing the study to the potential participants and the people who had accompanied them to the clinic. Most of the young people aged 13 and below were accompanied by adults for their check-up. The greatest challenge that I faced was in determining the rightful guardians from other significant household members.

The fact that the study was nested within the clinical trial meant that I had to abide by the trial consenting procedures. This implied looking for guardians who consented for the young people to participate in the trial, despite them not necessarily being involved in their day to day care at the time of the qualitative sub study. Some guardians had given consent when the trial had just started, which was almost five years before and were no longer staying with the young people. Some had relocated out of town while some had stopped coming to the clinic due to a variety of reasons including age, ill health and work commitments but they never came to the clinic to change the guardianship. Identifying the true guardians meant that I had to compile a list of all carers who gave consent in the trial and to look for them.

This caused delays as finding the carers was difficult. This was made worse by the fact that I could not go and look for them in their houses. There was a significant consideration of the risk posed by accidental disclosure. I had to wait for the guardians to come to the clinic and sign the consent forms. For those young people who stayed out of Harare I had to send the consent to get it signed by the rightful guardian and wait for the signed forms to come back before scheduling the interviews. This had financial implications as I had to meet the extra costs of finding the rightful guardians including the reimbursement of their bus fare for the consent forms to be brought back to the clinic. If this study had not nested within a clinical trial any adult household member accompanying the child to the clinic would have been allowed to give consent.

In the few cases where young people were accompanied by the carers who had given consent in the trial, the consenting process was less complicated. I explained the study and gave out copies of consent forms to take and read at home and would set a date for the interview.

Before the interview, we would go through the informed consent forms with the carer and the child explaining the purpose of the study, the procedure, confidentiality and all important information about the study.

I had one carer who did not agree with young people giving assent. I explained about the rights of young people in research and why it was important for young people to give assent but she was not convinced. I made it a point to explain to all the young people in simple Shona about the main ethical principles, such as the voluntary nature of the study, their right to withdraw at any time, confidentiality and anonymity. I also had information sheets specifically for young people with a reading level of below grade 6 (usual age for grade 6 is 11 years). I wanted to be sure that young people were participating in the research of their own free will and that their assent was based on a genuine understanding of the study. I tried to establish, before the interview, if the young people were happy to be interviewed. This was to ensure that the young people were not forced or coerced to participate in the study by their carers.

The participants/ carers' travel expenses for the interview were reimbursed at not more than USD5 per trip. I tried at any given time to answer their questions and address all the concerns and expectations. Of particular importance was explaining that the qualitative study was to continue for a few months after young people exited the ARROW trial. Young people who were participating were also going to be exited from the trial and their participation in the ARROW social study did not in any way mean that they would not be exited from the ARROW trial.

As is common with longitudinal research informed and written consent/assent were gathered from all the research participants during phase 1 and phase 2 and phase 5. Consent/assent to keep audio diaries was sought during phase 2 interviews. The rationale for seeking renewed consent at the start of each major phase was to ensure that participants were still willing to participate and understood that they had the option to withdraw from the study if they so wished. Written informed consent was also obtained from the carers and healthcare workers on the day of the interview.

There was an agreement that carers and young people's identities would not be revealed. Participants were informed that they were free to refuse to participate or to withdraw their participation at any time they chose to throughout the data collection and analysis phases without giving any reasons and with no interference/disruption to their participation in the main clinical trial. Carers and young people were also given a chance to consent to keeping an audio diary. Detailed discussions were held with each participant (n=12), who agreed to keep an audio diary. I explicitly explained the challenges involved in keeping the audio diary at home which included unguaranteed confidentiality and risk of unplanned status disclosure to

undisclosed household members. It was therefore, the child's responsibility to keep the audio recorder safe and confidential from all the household members. Carers and Healthcare workers were also asked to give written consent for participation in the adult interviews.

5.7.2 Privacy and confidentiality

All the interviews were held in a private room at the ARROW clinic. All study materials, including consent and assent forms were stored in a secure room in a lockable cabinet; identifiable details were removed from the transcripts and codes were assigned to each transcript. I ensured that no names appeared on the recordings, all participants were assigned study unique identities. All audio files and transcripts, field notes and notes taken during the focus group discussions were stored securely in password protected computer files and were backed up on a password protected study specific cloud. Pseudonyms of participants, communities and schools were therefore used throughout to protect participant's identity.

5.8 Data collection

This section outlines the data collection process including the methods that were used. As described above, the data were collected over a period of 15 months with three phases of in-depth interviews, focus group discussions, audio diaries and adult interviews. Initially data collection was scheduled to begin in May 2011; however, the local IRBs took longer than anticipated to approve the study. When the study was finally granted all the ethics approvals, I was due to go for three months maternity leave. These two factors resulted in there being a shorter amount of time than was planned between phases 1 and 2.

Qualitative research methods were chosen to allow for an understanding of the meaning people give to their experiences (Strauss and Corbin 1998, Bauer and Gaskell 2000). Triangulation is widely recognised as a strategy used to enhance the validity of qualitative research. Using different methods of data collection increases confidence in the findings and offers better ways of capturing and understanding the diversity of social experiences and lived realities (Barbour 1998, Mason 2006).

There is the notion that conventional research methods such as interviews and focus groups are less useful for data collection with young people than adults, given young people's relatively limited confidence in verbal expression, particularly in the context of a taboo or sensitive topic such as HIV (Clay, Bond et al. 2003). It is often assumed that young people have little to say about their lived experiences. However, it can be argued that conventional research methods, if used sensitively, can elicit rich data. For this reason, the study used participatory research tools tailor-made to make conventional approaches more conducive in accessing children's perceptions of social support and lived experiences of HIV. More so, the

study allowed room for rapport and trust to develop over time, allowing the participants to select a conducive venue for the interviews. In addition the study was designed in such a way that it moved from general topics of discussion to more specific ones over time.

5.8.1 Methods

Longitudinal study

Longitudinal qualitative research is becoming increasingly popular in health research (Calman, Brunton et al. 2013). Duration, change and building rapport overtime are the three main principles that shape longitudinal qualitative research (Saldaña 2003). The rationale for adopting a longitudinal approach was to build rapport with the young people and to allow them time to get used to the researcher and the interviews setting. Repeat in-depth interviews were held with young people over 15 months. Although 15 months might seem a short period of time to capture change overtime, I was able to capture changes in schooling as some young people moved from primary level to secondary schools. I also captured changes in care arrangements as some young people changed households during the course of the study. For some participants, this meant that they could no longer attend support groups.

In addition all young people transitioned from care within a trial setting to within the public sector as mentioned earlier in this chapter. The first two phases were conducted while young people were still participating in the clinical trial and receiving the best possible care. By phase 4 and the focus group discussion young people had exited from the trial and were receiving HIV treatment and care in the public (main population) clinics. This was a valuable aspect of the study design as I wanted to be able to assess the impact of this transition on social support and peer networks.

In-depth interviews

In-depth interviews are the most widely used method of data collection in qualitative studies (Green and Thorogood 2009, Mears 2012). In-depth interviews are described as a purposeful interaction in which the researcher tries to understand what the participant knows about a topic (Legard, Keegan et al. 2003). The epistemological approach adopted by this research entailed the use of exploratory research methods. In order to have a deeper understanding of what it meant to grow up with HIV and taking treatment, I used in-depth interviews to capture the personal feelings, meanings, perspectives and sociocultural contexts that shape children's experiences of social support. For some young people this turned out to be the first time they had openly talked about their HIV status with non-relatives since disclosure.

Participatory tools within in-depth interviews

Researchers, worldwide who have sought to access children's social worlds, have often met challenges around children's verbal skills, with some being too young to fully comprehend the research expectations (Barker and Weller 2003, Jorgenson and Sullivan 2009). In order to bridge these barriers, this study used a number of participatory research tools during in-depth interviews. These included the use of a semi-structured map as a topic guide, use of illustrations of faces, emotion maps/cards, talk cards, hypothetical scenarios and timelines. Participatory tools were used for three main reasons. Firstly, it was to make the interviews more fun for the participants while allowing young people a range of ways to communicate their perspectives. Secondly, the 'topic guide' maps were used to illustrate transparency, setting out clearly at the start what the interview would involve to help manage possible anxiety or uncertainties. None of the young people who took part in this study had participated in a qualitative research before. Lastly, it was to make the interview process participatory by giving the young people tasks to talk through.

In phase 1, a general topic guide was developed collaboratively with the investigators in the four ARROW sites. It was considered appropriate, considering the ages of the participants (11-13 years) as it was believed to be child friendly and was used to enhance the research relationship. The map was adapted, made bigger and translated to Shona. I printed it on a big chart that was very colourful and easily legible to allow the participant to see the areas of discussion to be covered in the interview. During the interview, the printed chart was placed on the table in front of the child. The interviewer and the child discussed each stage in turn. Putting the guide on the table was believed to reduce anxiety. The map was very useful in facilitating young people to tell their stories intuitively without too much probing.

Although I was involved in designing the study and developing the guide my other contribution was in adapting the guide to suit the Zimbabwean context and translating the questions from English to Shona. The topic guide was a semi structured map depicting various care environments shown in figure 5.6 below. This was then adapted into a much bigger colourful laminated map or chart. General simple open ended questions were asked to allow young people room to feel comfortable and room to talk confidently about their lives. For example, the first question asked was "Talk me through what happened yesterday". Starting the interviews with general questions was meant to establish rapport and to assess the children's confidence in responding to subsequent questions. The question proved to be a fruitful opening question, prompting young people to talk about taking their pills. This gave me a starting point to explore what the drugs were for, leading to open discussions about HIV and ARVs. The advantages of using the guide map are discussed below under participatory tools.

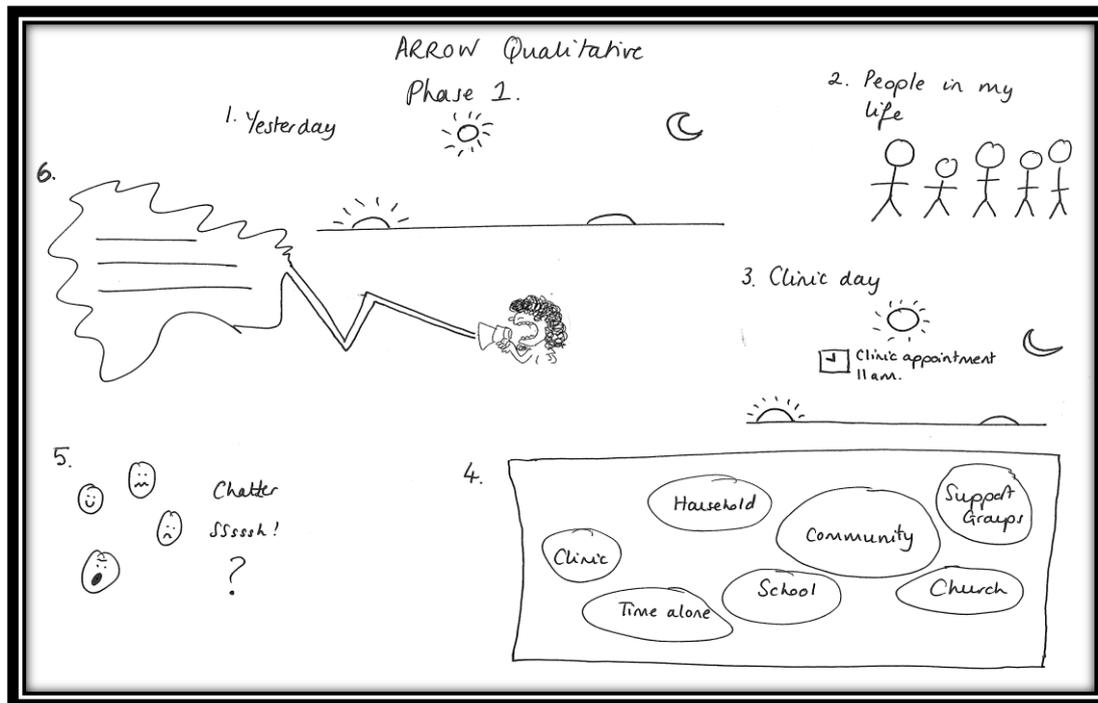


Figure 5.6: Phase 1 guide map

Young people were also given printed illustrations of faces and were asked to put names of the people in their lives on the printed illustrations. The rationale for using face illustration was to explore and understand household and family structure. These face illustrations were helpful in mapping out the most significant people in their lives. This was useful in exploring the participants' close and distant relationships as well as other people who may not have been relatives but having significant influence in the children's lives, for example, friends, healthcare workers, teachers and neighbours. One child, upon receiving the face illustrations, wrote her friend's name first then her other household members, including her aunt who was her principal carer. She repeatedly talked about her friend throughout the interview. I realised that she had a strong and unusual friendship with this woman and ended up interviewing the friend among the ten carers in order to get more insights into the nature of the friendship. This is the case that I mentioned in explaining the carer sample. Completed face illustrations became a useful tool to support further probing later on in the interviews when we were going through the different care environments.

Illustrations with real names made it easier to follow up on the people that they had mentioned, establishing the nature of the relationship and the connectedness of the labelled faces. These were also useful in mapping out household composition and in exploring some of the key investigation areas, for example, the extent of their HIV status disclosure within the different care environments.

I would ask the participant to divide the labelled 'faces' into categories of those who knew, those who did not know and those they were unsure as to whether they knew or not. Young people were asked to divide labelled 'faces' into categories of those that they would like to know their status and why and those that they did not want to know and why. Lastly, young people were asked to discuss what they thought their reactions would be if the individuals, depicted through these labelled faces, learnt of their status, especially their friends. Emotion icons were also used during this exercise to explore the various reactions that they might have.

Emotion maps were used as a task-based activity within the interviews and participants were asked to chart the location where different emotions take place within their home or other care environments. They were also used to explore themes that were regarded as sensitive, for example, disclosure and adherence. Emotion maps helped young people to express their voices in an authentic manner, whilst minimizing the possibility of leading the young people in the answers that they gave (Irwin and Johnson 2005). When young people were struggling to express their feelings, emotion maps were spread on the table to provide a 'shopping list' of emotions that they could select from. A Zimbabwean artist designed the 22 emotion maps with illustrations of black African faces and these were used in all the four ARROW sites. Emotions were added iteratively as the interview proceeded to incorporate commonly mentioned emotions. Face illustration and a sample of emotion cards showing worried, happy, content, sad, bored and frustrated are shown in figure 5.7 below.

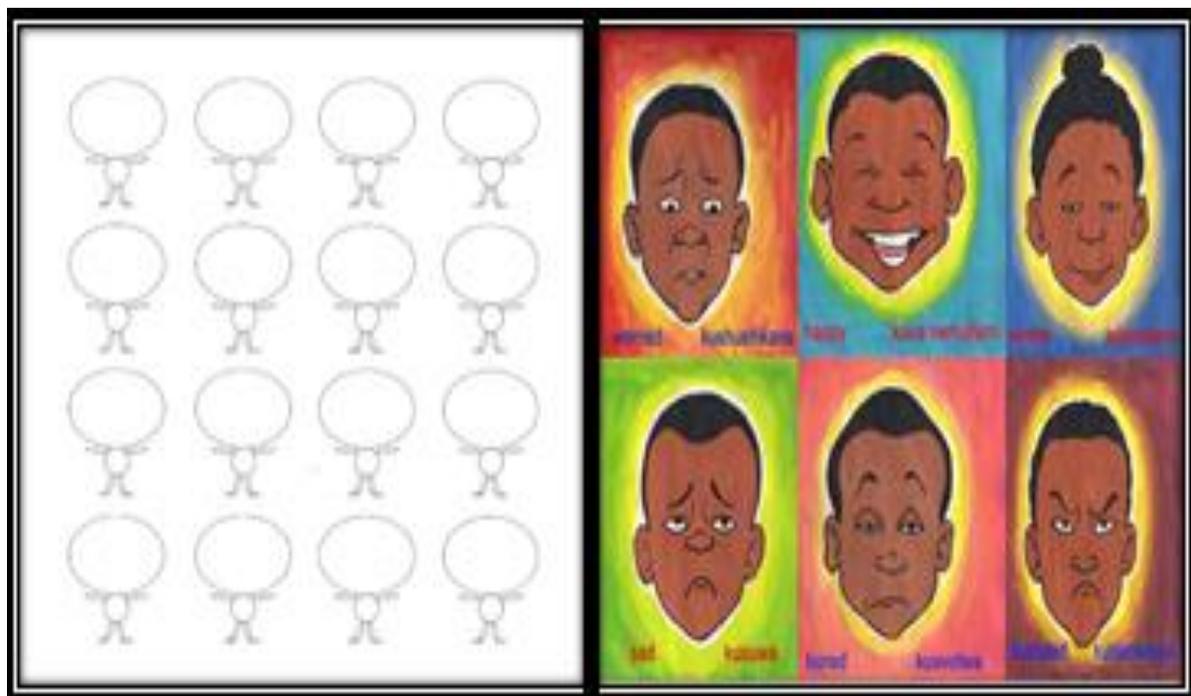


Figure 5.7: Illustration face and emotion maps

Silence appeared to play a significant role in young people's experiences which both made the interviews initially more challenging but was also revealing about their lived experiences of growing up with HIV. Talk cards (figure 5.8 below) were designed to help support discussion to explain the extent of talk or the presence of silence in different settings. Colourful talk cards ranging from 'unrestricted talk' to 'limited talk' were designed and used as another innovative way of facilitating children's story telling. Talk cards were mainly used to elicit discussion around HIV talk and in exploring where certain aspects of HIV knowledge got discussed in the different care environments. Talk cards were thought of as having a playful quality and to be less intimidating. Young people were asked to select a card that seemed most relevant to their own feelings towards HIV talk in different environments. Going through the different care environments young people were also asked to place a card that seemed most relevant to how other household members felt regarding HIV talk. This made it easier to follow up with probes regarding the nature of talk and how it was framed.

Literature on adherence suggests that young people were likely to have adherence challenges (Agwu and Fairlie 2013, Bernays, Jarrett et al. 2014, Gross, Bandason et al. 2014, Nabukeera-Barungi, Elyanu et al. 2015) but the baseline data indicated that adherence was good with young people reporting that they only missed drugs occasionally. Having reflected on how I could encourage young people to openly share their alternative experiences of adherence I recognised that I needed to have a collection of tools that I could use to try and elicit further information around subjects that were difficult to directly talk about. Hypothetical scenarios were used in phases 2 and 4 as a way of legitimising alternative accounts in which adherence was not exemplary.



Figure 5. 8: Talk cards and boy hypothetical scenario

Hypothetical scenarios or vignettes are short stories in pictorial or written form about hypothetical characters used to elicit perceptions, opinions, attitudes, behaviours and beliefs (Braun and Clarke 2013, Clarke and Braun 2013). The stories should appear plausible or can be around actual experiences directly provided by participants in the pilot interviews (Barter and Renold 2000). Hypothetical scenarios can be used to elicit information meant to enhance deeper understanding around perceptions, experiences and accounts of behaviour as well as in capturing influencing factors (Braun and Clarke 2013). They are considered to work very well in exploring sensitive topics as responding to a hypothetical scenario is less threatening than talking about direct personal experiences (Barter and Renold 2000, Braun and Clarke 2013). I believed talking about the ‘other’ in this case, the (hypothetical girl/boy) would make it easier for young people to move from public accounts to talk about their own personal accounts. Hypothetical adherence scenarios were constructed using actual experiences and adapted to suit the background of each participant using background information obtained in phase 1 interviews.

I would place the cartoon image of a girl/boy (shown in figure 5.8 above), depending on the participant’s gender, on the table in front of the participant and give a brief description of the boy/girl matching the participant’s information. For example, if I was interviewing a 13 year old, double orphan staying with an uncle. I would say let’s imagine that he (pointing at the

cartoon image) is a 13 year old boy who's a bit like you. He has lost both parents and lives with his uncle. The doctor has told him how important it is that he takes his treatment every day. He is supposed to take his treatment at 7am and 7 pm (matching the time to the participant's routine). Some days he takes them as directed, but at least once a week he misses his morning dose and sometimes takes his drugs at 9 am. What might be the reasons that he does that? I would try to elicit all the possible reasons for non-adherence and ask if the child had experienced any of the mentioned reasons. This worked well as a way of encouraging young people to talk about someone like them and to initiate discussion about alternative adherence experiences. I reflect on the value of using hypothetical scenarios within this study in Chapter 8.

In the last phase of in-depth interviews (phase 4) I used timelines. Timelines fall within the visual representation tools that have been used in qualitative research. Timelines support the exploration of perceptions and experiences, with the goal of gaining a deeper understanding of lived experiences from the participant's viewpoint (Berends 2011). Timelines have been found to be very useful in facilitating recollection, in capturing the significance and meanings attached to personal events (Berends 2011, Adriansen 2012). I used a timeline task in phase 4 to obtain a detailed summary of the major events in their lives that we had discussed throughout the interviews, as well as to gain insight into how the young people interpreted their significance and the meaning they attached to these events.

I went to the interview with a large piece of paper and coloured pencils. On the paper I had put three markings (birth, now and future). I started by asking about important events since the time they were born. Not surprisingly, young people reported the time their parents died, when they fell sick, were hospitalised, and repeated grades, changed households and so forth. I marked these events in the circles I had made on the papers. Each time a child mentioned an event, for example, parental death, I would explore when and how it happened. I also explored the relationships between events. When I had exhausted all the past events I moved on to ask about their present events and lastly what they wished to achieve in future. The future captured their perspective on carer, marriage and having families. The strengths and weakness of using timelines are discussed in Chapter 8, as well as why it appeared appropriate to wait until the final interview before introducing this biographical tool.

In addition to using and adapting tools that I believed to be child friendly, I invested considerable effort to show that I was listening carefully to the children's accounts. As a principle, to make progress in conducting research with young people it is important to listen and reflect on what they said and to pay attention to the way they communicated, the language they used and how they used it. Active listening was particular important as the majority of the

young people I interviewed took a long time to formulate their responses. I was very flexible and I gave them as much time as they needed to respond. It is also important for researchers to understand that some young people may have difficulty in believing that any adult would take their views seriously if their daily experience of adults dictates otherwise (Cloke 1995). I constantly reminded all the young people throughout the interviews that their accounts were very important to me and that they were interesting and valuable to me and for my research. I used probes and often nodded my head, smiled at them and strategically used silence to encourage them to keep talking in instances where I felt that young people were undervaluing the importance of giving details or where they struggled to open up.

All the interviews were conducted in Shona, my native language and the most widely spoken language in Zimbabwe. The exception to this were the healthcare worker interviews which were done in a mixture of English and Shona, depending on the preference of the participants. All the interviews were done in a private room at the ARROW clinic in Harare. The interviews ranged from between an hour to an hour and a half including breaks for the young participants. The majority of the interviews were conducted during school holidays to avoid disrupting school attendance. The few that were done during school term were either done before or after school. During the course of the study I received an HIV Research Trust Scholarship to attend the London School of Hygiene and Tropical Medicine (LSHTM), providing an opportunity to augment the training around qualitative data collection and analysis that had been provided by the principal investigator, Dr Bernays, in Harare and through regular skype discussions.

Focus group discussions

Focus groups discussions are widely considered to be valuable in exploring social norms (Green and Thorogood 2009). They have been described as very useful in gathering “meticulous descriptions of shared meanings, attitudes, experiences and perceptions on peer social support (Morgan 1996). Focus groups are best when you want to consider, not only children's own accounts of reality, but the way they negotiate these accounts with others, thereby showing divergence or convergence between their views (Morgan 1996). Focus groups are also helpful for brainstorming and in my case I wanted the young people to think about the findings and the best ways to disseminate the findings.

In my planning stage I had a lot of uncertainties concerning the use of focus group discussions with young people especially to discuss experiences of HIV and social support as this was regarded a sensitive topic. I assumed that young people would be uncomfortable sharing their experiences in a group setting. However, the focus group discussions worked well as designed

and young people were comfortable and happy to participate. This might have been as a result of them having all been part of the research for some time and had knowing me relatively well.

Having had a series of interviews with the young people I had developed a strong rapport with the majority of them. I used the focus group discussions as a way of developing a less individualised and intense relationship, as part of my exit strategy. It also helped to emphasise that the nature of our relationship had been as part of a research process, which had findings and was about to end. Although I was highlighting the research timeline throughout data collection phase I needed to make the exit easier for them to grasp by meeting them in a group and emphasising that this was the last time I was meeting them for research purposes.

The focus group discussions were conducted in the ARROW seminar room. The seating arrangement facilitated interaction among participants by allowing them to see and hear each other clearly and the moderator to hear and have good eye-contact with all the participants. Having good eye-contact helped me to observe the participants' non-verbal cues, to control the group, into bring shy respondents and for subduing dominant ones. I knew all the participants by their names and they also knew each other by name, meeting during clinic visits, hence there was no need for having name tags. The two who had not participated in the support group had several opportunities to meet and mix with other participants through the ARROW trial meetings, including the meeting held to officially mark the end of the trial.

Audio diaries

Audio diaries are a less used social research tool (Monrouxe 2009, Worth 2009), despite their potential to contribute rich personal, participant controlled data. They have rarely been used in resource limited settings. A handful of researchers have used diaries, for example, in health research of marginalized groups, including people with disabilities (Kenten 2010). It has been argued that diaries are an empowering method of data collection which allows the participant to reflect on their situation and be both an observer and an informant (Monrouxe 2009). However, the audio diaries have not, as far as I know, been used to research young children's experiences of living with HIV and taking ART. Audio diaries tend to better capture personal reflections, and can be an effective means of representing the voice of young people in their personal story-telling (Worth 2009).

This study assumed that audio dairies would allow young people to express their thoughts and feelings which may be difficult to express during face to face in-depth interviews due underlying emotions (Clay, Bond et al. 2003). For some young people, the interview may have been the only other time their HIV had been discussed and they are likely to have struggled to express themselves. Audio diaries allowed participants to record narrative on the subjects

of their choosing – they were not limited to the topics brought up by the topic guide – providing them with more autonomy over timing of talk and the subjects to record. I assumed that through the use of audio diaries, young people would be free to include and or place emphasis on the facts that were important to them or vital in their understanding of growing up with HIV on treatment.

One of the secondary objectives of this study was to assess the feasibility of using audio diaries with young people in resource stretched settings. The key concerns to be explored were whether young people would be comfortable using audio diaries (keeping them at home) and would the young people be able to use them, even with written instructions. Did the audio diaries pose any risks? What kinds of data were they going to produce and would these be different from what I was able to capture in the in-depth interviews and focus group discussions?

It is argued that instead of complying with rigid procedures, researchers must be prepared to adapt standard tools and practices in the interest of respecting participants and enabling their participation (Aldridge 2007). So as with the interviews, it was necessary to modify the conventional approach to suit the skills and needs of young people. All of the 15 young people who participated in phase 2 were asked if they wanted to keep audio diaries; however, only 12 (7 girls and 5 boys) young people took the opportunity to do so. Three young people refused to keep audio diaries citing confidentiality challenges of keeping the dairies at home as they were staying in large households with relatives to whom they had not disclosed. The rationale for using audio diaries instead of paper diaries was to make it as easy as possible for them to record their experiences, it was not only because of concern about literacy levels but to make the process more enjoyable and less like a school homework assignment.

In my original plan, all the young people were supposed to keep the audio diaries between phase 2 and phase 4. However, the limited number of recorders compounded by the lengthy transcribing process, resulted in eight young people getting the recorders between phase 2 and phase 4 and four young people had to keep their diaries after phase 4. I had five simple recorders that were rotated between the participants. This meant that I could not explore interesting issues that were raised in these four diaries in in-depth interviews. The recorders were designed to have standalone computer-free operation and had to be transcribed straight from the recorder which delayed the process. Transcribing took longer than anticipated. For these four recordings, interesting issues raised in their diaries were discussed more generally before the focus group discussions. Confidentiality issues were discussed and agreed upon before a child was given the recorder to take home.

The purpose of the audio diaries was to allow young people to be able to discuss their experiences outside the clinic environment where all the interviews were being held. As well as allowing participants time to talk about other aspects of their lives which they felt were important in characterising their experiences of growing up with HIV. I made a deliberate decision to provide diarists with very few guidelines so as to minimise the influence she had on the process.

Young people were individually called to the clinic to collect the audio diaries. Initially I wanted to call them at the same time and have a group talk concerning keeping and using the recorders but I thought that some young people might be intimidated by the group setting and might not ask questions if they had missed something. One-on-one talk gave me the assurance that the young people had clearly understood the instruction on using the recorders. In the one on one sessions I had time to demonstrate how to use the recorder and help them to practise using it. Brief Shona written guidelines on the types of information to record were also given for example they could record information a visit to other forms of care (traditional and faith healer or healing crusades). Participants were told that they were free to record anything they felt was important in characterising their experiences of growing up with HIV.

Olympus note coder (version DP-20), with 50 hours battery life and 1GM memory were used. The recorder's main key buttons (record, play and stop) are located at the front of the recorder, making it very user friendly. This model was chosen because of the simplicity of operation and because it was felt that their basic design was least likely to attract attention of other household members.

Reflections on keeping the audio diaries at home showed that almost all the young people enjoyed keeping diaries. All the young people acknowledged that the audio recorders were simple to use with only one child reporting getting stuck when the recorder could not turn on. I had forgotten to replace the batteries when I issued it. This was rectified and she was given new batteries. All twelve diaries were returned after two weeks and varied in terms of files recorded and when they were recorded. All the recordings were audible and the majority of young people recorded daily while the others chose to record at unspecified intervals. Audio diary interviews were conducted between April and December (over nine months) with a median gap of two weeks between handing the recorder to the next participant. The audio diary transcripts ranged from 7 to 57 pages of 1.15 line spacing.

The majority of the recordings were soliloquies with a few young people recording their interaction with other household members and their friends. The majority of girls recorded themselves singing church related songs while some boys recorded their scuffles with their friends among other things. The audio diaries tended to produce more detailed reflections on

daily events, feelings and relationships within the household space. The audio diary method encouraged more in-depth explorations of subsequent shifting of allegiance, relationships and expectations in the household care environment. For example, one participant talked about social events affecting his treatment taking behaviour and how this had compromised his adherence support (chapter 8). Additionally audio diaries captured sensitive emotions such as status disclosure within the household. Audio diaries also provided more context on how life is lived in the house and the community and their relationships.

Unlike other methods, the audio diary method provided an opportunity for previously unconsidered topics to be discussed. The unstructured nature of the audio diary allowed the participants the flexibility to choose what and when to record and to record topics that were not covered in the interviews. For example, the exploration of feelings and perceptions regarding perinatal transmission which was a subtle theme in the interviews. Reflections on how data generated through the audio diaries was analysed are presented in section 5.9.2 below under data integration.

Field notes

Detailed, structured field notes were written after every in-depth interview or focus group discussion that was conducted. The field notes captured the interview settings, including the context in which the interviews took place and the gestures which were not necessarily spoken. The interaction between the participants and the healthcare workers, counsellors' perspectives and thoughts of every participant were also captured in the field notes. I detailed all my reflections on every interview especially on what worked well and what did not work well and areas that needed improvements. I also reflected on any additional data that I needed to collect in order to clearly understand children's lived realities of growing up with HIV on treatment. These field notes were very helpful in contextualising the data. They added thick description in the analysis, making the data analysis process and findings more transparent (Bauer and Gaskell 2000).

For consistency, all field notes followed the same structure, depicted by a series of headings (background, interview arrangements, reflections on the methods and account and emerging themes). The background covered all the background information of the participant obtained during the interview and from counsellors and through my observation during clinic days. The interview arrangements covered how the interview appointment was set up until the time of going into the interview. I had a section where I reflected on the interview setting and its potential impact on the interview. I also had a section to reflect on the methods used and the account.

Under this section I reflected on the various research tools used assessing their usefulness in aiding children's story telling. I reflected on my questioning skills, the dialect and interview atmosphere and its potential impact on the data. Lastly, I reflected on the children's accounts, detailing the nonverbal cues which included their silences, avoidance and 'I do not knows'. I had a section on key investigation areas and this captured main the themes that were coming out of the data and areas that needed more probing in follow-up interviews. This structure helped to facilitate the iterative data analysis from the early stages of data collection. My reflections for example on the methods (tools and questions that worked well and not so well) helped to inform and shape data collection.

Interview summaries

Drawing on the transcripts, field notes and the sampling information, I wrote interview summaries for all the in-depth interview and focus group discussions. The interview summaries were both descriptive and analytical in nature. The interview summaries included a brief description of the cases, any additional information about the participant acquired after the interview, important themes that were coming out as well as how that particular interview compared to the rest of the interviews, making linkages with the carer and healthcare worker interviews. I also captured potential themes I could code for in the summaries, noting down the line numbers of the data excerpts with the potential themes. This became very useful during the final coding process. A sample interview summary is attached in Appendix D.

5.9 Data analysis

Having given a description of the data collection process, this section looks at the data analysis process. Data analysis was an ongoing and iterative practice. Initial analysis started after the first in-depth interview, when I was writing field notes reflecting on the interview process. I found simultaneous data collection and analysis very helpful in refining research questions and in improving questioning and depth of probing. This process however, required me to strike a balance between focused exploration and (attempted) open-mindedness.

This section is organised into three parts, the first part looks at the process of preparing the data for analysis. The second part addresses the key factors that shape the analytical approach, outlining the theoretical approach taken by this study. The last part demonstrates the data analysis process, including the different steps that were taken and how codes and interpretations were developed.

5. 9.1 Data preparation

The data analysis was based on 85 transcripts that were audio recorded using an Olympus DM-450 audio recorder (interviews) and Olympus DP-20 note coder (audio diaries). All the

transcripts were anonymised using pseudonyms. All the audio files were transcribed verbatim and translated from Shona to English by trained fluent Shona speaking research assistants and the researcher. Fluency in Shona was a requirement and this was done to ensure that all Shona idioms and proverbs were captured correctly. Children’s in-depth transcripts ranged from 60 to 75 pages. FGDs were 102 and 105 pages while adult transcripts ranged from 60 to 85 pages of 1.15 line spacing. Table 5.3 below shows the summary of the transcripts obtained.

Methods	Total	
In depth interviews	Phase 1	26
	Phase 2	15
	Phase 3	10
	Phase 4	15
Audio Diaries	12	
Focus groups discussions Phase 5	2	
Total	85	

Table 5.3 Data Corpus

Regular checks for accuracy in transcribing and translation were done throughout the transcribing and translation periods. I checked all the transcripts that were done by the research assistants by listening to each audio file while looking at the transcription, including more contextual details such as laughter, tone, long silences. A fellow PhD student (Webster Mavhu) checked all the 34 transcripts that I transcribed and translated. He has considerable experience in conducting and analysing qualitative research. Omissions in transcribing and inaccuracies found, were discussed and resolved in the team’s weekly meetings. The bulk of the inaccuracies were found in the first batch of transcripts and as the team got used to the process, the quality of the transcripts improved.

5. 9.2 Data Integration

This section describes how data generated from the different datasets (repeat young people’s interviews, carer and healthcare worker interviews, field notes audio diaries, Focus group discussions) were integrated and analysed. As is characteristic of longitudinal studies data analysis was a cyclical process. This process entailed defining and categorizing data, refining the coding frame, producing analytical ideas about the data and writing interview summaries and analytical memos.

A strategy of constant comparison was used throughout this study. Constant comparison is a process in which newly collected data is compared with previously collected data (Elliott and Lazenbatt 2005, Kolb 2012). It also included exploring whether data fit the emerging categories. In this thesis constant comparison involved comparing data from different participants (children, carer and healthcare workers), comparing data from different phases (children's phases 1, 2 and 4) and lastly comparing data within and across methods (in-depth interviews, audio diaries and focus group discussions). Longitudinal data analysis implies that codes remain active and the coding frame continues to change and evolve as more data were collected, coded and analysed.

This process requires that the themes I discuss and present in my analysis reflects the data I collected. For example, in chapter 6 I discussed why the majority of young people were unwilling to disclose their HIV status. After the phase 1 interviews I had an open code "fears around status disclosure" but as I continued with data collection and writing field notes and analytical memos I questioned how they learn to fear disclosure, I questioned their sources of their fear and their experiences of stigma. As I continued with coding I ended up with four specific themes: anticipated stigma, adult influence, fragility of friendship and secret is not safe. Although constant comparison and most of the analytical steps (iterative data collection) I took aligns with a grounded theory approach, I cannot claim to have used a grounded theory approach as some of my analytical thinking was influenced by a priori ideas gleaned from existing research. I adopted some of the strategies, as some of the steps were not practical considering the time limitations and also that analysis was to some extent informed by a literature review.

Both young people and adult accounts were considered as connected but grounded in the specific context in which they were given. Overarching patterns within the datasets were identified and a few detailed cases were also selected and will be referred to in chapter 6-8. Vertical examination of cases (case by case) and horizontal examination (across cases) was conducted focussing on changes in accounts. An example of how all the data sources were integrated is given below in Table 5.4. The case study of Sekai was used as she is one of the participants who took part in all the phase of data collection. Her carer was also interviewed.

Triangulation (integrating data from three methods) was used in this thesis. This did not necessarily involve looking for corroborations between multiple sources but instead aimed to identify complementarity, convergences and discordance between data sources. Inconsistencies were not regarded as reflective of a change in participants' perceptions, neither were they considered as problematic. Rather they were regarded as evidence of contradictions and tensions in both the way participants positioned themselves within

prevailing discourses and in their experiences at any given time. Analysing all the generated transcripts together provided an opportunity to analyse how and why some participants chose to present or conceal information when using different methods. For example differences in the presentation on experiences and perceptions regarding coping and living with HIV.

Case 1 (Sekai)	Engagement with time	Key turning points
Interview 1	Aware of HIV status Attending the Zvandiri community based support group Coping and accepted HIV status (positive picture of hope and coping) Contemplating disclosing status to close friends Good drug adherence	
Interview 2	Changed school to move to secondary level from primary school Unwilling to disclose status to close friends (rumour mongers/gossipers and social exclusion)	Changed school and friends Deciding not to disclose status to friends
Audio diary	Questioning why she got infected with HIV Complaining of taking pills (drug fatigue) unhappy about having the HIV infection	Unhappy about HIV infection Getting tired of taking ARVs
Carer interview	Sekai was disclosed as well as all the other household members Carer doesn't want her to disclose to her friends at school for fear that she will be stigmatised Stopped going to the community based support group- lack of bus fare	Stopped going to support group Not disclosed to anyone outside the family No post disclosure talk Could be moving households to stay with another relative
Interviews 3	Moved households to stay with a distant relative Stopped going for support group	Moving households Dropping out of the community support group
Focus group discussion	Challenges with disclosing to new friends/ not sure of the longevity of friendship Fear of stigma and social exclusion Pessimistic about ending stigma and discrimination	Strong conviction that friends are not to be trusted Resorting to silence and pretence

Table 5.4: Example case of data integration

Field notes were used in this thesis to supplement interview data and were analysed in the same way as the other datasets, using the constant comparative approach discussed in detail above. The analysis of field notes started as I was writing them to help foster self-reflection and to identify the key emerging themes and comparing them with other interviews.

5. 9.3 Analytical approach

The analytical approach was shaped largely by the theoretical framework, epistemological position and the intended audience for the research. My theoretical framework of bounded agency recognises that young people have to negotiate the social landscape that affect their agency (Evans 2002). Thematic analysis is compatible with interpretivist/ constructionist paradigms as it acknowledges the impact of societal discourses on realities, meanings and experiences (Braun and Clarke 2006). Thematic analysis was selected because of its flexibility; it allows the development of a coding frame through constant comparison across different datasets (Braun and Clarke 2006, Riessman 2008).

Thematic analysis

All transcripts, filed notes and interview summaries were imported into Nvivo 8 (QSR International, Melbourne, Australia), a qualitative data management and retrieval program. All the data was coded using the steps for thematic analysis outlined by Braun and Clarke (Braun and Clarke 2006). Familiarisation with the data was the first step that I undertook. Having conducted all the interviews, reading transcripts during the quality checks and in preparation for follow up interviews and reading while writing interview summaries meant that I was familiar with the data. The ARROW team (researcher included) individually coded line by line manually on printed transcripts the first five transcripts from our respective sites. We had a team skype call to discuss the preliminary themes that were coming from the data corpus. I had separate weekly skype call with Dr Bernays (qualitative study Principal investigator) to discuss the themes pertaining to the study. An initial coding frame was developed. The coding frame kept on evolving as data collection progressed, new codes were added while other codes were expanded to capture the new themes that were coming up.

Towards the end of data collection, there was a one week ARROW data analysis training in Uganda. The training covered coding and writing of analytical memos. During the training the team discussed the themes that were coming up from the transcripts we had individually coded before the training. Although a general coding frame was developed for all the four sites, I developed a separate coding frame for this thesis to look at codes that explored informal and formal peer social support (see coding frame below). After the training, I reprinted the five transcripts that I had coded before the training and recoded them incorporating insight from the training. I also printed the same transcripts and gave them to Webster Mavhu, who is a qualitative researcher currently leading the male circumcision studies at CeSHHAR. Most of the codes were similar, differences were discussed and resolved.

Once I was happy with my coding frame I had a meeting with Dr Bernays to finalise the coding frame, root codes and sub codes and rules were agreed upon. After the meeting, a final coding

frame was agreed upon and all the transcripts were coded in Nvivo 8. Table 5.5 below shows an example of a root code, sub code and the rules relating to the disclosure codes from the 'peer social support coding frame' that I devised for this thesis. The rules acted as a dictionary and I constantly referred to them throughout the coding process.

First level codes from the participant's accounts such as 'unwillingness to disclose', 'fear of being laughed at', and 'assumed stigma' were identified and labelled. The second step involved re-reading the transcript at an interpretative level, looking for shared meanings, actions, feelings, attitudes and perspectives. Examples of codes generated in this stage include 'fragility of friendship', 'secret not being safe' and 'normalising childhood'. The third stage consisted of an iterative search between and across codes in the transcripts to refine them. Data excerpts that belonged to each code were re-read in Nvivo and codes were re-examined, other codes were merged and regrouped. When I was satisfied with the sub codes that were developed I looked at the relationships between codes. Focus was put on examining links between codes, looking for both agreements and tensions in the codes. Related codes were grouped together under the root codes. Focus was put iteratively on the wider picture of the root codes found and the detail of the developing analysis until no further insights were generated. This resulted in the findings presented in the subsequent chapters.

During the data collection, transcription and coding phases, I wrote analytical memos of themes and codes as they emerged from the data. I recorded reflective thoughts, initial interpretations and questions arising from the data, deviant cases and connections between cases. Through the analytical memos, I was able to develop initial and narrow themes emerging from the baseline interviews into broader themes as the data collection progressed. For example, why young people could not trust their friends enough to share their status. In phase 2 it emerged that friendship was looked at as intrinsically fragile. Phase 3 data shows that very few had changed friends despite the relationship being persistently referred to as fragile.

Root Code	Sub Code	Rule
Disclosure to friends	The young person telling friends about their own HIV status	
	Accounts of	Descriptions of their experiences of and expectations around disclosing to friends
	Strategies to disclose	Strategies and tactics they use when they are telling friends about their HIV status
	Strategies to resist disclosure	Strategies and tactics they use when they are trying to avoid telling friends about their HIV status, e.g. How they avoid answering friends' questions about why they take drugs.
	Reasons to disclose	Reasons that are given which support or justify wanting to/ or actually telling friends about their HIV status, e.g. Bringing more support in helping them to take their drugs or stop being beaten for being late on clinic days.
	Reasons to avoid disclosure	Reasons that are given which support or justify why they would not want to tell their friends about their HIV status. This includes any discussion of the risks involved in disclosing their status, e.g. being bullied or teased no one wanting to play with them.
	Future expectations/ plans (including dilemmas)	What their expectations are of whether they will tell their friends about their HIV status in the future, including who, why, what would they say and when. This also includes discussions of any dilemmas or uncertainty they experience as to whether to disclose to their friends for example they don't think that they would ever tell anyone.

Table 5.5: Coding frame

Examples of analytical developments

I had a lot of unanswered questions from the phase 1 data, for example: why perinatal infection was not talked about even in a household where young people were staying with their biological parents? What role did the carers play in discouraging peer disclosure and why? Why were young people afraid of disclosing their status? Where had this fear come from and who decided it was time a child got told about their own status? In the baseline interviews, only a few young people had disclosed their status to other children. This provoked many questions for me: was there anything that was different between those who disclosed to other young people and the majority who had not disclosed? Where was the agency? What was my example of agency? Was it always among deviant cases and why was it that some were able to do it, if others could not, did it mean that they did not have agency at all? Influenced by the theoretical framework I thought bounded agency a potential theme. This informed the topic guides for the healthcare workers and carer interviews and many of these analytical questions were addressed through this focused wave of data collection.

I also developed an analytical memo around the fragility of friendship as I thought it could indicate a number of important issues that would help characterize the experiences of children. At the same time, it could elucidate some of the structural barriers in accessing social support. I had questions around this fragility, such as when does a friendship becomes stable? What are some of the traits that young people look into to assess the durability of friendship especially for the few who disclosed? Does this change with age? Is non-disclosure anything to do with the fragility of friendship? This became a central theme of my analysis .The analytical memos became the stepping stone to the final manuscript as I developed my thoughts from the memos I had written during and after data collection. An example of analytical memos is given in the text box below.

Analytical Memo; Fragility of friendship

ASSERTION: Childhood friendships are not stable and long lasting, young people become vulnerable if they disclose and then fall out of friendship

Disclosing status to friends: 19/26 not willing to disclose their status for fear of possible fall out

BM phase doesn't trust her friend to keep the secret if they fall out of friendship which she anticipated could be anytime. SG who is in primary school in her second interview mentioned that she can only tell her friends if they continue as friends in secondary school. PC currently in secondary school mentioned will disclose if they go into the same class after the upper secondary school screening. NM in her lower secondary school convinced that if they have a fight they will use it against her.

Feeling vulnerable: Young people realise that they will become vulnerable once they have disclosed their status to their friends considering that they are taking friendship as the most fragile among relationships.

Carer's perception: children's friendship is fragile. PC's aunt, SG's granny, GM's mother and granny- their children's friends are rumour mongers and will spread until it becomes public knowledge.

Development of hypothesis

There appears to be a difference between the perceived risks in disclosing to those who are in your household because they are 'family' and in disclosing to friends because these relationships are viewed as intrinsically fragile. This idea of the fragility of friendship may indicate a number of important issues that help us characterize the experiences of children.

- Young people think a lot about friendship. The friends that they have and how friends treat them appear to constitute important elements of how they view themselves and the quality of their day to day lives.
- Young people tend to be in control over whether, when and how they tell their friends. Disclosing to their friends is something that they are fearful of and give a lot of thought to. Having considered the consequences, they tend to choose not to.
- Carers justify having not initially told the young people in their care about their HIV status because they feared that these young people would unthinkingly disclose their own status to all of their friends. This assumption that young people do not appreciate the social risks inherent in disclosing an HIV status may both serve to justify the postponement of disclosure, but also mean that adults do not engage with how these social risks can be managed, alleviated or challenged. Could this be a reflection of carers' misunderstanding about the scope and extent of children's social awareness or a reflection of fear of the other consequences of telling the child, such as prompting uncomfortable and painful questions about transmission (see perinatal transmission memo), sexual behavior, illness and vulnerability, and the lack of competence/ capacity/ support they have

The use of verbatim quotes has become the gold standard for presenting qualitative findings and the inclusion of excerpts from transcripts helps to clarify links between data, interpretation and conclusions. However, in chapters 6, 7 and 8 I adopt a different approach. Data is presented using a combination of stories, explanations, case studies and summaries whenever it is not possible to use direct quotes. A key challenge that I came across analysing qualitative data from young people was that sometimes they used subtle utterances in expressing their ideas. For example, instead of getting a neat verbatim quote (monologue) which seems possible with adult interviews, young people used more words (long passages of texts in the transcript) to express their views, making it difficult at times to come up with short direct quotes from the transcripts. Verbatim quotes that I ended up using were selected on the basis of their representativeness of that data and their clarity in illustrating the theme being discussed.

5.10. Generalizability and transferability

The decision to adopt a qualitative approach, has at times been challenged by staunch positivists, who question the generalizability of findings from qualitative studies done on small sample sizes. Clinical trials, by nature, aim to generalise results to a wider population and most clinicians I was working with held this belief that the purpose of research is to be able to infer the results to a wider population. I had to explain that qualitative studies especially those informed by the interpretivist / constructivist seeks greater understanding of interpretations, reflections, shared meanings and multiple perspectives rather than to universally generalize the results.

5.11 Researcher reflexivity

Qualitative researchers are often faced with the dilemma of transparency and procedural clarity and their subjectivity affects research (Guba and Lincoln 2005, Jovchelovitch 2007). Reflexivity is therefore important in qualitative research as it enhances rigour and transparency of the research process. This research study adopted the definition of reflexivity given by Charmaz (2006:188) which is,

“The researcher's scrutiny of his or her research experience, decision and interpretations in ways that bring the researcher into the process and allows the reader to assess how and to what extent the researcher's interests, position and assumptions influenced inquiry”.

Being reflexive in conducting research is part of being honest and ethically mature in research practice (Ruby 1980, Tracy 2010). It has been argued that research influenced by the constructivist and interpretivist approach needs to be reflexive (Holloway 1997, Charmaz

2006). The constructivist and interpretivist approach argues that reality is not objective and exterior but is socially and culturally constructed and given meaning by the participants (Green and Thorogood 2009). The researcher was therefore not divorced from the issues under investigation. It was important for the researcher to take into account the impact of their assumptions and views on the research process and the findings in order to interpret the complexities of multiple realities (Green and Thorogood 2004). Reflexivity in this study was taken to include what had been emphasised, downplayed and missed out in the research.

Throughout the research process and at all stages I continually practised reflexivity and consider my researcher voice through reflections that I noted in my journal, field notes and memos. I recorded all my reflections upon different aspects of doing the research as well as my role within the construction of knowledge. Firstly, I reflected on the research process itself including the research design, recruitment process and the questions. The first aspect was acknowledging young people as participants and agents in their own right, who, despite their difficulties and bounded agency, managed to make sense of their social and medical worlds and, through a negotiation with those around them, play an active role in the co-production of knowledge (Skovdal and Abebe 2012).

The second aspect was acknowledging that HIV is not openly talked about in the Zimbabwean context, hence there was need for a design that allowed young people to slowly build trust and confidence in order for them to openly talk about HIV, as well as their lived experiences. Participatory methods and having participant-led interviews was very useful in getting young people to talk openly about their lived experiences. Ongoing analysis also helped to improve the research process. Questions that were not easily understood by the participants were revised and rephrased. Ongoing analysis also helped to revise the interview dynamics, learning when and when not to probe and in understanding the silences and I do not know that were sometimes used.

Taking short breaks was also helpful in reducing the rising emotions and discomfort caused by some of the areas of investigation, for example, HIV status disclosure. Young people who showed signs of emotional distress during interviews were asked if they wanted to stop the interview and they were referred and attended to by the trial counsellors immediately after interviews. It is an important finding that for many young people the interviews were the often the first time that they had spoken about being HIV positive since being disclosed to. Debriefing skype calls were scheduled as and when they were required to support me throughout the study. These were normally conducted with the principal investigator Dr Sarah Bernays and my primary supervisor Professor Frances Cowan. These proved to be very helpful especially during the initial stages of data collection.

Thirdly, I reflected on the relationship with the participants, both the young people and the adult participants. When talking about reflexivity, the issue of power comes to the forefront. I had to carefully manage the interview dynamics, where both the interviewee and the interviewer would act in certain ways according to their perception of each other's power. Poor management of the research relationship could result in the interviewer highlighting certain aspects of the interview while repressing others. All interviews were held at the clinic and the fact that I was introduced to the participants by the ARROW trial team had the potential to shape the children's accounts. Being identified as part of the trial staff had the potential for young people to downplay their adherence challenges and clinical experiences. I clearly explained my role to all the young people and their carers that I was not one of the clinic staff but I was a qualitative researcher and a student wanting to learn from their experiences and emphasising that that the study was highly confidential.

I also reflected on the influence of the interview setting, which was the ARROW clinic. This had the potential effect of shaping children's accounts to suit what they hoped clinicians wanted to hear. For example, this might explain why baseline data reported good adherence with young people reporting missing drug occasionally. Although the interviews were done in a private room, the fact that it was in the ARROW clinic might have contributed to positive accounts of the clinic and how they were treated on clinic days. Again I had to clearly explain that I was a researcher and not part of the clinical team.

Although I was an insider and had been resident in Harare long enough to know and share certain cultures and meanings with participants, I had to lay aside pre-conceptions and became aware that meanings were not fixed and stable, I had to probe and seek clarity on all vague terms that appeared common to the participants. For example, the term disease is widely assumed to refer to HIV in the Zimbabwean context so most of the participants used disease synonymously with HIV/AIDS, I had to probe to get the actual meaning of disease in participant's accounts.

When working with young children, another consideration is the age difference between the researcher and the participants (Heath, Charles et al. 2007, Hopkins 2010). This difference might generate imbalances in terms of experience where the adult researcher might be looked at as the expert. This has the potential to influence the research process. I constantly reminded the young people that they were experts, competent participants and I was coming in to learn from them. The ARROW trial team also knew that I was a PhD candidate hence this also had the potential of generating imbalances so I had to remind them that they had been working in the trial long enough to be seen as experts. Reflexivity was also addressed by attempting to

be as transparent as I could be in my analysis, detailing in the memos how the decisions and interpretation were reached at and the conclusions that were made.

5.12 Conclusion

This chapter started by outlining two epistemological approaches that informed this research design. The epistemological stance I adopt in this thesis is informed by interpretivist thinking, highlighting the need for human interpretation and subjective meaning, as well as the constructivist arguing for the co-production of knowledge in which the researcher plays a key part. The recruitment of HIV perinatally infected young people as the main participants of this research, as well as the selection of carers and healthcare workers whose relational influences framed and shaped children's accounts, is evidence of how this interpretive approach has provided an overarching framework for the thesis. The chapter also outlined the study design and the different methodological steps that were taken in this research project. A further aim was to map out limitations arising from both theoretical and methodological standpoints. Having theoretically and epistemologically positioned the study, the next three chapters (6-8) discuss the empirical findings of this study.

CHAPTER 6: RESULTS - CHILDHOOD FRIENDSHIPS AND HIV STATUS DISCLOSURE

6.1 Chapter overview

In this chapter, I explore how young people negotiate and manage their own HIV within friendship networks. One aim of this study was to explore the role of informal social networks on children's experiences of growing up with HIV. In particular the study sought to understand how young people perceived friendships, how they formed and maintained friendship and to consider how HIV either hindered or facilitated access to friendship. In chapter 2, I discussed some of the challenges that HIV infected young people grapple with in their everyday lives (disclosure, adherence, stigma and in accessing support). In this chapter, I explore whether these informal networks play a part in addressing or alleviating some of these challenges.

This chapter is based on children's interpretations and experiences of friendship. The chapter is organised into three sections. Section 1 discusses how friendship is defined and experienced by young people living with HIV. Section 2 highlights the social fears that young people have around being positive and how HIV influences peer acceptance and information sharing within friendships circles. It also outlines how structural and relational factors such as stigma and adults, influence children's social relationships. The common thread running through sections 1 and 2 is that young people invest significant efforts to conceal their HIV status. However, in section 3, I turn to the exceptions – young people who chose to disclose their HIV status to their friends in spite of the ramifications.

6.2 Defining friendship

6.2.1. Significance of friendship

All young people interviewed valued day to day interactions with friends and throughout the interviews, young people talked about their friends in a positive way. Friendship among the 11-13 year olds was depicted as very important in defining enjoyment. Friendship was achieved by being physically together, not being able to be with their friends was therefore considered a social and personal loss. Physical interaction with friends was the pivot upon which many evaluated the quality of any particular day and experiences.

Responding to the first question in the phase 1 interview, "talk me through what happened yesterday" almost all the accounts included going out to play or hanging out with friends.

"Yesterday when I woke up, I cleaned my room and I ate and took my drugs then I went out to play football and came back around 12 and bathed and stayed at home playing card games with my friends" (Garikai, IDI 1).

“It was a good day I was happy, I was at school with my friends and they were good to me we played together during break time and during the lunch hour we talked and laughed” (Paidamoyo, IDI 1).

“I started off by washing my face and cleaned the house, sweeping the floor, dusting the furniture and cleaning the plates. Then I cooked my food and ate and relaxed a bit, then I went to play with my friends next door” (Alleta, IDI 1).

Seeing friends and physically spending time with them was one common marker of a ‘normal day’. Failure to meet regularly with friends was seen as unusual and boring. Most young people described their time being completed by the social interaction with friends. A lack of social interaction with peers due to carer interference, illness or other commitments was noted as a social incompleteness. The company of friends was something all young people desired.

...“it was not an ordinary day because I spent the whole day seated at home with no friends to play with. It was boring, granny was outside talking to our neighbour and I spent the day loitering at home. ... Some days I will wake up early in the morning and ask granny if I can do the dishes and after doing the dishes I will wait a bit and my friends will come and we will go and play” (Faith, IDI 1).

“Yesterday was not good for me, I woke up in the morning with flu and I went to school during break time I could not go out to play with my friends and I went back into our classroom and told sir [teacher] and he told me to go home” (Simbarashe, IDI 1).

Crucially, young people placed considerable emphasis on having physical contact with their friends. Time was spent physically together, often playing, laughing and talking about varied subjects. However, regular contact depended on access to their friends as Simbarashe’s words illustrate, relies on being able to physically be with their friends. Commonly, such physical access relies on good health. In the absence of good health and play, young people worried about losing their friends as regular contact was perceived to be the social glue that sustained their friendship. Their narratives demonstrated that friendship was treasured and it formed an integral component of childhood. Day to day interaction with friends enhanced children’s happiness, self-esteem and lessened feelings of isolation.

HIV and illnesses, by removing young people from the spaces in which they would ordinarily be able to spend time with their friends, disrupted their participation and access to friendship. The majority of young people narrated how prolonged sickness and countless hospital admissions made it difficult for them to maintain social relationships. Before being initiated on ART, the majority of the young people were “too sick” to function normally on their own without assistance from family members, for example, being able to eat on their own or using the

toilet. Many aspects of being ill were described as difficult by the young people but a number of them prioritised this indirect social exclusion as one of the hardest experiences. Almost all the young people recounted the time they were sick with so much sadness and pain. As Rudo and Charity recounted:

“When I was in grade 2 (6-7 years), I became very sick that I couldn’t even rise from my bed. I was very weak and would vomit and was not able to eat, sit or walk. I was bedridden for more than a month. I would only go outside when my aunt wanted me to just have a glimpse of fresh air and they would carry me outside and they would carry me on my sleeping mat [reed]. When schools opened, I could not go because I was very sick and my aunt thought I was going to die and she had to call my mother” (Rudo, AD).

“... before I started taking these drugs I was sickly that I could not walk even to go to the toilet and I used to be carried around... I take my drugs every day and I don’t skip them because when I was sick each time I think of it I feel like crying” (Charity, IDI 2).

HIV prior to ART was represented by many young people and carers as taking away a normal childhood. This was most obvious when I look at how young people described how their lives were affected once they began ART. To signify the importance of friends, almost all the young people talked of rejuvenated health through the ability to play and participate in friendship networks. Rudo and Kennedy explained what happens in general terms to young people initiated on ART.

Zivai: “Okay so what happens to a child who is on medication?”

Rudo: “She will be able to eat her food without vomiting and the virus in her body will be reduced she will gain energy and if she was unable to play she will now be able to play with others” (IDI 2).

“...a child who is on drugs does not miss school and is strong and can go and play with his friends during break time” (Kennedy, IDI 2).

Reconstitution of health through improved access to antiretroviral therapy meant that young people were able to resume play and revive social relationships. The ability to play and make friends again was seen as the rebirth of normality and restoration of the once lost social lives.

6.2.2 Conformity with peers

In addition to being physically with friends, friendship also rested on being reasonably similar to friends. Physical markers of difference, if identified by friends, also significantly disrupted their sense of normality. Many young people talked of how having severe skin rashes deprived

them of a normal identity, prompting their peers to point fingers at them and to socially isolate them. Betty's narration of her experience highlights the consequences of the visual symptoms and scars.

"When I was in grade 5 (10-11 years), my whole body had ringworms and I would continuously scratch my body so all the people at school did not want to play with me. They were so afraid that I would infect them with the ringworms and they would not want to sit near me. I would just be by myself during lunch time and no one wanted to walk with me after school so I would go home by myself or with my brother if we finished school at the same time" (Betty, IDI 1).

Being socially different from their peers and alienated by their own friends was described as one of the most difficult events they had to deal with. Inability to conceal the physical markers of HIV was described as a source of stigma. Young people desired to be like their peers but for many, this desire was dampened by the visible symptoms of HIV on their bodies which marked them as different. Almost all young people recalled how they were treated as outcasts by their friends when they were sick.

Almost all the young people who have fully recovered and now bear no traces of previous illnesses reported reconciling while some made new friends. To them, being able to play and mix with their HIV negative peers without being marked out as different instilled hope in the benefits of ART and provided the motivation to continue taking treatment. Play was portrayed as having a number of roles in shaping experiences of growing up with HIV including the strong compulsion to adhere to drugs in order to be strong enough to play and to successfully conceal HIV. Grace mentioned in her audio diary that:

"At school I feel like any other child because no one can tell that I have HIV. I thank God for taking away the rash when I was young. I used to have rashes all over my body and my lips were red and my friends would ask what had happened to me and I didn't know what to say, but when I started taking my drugs the rashes disappeared and my lips were healed... Nowadays, no one can tell that I have HIV and this makes me happy when I look at myself that I look like my friends and I am not different from them, right now I can do anything, any sport at school" (Grace, AD).

For Grace, the restoration was not limited to health alone but also her sense of self-worth and a more positive perception of her body image. Having no visible marks associated with HIV meant that she had unobstructed access to social interaction with her friends. Belonging to a friendship circle brought the much needed uniformity with peers and the strong compulsion to conceal HIV. Although concealing HIV status has a protective effect in that young people pass

as normal and are able to participate and maintain social relationships, it makes it difficult for them to access to emotional, social and informational support.

Although accounts of illness and stigma were usually talked about in the past, this did not mean that the consequences were in the past. Three out of the twenty-six young people interviewed reported being isolated by friends throughout the study. The restoration was not complete or secure but manifest in explicit ways, for example, Lucia's condition. She was diagnosed with obliterative bronchiolitis at initiation on ART and has been on drugs for more than five years. Her condition has not reversed with ART. Lucia's abnormal breathing, coupled with white speckles all over her face continued to mark her out as physically different from her peers. Her condition and her friends' reaction to it served as a constant reminder of her past and present illness. In her baseline interview, she narrated how her friends were laughing at her as a result of her illness and the irreversible visual scars of HIV.

“My friends just don't laugh at me they gossip a lot spreading all over that I have the disease [HIV] and some actually said to me that your breathing irritates us. They always ask me about it [breathing] saying when will you get cured.... no one wants to seat next to me in class because of my breathing and during break time I will sit on my own... even if they stop talking about my breathing I still don't want them to know that I have the disease. I don't trust them and they are not nice to me, they are always laughing at me and it makes me sad all the time when I am at school” (Lucia, IDI 1).

Lucia's reflections about her own condition were framed in relation to the response of her peers. This showed the significance of friendship in defining the meaning and quality of experiences. In her phase 3 interview (conducted 13 months after the baseline interview) she reported the same sad and lonely story of social isolation. Her relationship with her peers had not changed as she continued to be taunted despite being on ART for a longer time.

Zivai: Ok, last time [second interview] you said you did not want to play with other young people at school has anything changed since the last time I talked to you?

Lucia: Uh, I do want but they actually discourage me from doing so

Zivai: How do they discourage you?

Lucia: I dislike the fact that they often want to question what I suffer from

Zivai: is it each time you play with them that they ask you what you are suffering from?

Lucia: yes they ask me but Florence is the chief culprit she always says what do you suffer from that makes you exempted from sweeping and mopping the classroom. She gets jealous because I am exempted from all the dusty duties at school.

Zivai: Uh so what do you tell her?

Lucia: Ah, I refuse and say 'Why do you need that information? Are you a nurse? If you are one that's when I can tell you' (IDI 3).

The narrative expressed Lucia's frustration at being constantly asked about her illness. Unlike Grace, Lucia's body continues to evidence her HIV status. Since her HIV infection could not be concealed it was now disrupting her social interaction with some of her friends who were afraid of contracting her disease. Her frustration was understandable as she was constantly reminded of her undesirable differentness which made it difficult for her to conform to her peers. Lucia's narrative expressed how she found the company of her peers discouraging as they continually mocked her and asked about her illness. All three of her in-depth interviews confirmed the profound effects of social isolation on her general well-being.

Lucia's account shows how her body continues to play a significant role in her social isolation and stigmatisation. Firstly the lesions and the abnormal breathing provides physical and visual evidence of her condition. This accounts for the negative reactions and comments she continues to receive from her friends and other schoolmates. Secondly her body is acting as the symbol and source and a cause for self-stigmatization. This undesired distinctiveness has negative implications on her social interaction with her peers as in her third interview she also talks about avoiding the company of her friends at school

"During break time I sit alone and sometimes remain in the classroom while others are playing outside. I cannot go and play with them because they do not want to play with me because of my breathing" (IDI3).

Lucia's experiences of living with HIV is therefore shaped to a large extent by how her friends interpret and interact with the visual marks on her body. The reaction of friends and other people to the visual marks on their bodies' impacts on their emerging self-image. Young people see themselves through the eyes of their friends and other significant people in their lives, they are conscious of what others think of their bodies and this significantly defines how they look at themselves and their identity. Lucia's abnormal breathing is likely to make her have a negative perception of her body image, as a result of her friends' interpretation of it. The fact that Lucia is now isolating herself and is no longer confident enough to go out and play with her peers, points to the low self-esteem and the enacted stigma that she is experiencing at school.

Visual scars of HIV and the need to keep HIV a secret lingers in some children's memory for a long time, highlighting some of the limited effects of ART on children's reintegration into social circles. Lucia's narrative demonstrated the profound effects HIV infection on identity and well-being. Late diagnosis and late initiation on ART meant that some young people were already wasted and could not fully recover and as a result, they could not successfully conceal their diagnosis. For some children, this image was fixed and there was little restoration. Many young people needed to put in extra effort into concealing their scars, treatment taking and routine clinic visits. Even if they were able to conceal all this, the risks that someone else would reveal their status remained. This helplessness lingered in their minds and continued to shape their interaction with friends and more broadly, their engagement with treatment.

Similar to Lucia, Farai's account also demonstrated how his persistent ill-health continued to disadvantage and limit his access to play. During the baseline interviews, he was frail and one could tell that he was failing on first-line therapy. Farai was switched to second-line therapy after the second interview but had not yet shown signs of recovery by the end of the study. Farai mentioned that he was different from his peers in that he could not participate in sports. The doctors had discouraged him from taking part in sports because of his recurrent chest problems.

Throughout the interviews, he talked about his failing health and his desire be healthy and to participate in sports just like his friends. Although he was fully aware that he should not participate in sports, the desire to be like his friends sometimes compelled him to play social football. Farai, who often played football behind his mother's back, admitted to having chest pains and a bad cough afterwards. With visual markers of HIV written all over their bodies, it continued to be difficult for some of the young people to access play and thus take an active role in maintaining friendships. These visual markers made it difficult for young people to conceal HIV and undermined the opportunities for inclusion and well-being. This also highlights how the restorative opportunities brought about by ART can be incomplete or uneven.

Lucia's narrative reflected the value that young people put on being socially acceptable and having friends. Despite being gossiped at, laughed at and discriminated against, Lucia still referred to them as her 'friends' showing the desire for friendship; lack of friends was a great source of distress.

Notably, exemption from doing school duties mentioned by some of the young people for example Lucia (quotes cited above), although for good reasons, further marked Lucia as different and further isolated her from her peers. Young people who reported being exempted

from school duties cited citing non HIV related conditions to their teachers such as asthma, heart to avoid disclosing their HIV status diseases. In Lucia's case, for example, her teachers were told that she suffered from severe bronchiolitis, hence she was exempted from cleaning duties and some sporting activities. There was no discussion or reflections on whether the young people thought that the teachers believed the reasons they gave.

Twenty three young people out of the 26 that were interviewed in phase 1 stated that they did not want their status disclosed to their teachers. They feared stigma and discrimination and had examples of teachers stigmatising HIV infected young people.

"I don't want them to know because when I was in grade 6 I was taught by another teacher, I used to go to hospital and she would tell people that I have gone to collect my pills and I did not like it so since that time I said I am not going to tell any other teacher about my status. I would rather be punished for missing school than disclose that I had gone to the hospital" (Charity IDI 1).

"I don't want my teacher to know my status because he does not keep things to himself. There is a certain girl in my class who went to the clinic with aching yellow eyes. She has a kidney problem then our teacher told everyone including other teachers that she suffers from a kidney disease. The whole school got to know about it. She was not happy with it and reported the matter to the school headmaster who reprimanded the teacher" (Rudo IDI 1).

"If one gives a wrong answer our English teacher normal says 'oh do not mind her HIV has gone in to his/her brains' so I will never tell him my status in case he uses me as an example" (Kumbirayi IDI 1).

Only three young people had disclosed their status to their teachers during phase 1 interviews. The three who disclosed mentioned that they wanted to be given a chance to write the tests or school work they would have missed or not to be punished for missing school. .

"So that when I miss school the teacher would know that I have gone to the hospital and would be given the work I would have missed for example if other write tests in my absence" (Kennedy IDI 1).

6.3 Young people's fears

Section one has illustrated how friendship is conducted among young people and its significance in shaping identity. In this section, I explore young people's fears and their expectations of disclosure to friends. Secondly, I try to identify the sources of their fears and

how such fears shape their friendship and more broadly, their experiences of growing up with HIV.

Almost all the young people perceived HIV status disclosure to be associated with more harm than good. Instead of leading to stronger and more meaningful friendship bonds, self-disclosure was consistently perceived to expose them to gossip, stigma and discrimination. Throughout the interviews, the need for acceptance and social inclusion made it difficult for young people to disclose their status. HIV was therefore managed through silence and secrecy.

6.3.1 Anticipated stigma

The majority of young people acknowledged that they were not ready to disclose their status and could not envisage a time they would be able to disclose their status to their friends. By successfully managing information sharing, young people hoped to stay within acceptable physical and social standards that were not only set by their peers but by the community at large. Conforming to peer standards minimized social isolation and facilitated integration in friendship circles.

Even though the majority of young people had no personal experience or had seen anyone being stigmatised, they still considered themselves vulnerable to HIV-related stigma. Fear of enacted stigma perpetuated non-disclosure and young people negotiated HIV through pretence and secrecy. The persistence of secrecy in children's friendship demonstrated that, regardless of universal access to ART, stigma continued to have a profound impact on children's experiences. As long as HIV continued to signal shame and deviance, young people would always feel the need to protect themselves from anticipated stigma.

The overwhelming majority of young people feared being assumed to be HIV positive. Responding to what they thought would happen once they disclosed their HIV status to their friends, the majority of young people mentioned that their friends would "refuse to play" or "share food" with them at school or "see them as infectious". The majority of young people also expressed fear that their friends and adults could use their HIV status to isolate or limit their participation in social activities at home or school. A number of young people shared anticipated experiences of social exclusion and discrimination as a result of HIV status disclosure.

"When playing chuti [ball game] people will not include you in their teams saying '*uri muzhanje*' (literally, you are nothing but a *muzhanje* tree) so I am never going to tell them about my status" (Sekai, ID1 2). [*Muzhanje* is a traditional fruit tree considered

weak because it does not have any bark but the word is used as a symbolic metaphor representing a weak person or easiest target, the terms connotes liability].

“Some adults when they hear of it [HIV infection] they will not want to go anywhere or do anything with you because they will be afraid you might say you are tired and you fall and die on the way or might slow their pace” (Elias, IDI 2).

“They might say when we are playing football and you get fouled they might say, 'You HIV weakling, get out of the match'. They will be saying do not get in the match because you are not strong and you make us lose the game” (Garikai, IDI 2).

Only a few young people shared actual experiences of stigma and discrimination as a result of their HIV positive status.

“Ah people would not want to sit next to me or even to ask me to do other duties like the other day there was a church meeting and we were sent to fetch water and one church lady said, 'Don't go with this one, she might faint along the way' and I was annoyed but I ignored her and took the bucket and joined the others” (Betty, IDI 2)

Despite there being a few young people (only 2/26) who encountered stigma directly, the fear of being seen as “weak”, “infectious” and “easy targets” and the need to participate in social activities prevented young people from talking about their condition and experience. The two cases are discussed later in this chapter. This fear of stigma appears to emanate from the fear instilled in them by their caregivers as well as through seeing their friends making fun of them.

A number of young people cited how young people were sometimes teased for having a chronic illness, for example, epilepsy and asthma. Grace and Lydia gave examples of how chronic illnesses were used to discredit or mock people by their schoolmates.

“There is this girl in my class who had a dispute with another girl and she began to shout at her saying, 'That is why you are always falling' as the other girl has epilepsy so she was mocked because of the epileptic seizures” (Grace, FGD).

“There are some pupils in my class who when they hear of one's condition they start to look down upon you or to give you a nickname of the disease. There are people with that habit at my school (Lydia, FGD)”.

Although chronic illnesses were regarded as a source of stigma, young people were more afraid of HIV stigma. Many of the children, when asked about their conditions, cited other chronic conditions. Betty's account below illustrates how other chronic conditions carried with them less stigma when compared to HIV.

Betty: Sometimes I lie to them, they ask me and I tell them that I have asthma.

Zivai: Why do you say you have asthma?

Betty: Because asthma is different

Zivai: How is it different from HIV?

Betty: HIV and asthma

Zivai: Uh how do people differentiate them?

Betty: Asthma you will just be having shortness of breath but then with HIV you will be taking drugs and all the people will be... you will be told to take drugs but people might tease you when they hear that you have HIV

Zivai: With asthma, don't people take drugs?

Betty: They take drugs.

Zivai: So where is the difference? What makes people tease people living with HIV but not at people with asthma?

Betty: Silence

Zivai: What do you think?

Betty: Young people living with HIV are teased because the disease is generally thought to be acquired by adults [this therefore implies that the young person is sexual active and therefore acquired it sexually]

Zivai: Uh.

Betty: So they will be saying where did this child acquire it from? Some people don't know that one can be born with it but asthma has always been there and people understand that one can acquire it naturally and not from someone.

Zivai: Ok when you say you can't acquire it from someone else what do you mean?

Betty: It won't... it's not spread by people, you won't be infected by someone else but it's God who decides that this one should have it (IDI 2).

Crucially, the choice to consistently lie to their friends about their illness, giving false diagnoses by citing other chronic conditions denoted the deeply discrediting nature of HIV. The narrative convincingly showed that young people feared HIV-related stigma more than the stigma that

comes with other chronic conditions. Many vividly described how this would manifest, suggesting that fear of stigma occupied their thoughts making it very real to them. An HIV positive diagnosis threatened how they affirmed their identity by being with and 'doing' friendship and play. Young people were concerned that they would be segregated against because of the presumed infectiousness of HIV.

Betty's account highlighted the implications of community beliefs of HIV transmission; HIV appeared to attract more gossip, discrimination and hostility than other chronic conditions. The construction of HIV transmission in terms of negative social markers such as perceived immorality, further alienated people living with HIV. Coupling HIV with deviance made it more discrediting than other chronic conditions. The narratives demonstrated that the reframing of HIV as a chronic condition had minimal influence on the lived experiences of young people, despite them having acquired infection in a non-behavioural way. HIV disrupted and or destroyed the relational bonds and social activities which were key to their experience of childhood.

For many children, denying and keeping their status a secret was not enough but they needed to be involved and to participate in friendship to avoid attracting attention. Farai is one example; despite being discouraged from playing sport by the doctors, he played football with his friends. His desire to be involved made him to play football despite worsening his chest pains. Farai played football because he liked it and to assume a desired social identity. Having the same identity as others was perceived to be crucial. For boys, this was mostly achieved through playing sport, participating in horseplay and through teasing other young people suspected of having HIV.

In addition to playing sport, girls also achieved this involvement through doing school chores. In her audio diary, Rudo demonstrated how young young people avoided drawing attention to themselves by participating in other school activities. She mentioned how at school she took part in almost all school chores, for example, washing sports kits, gardening and sweeping the school yard even when she was not feeling well. At home, her mother exempted her from doing many of the chores she performed at school. Avoiding detection was important in ensuring that their status remained a secret.

6.3.2 Adult influence on children's peer relationships

Adult accounts highlighted how they underestimated the significance of peer relationship in children's lives. Such relational influence significantly influenced how friendship is conducted as well as status disclosure within peer relationships. Almost all carers stressed that young people were incapable of keeping secrets and that the safest way to maintain the secret was

to discourage young people from disclosing status to their peers. The majority of carers perceived status disclosure in childhood peer relations as a great social risk which should be avoided. They convinced young people that there were no guarantees that their friends would keep the “secret”.

“What makes them [HIV-infected children] afraid is that even the people they call best friends might also have their own friends and they might tell them then those other best friends have their home and might also tell their family members and their status might end up being the talk of the whole school or neighbourhood” (Rudo’s mother, 42 years).

Adults tended not to trust their children’s friends, but crucially also not to trust their children. A number of carers reported having not initially told young people in their care about their HIV status because they feared that these young people would thoughtlessly disclose both their status and their parent’s status to all of their friends. Even though I have shown how young people were careful regarding disclosing, most of the carers felt that young people would not treat the information carefully. The need to contain HIV status within the household as well as protecting young people from perceived stigma and discrimination led carers to conclude the disclosure event with “but do not tell this to anyone”. A significant number of carers admitted to having “instructed” young people not to disclose their HIV status to other people regardless of the relationship.

“Yes I told her that you are not supposed to tell anyone like her friends at school or at church or even the neighbours this is not for all the people to know that you are HIV positive it’s not good for people to know. ...I told her this because a lot of people lack information on HIV so they might say words or things that will distress my child” (Sekai’s grandmother, 66 years).

I must say the secrecy starts with us carers at home, the drugs are brought from where they will be hidden when its time [drug time] and are brought clandestinely and they simply whisper to the child that you should take. It does not end there, we also tell them not to tell anyone including their friends to say if so and so get to know about it they will refuse to play with you and friends cannot be trusted. So young people are not given the choice to disclose their status because they are afraid of their carer’s reaction if they get to know that they told their friends about it [status] (Betty’s aunt, 43 years).

HIV-infected young people have come to understand that it is taboo to disclose or talk openly about HIV: young people do not feel comfortable disclosing or talking about HIV to health professionals, social workers and even researchers without the approval of the carers. All healthcare workers reported that they discovered that the majority of young people professed

not to know their status and would only open up when their carers approved that they talk about it.

“From my ARROW experience you find that when young people come to the clinic and you talk about HIV they will look at their carers especially those below 13 years, they look at their parents as if to ask for permission or acknowledgement from the carer to talk about it [HIV] the child will not acknowledge HIV until the carer says it's ok you can talk about it and then the child will open up. So I feel it's a subject which is not freely talked about and young people appear to be under the instruction not to talk about HIV” (Counsellor, 48 years).

A commonly held view among the healthcare workers is that the carers instilled this fear in young people as a way of ensuring that the status was kept within the household. The majority of young people had kept their status a secret, not out of their own will, but because they had been told to keep it a secret. Healthcare worker's conviction that carers instilled fear in young people is represented in the following quotes.

“it's because of the fear instilled in them by the parents I think their worst fear is stigma they are not sure how their peers or other people would react when they know that they are HIV positive” (Counsellor, 45 years).

“Sometimes this fear comes from their parents, the carers are the ones who feel that they will be stigmatized because they feel that if people know that their child is positive they will know that even the parents are HIV positive so in such instances you find that the parents stop talking about HIV with the young people and they emphasize to the young people that they should not talk about HIV and do not say you are taking any drugs to anyone” (Charge nurse, 35 years).

Young people's lives are therefore invariably bound together with adults whose dominance continues to shape the course of their friendships. This is more so with HIV as revealing a child's status also points to their parents. Parents may be perceived to have acquired the infection through morally unacceptable behaviour. HIV is presented as a threat to the carer and the young people's identity as it bears connotations of promiscuity which is socially unacceptable. HIV is regarded as a household disease and the responsibility of preserving the secret was jointly shared with carers. Young people were taught not to trust their friends especially with family secrets. Loyalty and pressure from carers to preserve the HIV family secrets made it difficult for young people to disclose status to their peers.

6.3.3 Fragility of friendship in childhood

For many young people, fears arose from not knowing how their friends would react if they found out limited opportunities for disclosure. This fear was also worsened by carers and healthcare worker who told them that their friends were not to be trusted. There was consensus among healthcare workers that young people were afraid of how their friends would react to them. One healthcare worker mentioned that:

“I think that fear of just saying if my friend knows that I have HIV will they relate to me the way they are relating to me now or they might put some barriers that’s the greatest fear. The issue is of sharing lunches, playing together, horseplay, chasing each other will they be able to do that when they know that I have HIV yah that the main issue that the young people talk about so it’s just that fear, they have that fear of the unknown to say what will happen when I tell him or her that is what hinders them from disclosing” (Doctor, 38 years).

Fear of not knowing how long their friendship was going to last for also acted as a barrier to HIV disclosure. Many young people worried that their friendship may be disrupted by arguments, or they may lose touch if they change school or classes. Failure to see each other regularly places an inherent fragility on the friendship. Most of the young people mentioned how “trivial quarrels” and “misunderstandings”, “school transfers”, “class allocations” had the potential to end “friendships”.

“I don’t want my friends [at the new school] to know that I take drugs because we became friends recently when I moved here so it’s too earlier to let them know that I take drugs. I don’t really know their behaviours and I am afraid that if we have an argument they might shout about it saying that’s why you are on HIV pills and publicise to other people that the newcomer has HIV (Kumbirayi, IDI 2).

“Because I am thinking that if I tell her now we might not be in the same form [class] because we were told that we were going to be screened according to our grades when we are going for form 3. I am suspecting that we might not end up in the same class and we might not continue as friends. I might be in another class and might have new friends so that’s why I am saying I need to wait a bit” (Charity, IDI 2).

Within the context of HIV, there is an additional layer of risk in telling them, because they are aware of the general threats to the longevity of their friendship. Their friends may be tolerant of their status now, but at a later stage, if their friendship is not as strong then they may have a different reaction and might tell others.

Carers and healthcare workers are part of the reason why young people framed friendship as being inherently fragile. They talk about the risks of friends falling out once they have learnt about their HIV status and how they are then bound to disclose it to other people.

“Because we tell them that those people might then segregate them [HIV infected children] and not want to play or associate with them if they get to know that they have HIV” (Grace’s grandmother, 68 years).

Despite this generalised understanding of friendship as intrinsically fragile, it was relatively long lasting. Although the study was short (15 months), the majority of young people maintained their friends throughout the duration of this longitudinal study, in spite of small fights. Only two out of the 15 that were followed up reported having fallen out of friendship as a result of status disclosure. Their narratives highlighted how they were socially alienated by their friends and classmates when they got to know that they were HIV positive. Moses who stayed in a farming community out of Harare, mentioned how his trusted friend leaked his status to his classmates. He narrated how he was teased and laughed at that his body “smelled HIV pills”. This led him to fall out with his best friend as he could no longer trust him. Similarly, Faith was also socially alienated by her school mates who accused her of wanting to “infect them with her disease [HIV]”.

Faith and Moses’ accounts highlighted that some young people still defined and conceptualised HIV as infectious and deadly. The accounts also showed the intricacies regarding the normalization of HIV in their communities which was that it was regarded with so much fear. The narratives also demonstrated that children’s fear of status disclosure and loss of friendship, though largely based on felt rather than enacted experiences of stigma, are not overstated. HIV stigma perpetuated by inadequate information on HIV transmission continued to be a crucial barrier to HIV status disclosure in childhood friendship. Fear of contagion led some young people to stigmatise their peers. The common pattern among most of the young people was postponement of disclosure. Young people in primary school kept saying they would disclose when they got to secondary school while those who were just starting secondary school thought that they would disclose when they got to tertiary education. Fear of telling continued to exist throughout the duration of the study.

6.3.4 Secret is not safe

As discussed above, the concern in telling friends was not limited to how they would react, but more to what would happen if the wider community got to know about their status. How would they also react? Almost all the young people viewed their friends and neighbours as potential ‘rumour mongers’ who would publicise and gossip about their status. Telling one was perceived as telling thousands, making it difficult to contain their ‘secret’.

“I do not know how to tell them [friends] because I am afraid that if I tell them they might refuse to play with me or they might tell others who are outside of our friendship circle and the whole country will get to know about it [my HIV status]” (Sekai, IDI 2).

“I do not think I will tell her [friend] because I don’t want the whole neighbourhood to know that I take HIV pills. People will start gossiping about me saying have you heard that Mrs Hanyire’s last child has the disease [HIV]” (Lydia, IDI 2).

Sekai and Lydia’s descriptions of their status becoming known by the “whole country and neighbourhood” respectively highlighted the magnitude of children’s fears.

“It is very distressing that one would have confided in her best friend trusting her to say ha this is my friend who knows about my life and she deserves to know this secret not knowing that your friend is the one who will betray you and publicize your status. ...so you must not tell this [HIV status] to people that you have not known for quite some time. I think it is very important that this be known only by your close relatives those people that you are confident that they don’t look down upon you” (Rudo, AD).

6.4 Decision to tell or not to tell (status disclosure)

The decision to disclose or not to disclose a status was influenced by many factors which included the establishment of a trusting relationship with friends. There was however, a noticeable gender difference in the way boys and girls built trust in friendship networks. Boys were quick to trust their friends while girls took longer to establish trust. Girls had numerous considerations which included one’s religion, honesty and trustworthiness. The majority of boys mentioned their main consideration as the ability to keep secrets. Three out of the twelve boys interviewed during phase 1 had ‘fully disclosed’ their status to selected friends.

They all cited the fact that their friends were not “talkative” and were “not gossipers”. Once they were satisfied that their friends were not rumour mongers, this was adequate justification to disclose their status. Their narratives showed that they perceived their friends’ characters to be fixed and stable and were therefore not worried about the impermanence of friendship.

Only two out of the fourteen girls who participated in the study had fully disclosed their status and one had partially disclosed. Girls had many expectations which included being able to keep secrets, honesty, being dependable and being God fearing. Trust development for girls was a slow and thoughtful process characterised by many practical tests. Character testing was one such test. This was done in silence - the HIV-infected young people allowed HIV discussion while they observed their friend’s attitudes towards HIV. In most cases, discussion about HIV was prompted by lessons that taught HIV/AIDS. For example, Charity cited that they had discussed HIV and equated it to diseases that were stigmatised in the Jewish society

during a Religious Studies lesson. Equating HIV to diseases such as leprosy sparked a social debate on HIV well after the class. Some young people also talked about HIV after Guidance and Counselling sessions which also included HIV as part of the topics.

When asked about what it took for them to be able to disclose their status to their friends, Charity had this to say:

“I first look at their character to see if they are not mischievous. I also assess if she is a good friend who doesn’t gossip and who is friendly to others, who speak well about others and who relate well and not rude to others” (IDI 2).

Almost all the girls mentioned that they assessed their friend’s trustworthiness by sharing less defamatory secrets. If the secret did not come out, one would be convinced that their friends were trustworthy.

“I disclosed to her because I have told her some things before and she has never told anyone. I do not just tell people about my status but I tell the people who fear God and are not gossipers but who are honest and special. So I can tell only people that I trust and I don’t tell those who are not trustworthy” (Grace, IDI 2).

Almost all the girls used character testing as one component of their decision but for many, they needed other conditions to be in place for status disclosure to occur. For example, Charity wanted to know that they would still be in the same class following year. The majority of young people interviewed were about to move from primary into secondary school. This was a big transition for them which involved changing schools, possibly friends and going into a new environment. Character testing was therefore used as a strategy of planned disclosure. Only Grace and Faith had disclosed their HIV status out of the all the girls who talked about character testing.

In many cases, however, passing the test was no guarantee that disclosure would occur. In Charity’s case, after examining her best friend and being satisfied that her friend was able to keep secrets, she still could not disclose her status.

“We have shared so many things like how I grew up as an orphan and she also told me about her life but she has never shared with other people, not even a single one. So I found out that she is a good friend who doesn’t enjoy gossiping and when she sees me misbehaving, she rebukes me and I also rebuke her when she does things that I don’t like and she treats me like a sister but I will not disclose to her now as we might not be in the same class next year and I like I said earlier on.” (Charity, IDI 2).

Instead of disclosing to her friend, which was initially the purpose of the scrutiny, Charity kept on adding new rules and postponed disclosure. For Charity, the risk of being in different classes was seen as a great threat to their friendship. Young people constantly weighed the risks and benefits of disclosing their status.

Once young people ruled out risks through character testing, there was still need to look at the benefits of disclosure. In this case, Charity might have considered the impermanence of friendship as not a risk but as a reason why she might not benefit. The possibility of being in different classes might mean that her friend might no longer be able to offer the same support and companionship she wanted. As shown earlier in this chapter, proximity and seeing each other regularly were key components to sustaining the friendship. The distance that she perceived would result from being in different classes meant that if this occurred she would need to make new friends. Not meeting regularly would disrupt their friendship.

6.5 Status disclosure

The previous sections identified that a primary concern amongst the majority of young people was protecting their status from being disclosed to others. This last section discusses the circumstances surrounding the exceptional young people who chose to divert from the norm and disclosed their status. Additionally, it explores why they chose to disclose and what effects they perceived it to have on their experience of growing up with HIV. It concludes by looking at how some young people managed to build resilience from the support they received from their friends after disclosure.

6.5.1 Inadvertent disclosure

First, I turn to the cases where disclosure happened inadvertently. Despite discouraging status disclosure to non-family members, some carers inadvertently disclosed their children's status to their children's classmates, friends and other people. Two young people reported disclosing their status as a result of circumstances beyond their control. Elias made the decision to disclose his status to his classmates when her stepmother raised suspicion among schoolmates by bringing in the drugs he had missed in the morning to school.

“...because they all [classmates] saw my mum coming with the drugs to school. I had forgotten to take them that's when they asked what the drugs were for. They kept asking me and some even insinuated that I had "the disease" [HIV]. I eventually told them that I was HIV positive and I take my drugs at 6: 30...” (Elias, IDI 2).

He mentioned that his friends kept asking what the drugs were for to the point when he got fed up with the questions, gossip and suspicion regarding his condition and made the decision to disclose his HIV status. For him, keeping the status a secret was a huge burden as he felt

most of his classmates were convinced that he had HIV. He was also worried about them finding out the truth from other sources.

“I am very scared that they might one day find out that I have "the disease" [HIV] and that I take pills, they will refuse to play with me...” (IDI 2)

Elias mentioned that he worried greatly about how his friends and classmates were going to react to the news. In his first interview, he indicated that his friends were gossipers and he was confident that they were going to tell other people that he took HIV pills. Elias' first interview highlighted his mistrust.

The pressure from his friends, however, pushed him into disclosing his status. Contrary to his expectation of social rejection and being gossiped about, his experience was positive. Elias reported that his friends were very supportive and continued to play with him. His experiences after disclosure showed no reference to stigma though he had anticipated it. When I probed as to the reason why his friends and classmates were supportive, Elias mentioned that he was not stigmatised because “they are now aware that they will not get the infection through playing or sharing their food with me”. Elias's case was crucially different from Faith and Moses' cases cited earlier on.

Unfortunately for Faith and Moses, their classmates saw them as highly infectious and they were rejected. This could also reflect the climate in the schools and how HIV is represented for example the sort of remarks that teachers and other pupils make. Elias's case was different as his community was aware that HIV was not as contagious as they previously thought or had been told by adults. Mbare, being the oldest and most impoverished suburb in Harare, attracted a lot of non-governmental organisations (NGOs) conducting a range of HIV activities. It is possible that HIV might be normalising and the majority of young people had had first-hand contact with infected or affected people and had been exposed to HIV programmes hence HIV was now being treated as any other chronic condition.

Faith and Moses' communities on the other hand, had very limited NGOs and little exposure to HIV programmes hence HIV was still being treated as a deadly infection which could spread through contact. This pointed to the fact that there were a few communities in which attitudes to HIV were normalising and people were no longer seen as outcasts; the majority of the participants came from residential areas where HIV-infected individuals continued to be feared, labelled, blamed and devalued.

Charity was another example of inadvertent disclosure, her aunt disclosed her status to their housemate when Charity missed her drugs after visiting her maternal grandmother. Charity was among the two exceptional cases (discussed in Chapter 5) where two carers were

interviewed from the same household. Charity confided and had strong friendship ties with a tenant 24 years older than her. I had to interview the carer and the tenant / friend to get a full picture of the nature of their relationship. The quote below came from an in-depth interview with the married tenant / friend.

Zivai: how did you find out about her HIV status?

Charity's friend: I got to know about it through her aunt. She [Charity] was not around so her aunt was worried that she had not yet come and then she told me that she was supposed to take her drugs at 7. So I asked if it mattered if she took them when she got back and she became elusive. So from that day on, I suspected that something was wrong with Charity. The following day, I asked her [Charity] about the drugs that she was taking so that I would understand how they work. She was not open to tell me that she was taking drugs and it just passed like that. After some time, she was late again and I confronted her and she denied taking drugs saying she finished the course [the drugs] a long time ago. Two days later, I told her that, 'You were dishonest with me maybe because you probably thought I would spread the news but the way I get along with you is different from the way I get along with your aunt's child. Just be open with me so that I know and I will not tell anyone'. That is when she told me that she took drugs at 7 in the morning and 7 in the evening. I asked her if she had "the disease" and that's when she explained that she was born with it [HIV] (Charity's friend, 37 years).

Although in this case disclosure was not planned, Charity had a limited choice as she was directly asked whether or not she was HIV positive. Charity explained that she had to disclose her status as she was continually pestered by her friend. In the first interview, Charity did not want anyone, including her other aunt and niece whom she was staying with, to know her status. Charity cited her other aunt's rowdy behaviour and being too talkative as the reason why she did not want her to be told about her status. She considered her niece to be too young to keep her status secret. Charity's case demonstrated that not only did she not trust her friends who were non-family members but even some of her immediate family members.

Charity made the decision to confirm the mounting suspicions of the tenant despite her expectation of stigma and discrimination. Like Elias, Charity also received support from the tenant and this marked the beginning of their strong friendship. This exceptionally strong bond led me to interview the tenant with the permission of the carer. Charity's friend became a de facto carer as the aunt was often busy and had no time to spend with the children. She set a pill reminder on her cell phone and would constantly attend school consultation meetings and assist and sign her homework books which her aunt had never had time to do ever since

Charity started staying with her. The friendship changed for the better soon after disclosure and Charity felt that the support she was getting from her friend had improved.

6.5.2 Planned disclosure

Although status disclosure was very limited in most friendship networks, a few (only 5 out of 26) young people defied widely-held perceptions of stigma and the notion that childhood friendships are fragile and chose to share their secret with their trusted friends.

Autonomy

The five young people who told their friends that they were HIV positive demonstrated autonomy in disclosing their status. Garikai was one such child who appeared bold and self-sufficient. Despite being instructed by his mother and grandmother not to disclose his status, he fully disclosed his status to his best friend.

“I told him [best friend] because he is not talkative and even if we quarrel he doesn’t say anything but I did not tell anyone at home about it and they all think that my friend does not know my status” (Garikai, IDI 2).

Garikai’s mother and grandmother both mentioned, in separate interviews, that they were confident that he had not disclosed his status to anyone. Responding to why she was confident that her son had not disclosed his status Garikai’s mother responded,

“...because I told him that you just don’t tell everyone that you are on drugs or you are like this [HIV positive] so even when other people talk about it at church or any other place, he gives me that look to say, 'Did you hear what they were talking about it?' or he would say when we were on our own, 'Did you hear what they were saying how can they openly talk about HIV in church?' (51 years)

Carers’ assumption that young people were keeping their status a secret demonstrated the agency that some young people had over their status. This contradiction between carer and children’s accounts highlighted the challenges of using carers as proxies as their accounts might not reflect children’s actual experience. Most of those who disclosed their status intentionally did not inform their carers that they had done so. Two carers suspected that their young people had disclosed status to their friends and other non-relatives and showed concern that their young people might suffer stigma.

Social support

Full disclosure in some cases was necessitated by the need for social support from peers. For some children, the need for social support outweighed the perceived risks of disclosure. For some children, having access to support in terms of school work and emotional support made some of the challenges less difficult, for example, being given notes or homework when they missed classes during check-ups and ART refills. Young people who disclosed their status

acknowledged being comforted and encouraged by their friends when they were sick or feeling low. For some children, friendship was not just about calculating the risk but was also about being in a position to realise the benefits.

“when I fall sick, my friends will come home and pray for me and if it happens when I am at school, they take me home and make sure I am okay” (Shamiso, IDI 1).

“When I miss school, I am not very worried because I know that my friends will help me with the notes and homework. After my clinic visit, I just go to their houses and get the notes and I don’t have to explain why I missed school because they all know I would have gone to the clinic” (Bernard, IDI 1).

Adherence support

With regards to HIV management, there were a few young people who felt that disclosing to their friends had helped improve their adherence as their friends would take the responsibility for reminding them to take their drugs. Elias mentioned that before he disclosed to his friend, he would “get carried away playing” and would “skip taking pills” or take them “well after time”. This, however, changed when he disclosed to his friend who now helped him with time management. Elias did not have a wrist watch and when they were out playing, his friend who has a wrist watch would tell him when it was time to go home for his medication. Elias stated that his friend ensured that they got home on time for Elias to take his evening drugs or that they went and played closer to home where Elias could easily take his pills on time. During the weekends and school holidays, the friend double checked to see if Elias had taken his drugs before picking him up to go and play away from home.

Faith and Garikai also appreciated the support they were getting from their friends after disclosing their status, which both related to adherence.

“Sometimes I might not have taken my pills, I might have been carried away playing then they will ask if I have taken my drugs and I might say I did not and I run home and take them so they do remind me” (Faith, IDI 2).

“... I was fed up taking drugs and was throwing them in a flower bed at home but my friend advised me against throwing them away. He encouraged me to take them [pills] saying, 'A cure will be found soon but if you don’t take your drugs, you will be dead by the time they find a cure' and so I continued taking my drugs (Garikai, IDI 2)”

The value of disclosing to friends was consistently described as being helpful for adherence through reminders, time keeping, and giving emotional and moral support when one was experiencing adherence fatigue. Although the majority of young people had not disclosed their status by the end of the study, they acknowledged that friends could play a significant role in

helping them to adhere to their medication. Their accounts demonstrated that friends were a useful underutilised resource in terms of HIV drug adherence. However, actual and anticipated experiences of stigma hindered their capacity to disclose.

6.6 Conclusion

Young people define and maintain friendship through day to day interaction. Although non-disclosure hinders young people from getting HIV-related support, being able to play and maintain contacts with friends offered an identity, which was focused on the priorities of children. Young people appreciated friendship networks in lessening feelings of loneliness and in restoring hope and well-being. Fear of social rejection and the need for love and social inclusion meant that young people were hiding their status from their friends. The findings have shown the role that carers play in instilling fear of stigma and through that emphasising the need for their young people to keep their status a secret. Carers kept telling young people that their friends are not to be trusted and that their friends will disclose their status to other people. Even though carers underscored that young people must not disclose their status to friends, they compromised the need to safeguard the secret through their actions. I have cited two cases where carer's action (Elia's mother brought the pills to school and Charity's aunt shared her fears about Charity missing her medication with her neighbour) this contributed to the inadvertent disclosure leaving young people with no options except to disclose their status. Although social structural issues including stigma and adult interference greatly influence information sharing and HIV talk, some young people tend to have reasonable control of whether, when and how to disclose their status to friends. Having highlighted the complexities of childhood friendship and the need for play and acceptance, the chapter concludes by suggesting a more cautious approach in campaigning for blanket status disclosure. There is need to pay attention to children's concerns and fear around status disclosure as, in most instances, the need for secrecy was based on the rational desire for love, acceptance and conformity to social norms. The following chapter looks at the role of formal peer support networks in shaping the experiences of growing up with HIV.

7.1 Chapter overview

As outlined in Chapter 1, this study sought to explore the role of informal and formal peer networks on children's experiences of growing up with HIV. Chapter 6 explored how young people defined and experienced friendship and how young people negotiated and managed onward disclosure, as well as what influences their decision to tell or not to tell their HIV status to their friends. It also explored how carers instilled fear of stigma and potentially overstated the need for keeping the status a secret. In this chapter, I now turn to children's perceptions and experiences of formal peer support. As defined in Chapter 2, formal support is the support that young people receive from organizations or agencies. In this particular chapter, I specifically define it as the support that young people receive through their interaction with other HIV infected young people and facilitators during or after attending support groups as well as their exposure to support groups.

The chapter begins by outlining the nature of formal psychosocial support available to HIV infected young people in Zimbabwe, focusing on the support available to study participants. Support groups and counselling are the most common available psychosocial support services. A description of the trial and the community-based support groups will be given as these were the only peer support groups that the young people were exposed to during the course of the study. It is important to contextualise how these two different types of support groups were run as this has direct bearing on children's experiences of formal support discussed later in this chapter. Having contextualised the types of support groups, I then present how perceptions of support group shaped children's lived experiences of growing up with HIV on treatment. Carers and healthcare workers' perspectives are also discussed. I also reflect on whether support potentially flows from formal peer support interventions to integrate with other more informal support opportunities.

7.2 Psycho social support services for young people in Zimbabwe

Access to psycho-social-support (PSS) for HIV-infected young people has been a notable concern in Zimbabwe. Young people infected with HIV face multiple psychosocial problems associated with disclosure, adherence, stigma and access to social support (described in Chapters 1 and 2). Until recently, there has been focus on clinical and material needs of HIV infected children, although this was sporadic and uneven. What was neglected, potentially because it was considered a less urgent need, were the psychosocial needs of young people living with HIV. To date, there is no 'standard of care' in terms of psychosocial support in Zimbabwe. The Ministry of Health and Child Care is currently working towards defining the

standard of care as well as strengthening psychosocial support for young people living with HIV. This comes after the realization that care and support services are key in managing the HIV epidemic.

Existing psychosocial support services for young people living with HIV in Zimbabwe are provided by public and civil society organizations. Two of the three referral hospitals in Harare and a few selected Harare City Clinics run their own support groups. The hospital-based support groups are centralised and sporadic as they are only run when young people come for the scheduled clinic visits, which is normally after every 3 months.

The majority of support groups in Harare and the surrounding areas are run by civil society organizations. Africaid which runs the Zvandiri programme (www.africaid-zvandiri.org) and Child Protection Society (CPS) (www.childprotection.co.zw) are among the few community based organizations providing psychosocial support services to HIV infected young people through support groups. The support groups are running in most low income residential suburbs in Harare. The intensity and nature of these support groups vary widely. Current plans are to adapt and implement the Africaid Zvandiri model countrywide. The Zvandiri programme is a community-based psychosocial support program for positive adolescents which has been documented as a United Nations UNICEF and SADC best practice, and was recommended for adaptation and regional scale-up in AIDSTAR-One's June 2012 technical brief (Sharer and Fullem 2012).

The support groups are largely designed to help young people (7-18 years) cope with HIV and the related stigma and minimise the negative effects of being HIV positive on their lives. This is normally done through providing a platform where young people meet and share, feel loved, accepted and supported. Support groups for young people are sometimes coupled with those for carers which are designed to improve the care giving rendered to young people living with HIV in Zimbabwe. The thesis reflects on who and what the support groups are supporting and whether or not they are meeting the intended purposes. Emphasis is on support group practices in relation to how the context shapes what forms of support it enables.

In general, HIV positive adolescents and their carers are referred to the support groups by their paediatric/adolescent HIV clinics, hospitals, families, schools, churches and communities. Non-Governmental Organisations (NGOs) that run support groups also run demand creation activities in their communities of operation. This entails handing out flyers and publicising their activities through the media. Referrals to support groups from the many clinics and hospitals without support groups are only done after status disclosure. Almost all support groups in Zimbabwe are designed for young people who are fully aware of their HIV status.

In this qualitative study, 24 of the 26 young people participated in the trial and community based support groups (CBSG) as shown in the table 7.1 below.

Support group	Ever attended	Still attending
Trial-run support group	24	0
Community-based support group	9	5
Non support groups attendees	2	N/A

Table 7.1: Support group attendance

7.2.1 Trial-run support groups

As mentioned in the methods section, there were two concurrent support groups (trial-run and community based support groups). Twenty-four out of the 26 young people who participated in the study had attended the trial-run support group. The trial-run support groups were implemented between 2009 (January) and ended in March 2011 (6 months before the qualitative study started). Young people were grouped into three age groups (5–9 years, 10–12 years and 13 years and above). The trial held a total of 15 support group meetings per group. The meetings were facilitated by the trial nurse, counsellors and doctors and were held at the ARROW clinic. Over the course of the trial, lack of funding led to the premature termination of these support groups in March 2011.

7.2.2 Community based support groups

Nine out of the 24 young people who participated in the trial-run support groups were also attending or had attended a community based support group at some point. The earliest point of attending was soon after disclosure but this varied widely among participants with some taking longer to join the groups after referral. Community-based support groups represented six different groups and operated in different suburbs in Harare and surrounding areas. Four of them were NGO supported while two (Batsiranayi and Chiedza) were community funded organizations. The community-based support groups varied in size and focus, with some accommodating more than 20 young people aged between 7 and 18 years in one meeting.

The majority of groups met once every month (every first Saturday of each month) and a few groups met twice per month. These meetings were mostly held in community halls and clinics. The meetings covered different issues including drug adherence, HIV stigma, managing disclosure, nutrition and positive living. The facilitators' expertise also varied widely by provider and the facilitators ranged from social workers, trained counsellors, lay counsellors, volunteers and peer adolescent counsellors. NGO-run support groups had trained facilitators while two of the community-based organizations used untrained volunteers as facilitators due to

financial constraints. The table 7.2 below summarises the community based support groups which the study participants attended. Some groups had problems with sustainability, forcing some to close while some others held irregular meetings largely due to the political and economic instability in Zimbabwe during the study period.

Name of organization	Type of organization	Exposed participants	Participants who were active members
Africaid Zvandiri	NGO	4	3
Mashambanzou	NGO	1	0
Batsiranayi	CBO	1	0
Chiedza	CBO	1	0
Child Protection society	NGO	1	1
SOS children's village	NGO	1	1
Total		9	5

Table 7. 2: Community based support groups

7.3 The perceived role of support groups

In the previous section I gave a detailed background of the trial run and the community based support groups. In this section I present children, carers' and healthcare workers' perceptions and experiences of support groups. I also discuss how non-attendees perceived support groups. Overall, young people appreciated the value of support groups in lessening loneliness, filling their knowledge gaps and in giving them a sense of purpose. Support group attendees, regardless of the length and consistency of attendance, found them to be very helpful and a significant source of emotional support, especially when they were able to attend them after having recently been disclosed to.

7.3.1 HIV knowledge

Experiences from community-based and trial-run support groups are presented jointly and a distinction is only made where there were major differences. Almost all the young people conceptualised support groups as a primary source of HIV information. The majority of young people who attended both the trial-run and community-based support groups acknowledged that they learnt a lot from the support groups. The quotes below summarise what young people learnt from the support groups.

“...at the support group they will be teaching us what HIV is and what causes it and that there is no cure for HIV but one has to take treatment to suppress the virus so that it does not multiply and make us ill” (Talent, IDI 1)

“They [support groups facilitators] taught us that if you have a boyfriend or girlfriend you must disclose to them or that if you get pricked by a needle you must inform other household members so that they get rid of the needle or and that you are not supposed to keep quiet because someone else might use it and they might get infected by HIV” (Paidamoyo, IDI 1).

The chronic nature of HIV and the purpose of taking treatment for life and the need for HIV prevention summarises the key messages they learnt at the support groups, issues that they had not necessarily been clear about following discussions with clinic staff. This also demonstrated that although the clinic staff may have thought that these issues were being learnt within the clinics, it was in the support groups that young people felt that they properly understood.

The information they received from both support groups reduced the panic around what being infected with HIV meant and emphasised the possibility of living positively with HIV. This was considered valuable in ameliorating the more terrifying descriptions of HIV that they had heard within the community.

“They say [community members] if one is diagnosed with HIV he or she will be wasted in no time, if it’s a woman she cannot have babies or the babies will die at birth, they say one can drop dead any minute but aunt [facilitator] said we can live normal lives and just be like other young people who are negative” (Talent, IDI 1).

“At school if people hear that someone has HIV they look at the person as if he or she will die tomorrow and no one will pass near them but we were taught [at the community based support group] that one can live longer if they take their drugs well” (Memory, IDI 3).

The majority of carers, particularly those whose young people were participating in community-based support groups, shared the same thoughts, that support groups promoted positive living.

“She used to worry a lot about her status but when she joined the support group, you could tell that she was loosening up a bit. She used to think that she was going to die at one time she refused to go to school saying what is the point when I know that I am probably going to die next year. She used to continuously talk about death and dying asking if she was going to heaven or not. This changed when she joined the support group and got to meet other young people who were just like her and also being told that she can live longer and get to have her own family I think this inspired her and she rarely talks about dying nowadays” (Grace’s grandmother, 68 years).

“I think the teachers [support group facilitators] know their fears because almost every session they are reminded that having HIV does not mean that they are dying but they can live longer. He used to be very worried about dying and falling sick but these days you can actually see that his attitude towards life is changed. He is now very positive and you will hear him saying ‘you are all going to die before me’. I think he now understands that he is not going to die tomorrow or anytime soon” (Elias’ stepmother’s mother, 47 years).

Both young people and adult narratives demonstrate that the support groups emphasised positive living. The distinction between horror stories of HIV and the positive living stories shows difference in the cultures of talking spaces. Different talking spaces enabled different narratives of self to image. Care environments are portrayed as framing the talk differently which enables young people to engage, think and present themselves differently. At school or in some communities HIV talk was described as being around contagion, terminal illness, death, barrenness while at the support group and HIV clinics the talk is framed around living without getting sick and living normally like their HIV negative peers.

Although the majority of support group attendees mentioned acquiring HIV information, there were still many key aspects of HIV knowledge that were missing in the support groups. HIV transmission and how they themselves might have acquired was not addressed in most support group meetings with the exception of a few NGO funded community based support groups. Betty, who attended the Zvandiri community-based support group reported:

“I became aware that I was born with it [HIV] and they would explain that since we were born with it we will grow up with it, just taking pills and we should not stop taking pills; that’s the norm” (Betty, IDI 2).

Charity was another example; she attended the Mashambanzou support group and talked about how her support group facilitator taught them about the different HIV transmission modes.

“you get it through sucking milk or might use a razor blade that have been used by someone with HIV or even a needle then you prick yourself if that needle is used by someone else and they also prick themselves or sexually that what I know” (Charity, IDI 2).

Charity was among the few young people who understood that she had acquired HIV perinatally, she was convinced that she acquired HIV through sucking her “mother’s milk”. The majority of young people who attended support groups had similarly sub-optimal knowledge of HIV as the two young people who had not attended support groups. Discussions suggested

that the significant majority of participants did not know about HIV transmission routes and the difference between HIV and AIDS. Elias' case below illustrates this lack of knowledge. Although Elias reported consistently attending both the trial-run support group whilst it was running, and a community-based support group, he still had not fully understood HIV transmission:

“A fly might contaminate the food with the dirt it would have taken from the rubbish bin then, if one eats the contaminated food, one becomes sick and if he does not go to the clinic he will end up with a headache and hot body and will end up having HIV” (Elias, IDI 2).

This lack of understanding may be explained by the lack of consistency in support group, as modes of transmission was unlikely to be discussed at every meeting. In addition, some groups were not tailored to suit the different age groups present in one meeting. The potential lack of age appropriate information might have made it difficult for younger young people to absorb and consolidate HIV information.

This lack of knowledge was important for a number of reasons, not least because young people cited needing good information to support them to adhere. In general, young people tended to associate not knowing how they got infected with HIV with poor adherence. Rudo mentioned that, if she did not know how she got infected with HIV, she was unlikely to take her drugs well. Giving the example of malaria, she said:

“Then they [healthcare workers] say I have malaria... so they will give me medicine for malaria but I cannot start taking the medicine if I do not know where I got the malaria from” (Rudo, FGD).

Not knowing how they got infected was a significant concern for many of the participants and also had the potential to disrupt positive living. Positive living has been conceptualised as the ability of HIV infected individuals to enhance “self-fulfilment” despite the challenges associated with living with a potentially life-threatening health condition (Levy and Storeng 2007:56). As discussed in Chapter 5, not being given enough information regarding their circumstances seems to make some young people sad, angry and frustrated and this anger and sadness is sometimes hidden from adults and the young people suffer in silence. This lack of knowledge may have added to the confusion, shame, guilt they feel which in turn results in them being unwilling to disclose their HIV status.

As presented in Chapter 6, the effectiveness of informal peer networks as a source of social support is compromised by the silence and secrecy around HIV status. The majority of young people kept their status a secret from their peers. Not having enough information themselves meant that they had to put pieces together on their own, which is difficult to do in resource

limited settings such as Zimbabwe where there is very limited access to other sources of information through the internet or libraries. Children's narratives portray support groups as vital for filling in gaps in their knowledge and as a critical resource for young people growing up with HIV.

Despite not addressing all aspects of HIV, carers and healthcare workers believed that support groups were providing useful information to young people on HIV and related topics. Of the 10 carers interviewed, seven mentioned that support groups were meeting the informational and educational needs of HIV-infected children; whilst carers whose young people were no longer attending support groups, felt that the young people they looked after were missing out on important information about HIV. Faith's father described that in his opinion, young people who attended support groups had more HIV information and understood HIV better than young people who were not in support groups because it was at the support group that "HIV is mostly talked about". Almost all the carers were convinced that by attending support groups, young people gained "enough" HIV knowledge.

All five healthcare workers who were interviewed agreed that support groups were helpful in informing young people about HIV and related issues. They described community-based support groups as being specifically tailored to provide HIV information and to respond to children's questions as they had more time to talk about HIV than in any other care environment.

"The few that I have asked actually say they do learn a lot from support groups. I am confident that they teach them about HIV. There are many trainings and HIV workshop that are conducted there [community based support groups] especially support groups that are run by Africaid. They do talk about HIV a lot and they have a good library we used to refer our young people to borrow books from their library and the facilitators are well trained" (Counsellor, 45 years).

Trial-run support group meetings were also tailored to give clinicians more time to talk at length about social issues, something they did not have time for during the scheduled visits.

"We used to say a lot during the support group sessions, that's when we had time to discuss other issues. We would discuss stigma, well social life and the medical side. On the social side it was stigma at school, home and church then relating it with community, then the scientific side we continually hammered on adherence and also what would happen if they don't take medication. During the doctor's visit we will concentrate on their health and filling in the doctor's forms (Doctor, 33 years).

The two quotes above illustrate the differences in terms of content, skills and effectiveness between the trial-run and the community-based support groups that were run by the NGOs. The counsellor acknowledged that community-based support groups had more resources, specialised training in support group facilitation and young people were exposed to the numerous HIV workshops where they interacted with young people from other support groups. The most cited workshops were the Champions for Life and Youth Camps which were sponsored by the Celebration International Church and the Africaid Zvandiri programme, respectively. Discussions with healthcare workers suggested that NGO run support groups were more effective in teaching young people about HIV and related issues. Mixing fun (organised camps and outings), participatory learning, and different venues and meeting other facilitators who were not their usual clinicians might have provided a less authoritarian and more relaxed learning space which was very different from their clinic experiences.

The doctor's narrative suggested that the trial-run support groups maintained the medical focus where importance of drug adherence was emphasised possibly at the expense of acknowledging social issues that made young people less likely to adhere. The clinicians took support groups as an extension of the medical consultation and as being designed to support medical interventions. The same quote also implies that the trial-run support groups meetings were not participatory but were a repeat of the doctor patient relationship where the clinicians 'hammered' on adherence and young people may not have been given space to talk and or interact and to ask questions. Although there was mention of social issues being discussed during the meetings, all the healthcare workers' support group narratives emphasised drug adherence.

Children's narratives highlighted how emphasis on good adherence in the trial-run support groups restricted talk about non-adherence.

"It is difficult to tell them [healthcare workers] in the support group that I am having problems at home and I am failing to take the drugs because they say you have been coming here [ARROW trial] all these years and you still don't know how to take your drugs well" (Memory, IDI 3).

"what makes it difficult to tell them about missing drugs is that in the morning [during scheduled clinic visit] you would have told them that I am taking my pills well and my aunt will have assured them [clinicians] that I have no problems taking my drugs so when the sessions [support group meeting] start I cannot then say, 'Ah I am struggling ah to say eh they are days that I forget to take my drugs'... what will they say about me or my aunt..."(Betty, IDI 3).

These quotations highlight some of the challenges of having the same healthcare workers facilitate support groups meetings as provide clinical care especially when they coincide with their routine visits which was the case in the trial-run support group. The desire to maintain a positive image of adhering well to treatment override the importance of acknowledging adherence challenges.

Besides restricting non-adherence talk, the trial-run support group also limited children's capacity to ask about their other social concerns. Young people reported feeling ashamed to ask questions that were supposedly silly from the medical perspective. An example of this is given by Grace who attended both the trial-run and the community support group but was too shy to ask whether she could be cured of HIV during the trial-run support group.

“for quite some time I was worried and wanted to know if I will be cured of HIV and I wanted to ask it here [trial-run support group] but I was concerned about what they will think of me so I ignored it... When I joined the Zvandiri support group I just asked aunt [facilitator] if HIV was ever going to be cured and she said that it was never going to be cured but one will keep on taking the drugs until one dies” (IDI 3).

Given the carer's contentment with the way support groups were being run in general, they seemed not to have realised the implications of the biomedical approach that the trial-run support group used. Carers saw the trial-run support group as meeting the needs of their children, despite the challenges this approach presented in addressing the needs of young people who might were struggling with non-adherence.

“I was happy with the support group [trial run] I thought they were doing a good job. The fact that my child got to meet others and mingled with them and got used to seeing others who were just like her for me that was good enough” (Faith's father, 46 years).

Satisfaction with support group's conduct was largely influenced by the carer's expectations of what support groups should do. As shown in the quote above Faith's father was satisfied with the opportunity for her daughter to mix and mingle with other young people living with HIV.

There seemed to be inconsistencies between the information young people were perceived to be getting from the support groups by their carers and healthcare workers and the actual HIV information that young people were receiving and absorbing from the support groups. The study found that for most of the young people, the information they absorbed was actually much narrower than may have been the stated aim of the groups. The majority of the young people could not say exactly what they had learnt from attending support groups although they mentioned how they could be normal and not think about HIV and be themselves. They consistently emphasised the benefits of learning valuable information through attendance,

particularly about drugs. Given the confusion that the study found circulating among young people about how they became infected and some of the broader implications of living with HIV, it was questionable whether the information that young people absorbed could be considered “sufficient”.

However, this discrepancy may be a question of on-going exposure to consistent information. The study found that in general, the five young people who had been regular attendees of community-based support groups over a prolonged period tended to have more knowledge compared to young people who had only attended the trial-run support groups and those who had not attended any support group. Charity, Grace and Sekai for example, had sound information regarding perinatal transmission as shown in the quotes cited earlier in this section when compared to those who did not consistently attending support groups.

Elias was the only exception who continued to show suboptimal knowledge despite attending both the community based and trial run support group consistently. It is interesting to note that despite this, Elias is among the five participants who intentionally pretended not to know their HIV status (discussed in detail in the following chapter 8). This may mean his apparent lack of knowledge could have been an extension of his strategy to demonstrate his reluctance to talk about HIV. Pretending not to know how HIV is acquired would go hand in hand with not knowing his status and the reason why he was attending support groups. Elias is a bright child and this rules out the possibility of a cognitive deficit related to his HIV. This therefore, indicates the agency that young people have when it comes to disclosing and talking about their status and HIV in general to individuals they are not comfortable with.

Knowledge acquisition was not limited to young people alone. All the carers who attended support groups mentioned learning about HIV.

“yes I got such information for example here [ARROW clinic] we used to have a support group for carers, so those support groups were very helpful because the main challenge in disclosing to the child is that you as a parent won’t be having enough knowledge but now we have been given such information that the disease is acquired in this way and when one is infected how do you accept it, ways to accept it so it covered all those issues to do with disclosure, stigma and adherence. The knowledge they gave us makes us confident to talk to our young people about HIV” (Charity’s aunt, 45 years).

Limited HIV knowledge among the carers could potentially limit disclosure and restrict HIV talk at home. Charity’s aunt highlighted some of the challenges that carers face in explaining HIV-

related issues to young people when they were both uncomfortable and uncertain about their own level of knowledge. Although Charity's aunt shared the anxieties that carers might have, these might not be shared with the young people in their care. Carers required help to understand why it is important to talk with young people and to try and overcome their anxieties. The carer's narratives cited above suggest that knowledge gained in the support groups potentially influence HIV talk in the home and illustrate some of the indirect effects that participation in a support group might have in shaping how carers interact with young people in other care environments.

Across the three samples (carers, healthcare workers and young people) there was a presumption that formal support groups were primarily a source of HIV and drug information rather than a form of support for living with HIV. Evidence from both the young people and adults portrayed how support groups were perceived as sources of information. Limiting formal support groups to merely providing HIV and adherence information (even though crucial) falls short of the intended target, which is to provide holistic psychosocial support services to young people living with HIV such as being able to share and learn from peers. This has implications for future implementation of such interventions and will be reflected in chapter 8.

7.3.2 Access to HIV materials

Young people who attended the Zvandiri and Child Protection Society support groups reported being given books and other HIV materials to read during and after the support group meetings.

“We were given books to read at our support group. I enjoyed being taught and also to be given books to read and watching films. Some of the books were written by other young people living with HIV in Zimbabwe and in other countries such as Uganda and South Africa, talking about how they came to know about HIV and what they went through and how long they have survived with HIV ...” (Sekai, IDI 3).

Sekai felt knowledgeable and that some of her questions were answered by shared experiences from the book and the short films they were shown during the support group meetings. She was able to relate with some of the experiences shared which were not limited to Zimbabwe and got inspired by learning that one can live with HIV for many years. Grace was another example of a participant who appreciated access to HIV material;

“I was given the Zvandiri Our Story book to read at home and I learnt that this disease was also in other countries and that one can live longer if they take their drugs well. I used to think that it was only in Zimbabwe but I read that people all over the world can

have HIV. The book taught me to be strong and not to cry all the time because I have HIV and I read that I can live long if I take my drugs well” (Grace, IDI 3).

Access to books and HIV materials, although limited to few support groups, provided young people with the knowledge they needed to understand their condition better. Learning about other children’s experiences beyond Zimbabwe’s borders was described as comforting and encouraging. Grace felt inspired and this helped her not to give up but to stay focused on living positively. Reading about other children’s experiences might also have reduced their level of uncertainty regarding their life expectancy. Support groups appeared to equip young people with more knowledge than they could gather although there were limitations discussed earlier.

Both carers and healthcare workers acknowledged that the books young people were given in their respective support groups were a useful resource. The books were perceived to provide additional information on HIV and ARVs as well as words of encouragement, advice and support to young people living with HIV. The quote below suggests that carers appreciated the usefulness of the books.

“I think they [books] were helpful because she used to think that she was going to die and no matter how much we explained to her that she was going to live a long life but when she read a stories about a girl who had lived with HIV for more than 12 years, she believed what we have been telling her that she can live a long life if she takes her pills as we are told by the nurses” (Sekai’s grandmother, 66 years).

“The materials they were given I can say were very useful, I can give an example of ‘Our Story book’, that book answers to a lot of questions that young people ask about living with HIV. The message is presented in a way that is comprehensible to young people because the book was written by HIV positive young people and the experiences and testimonies are so real and very touching but at the same time instill hope that one can live a healthy and normal life which is what we always tell them” (Counselor, 45 years).

7.3.3 Platform to ask questions

Young people were also appreciative of the social space to ask questions in an anonymous and less intimidating way. In some of the community-based support groups, young people reported having drop boxes where they could drop their questions and the questions would be responded to towards the end of each support group meeting. Young people were given the first priority to respond to the questions while the facilitators would correct or give additional information, depending on the responses given. Anonymising the questions might have been an effective way to get young people to ask their questions without feeling intimidated. In Chapter 5, I have shown how some of the young people felt uncomfortable asking questions,

especially to their clinicians and carers due to the presumed sensitivity, silence and secrecy around HIV. The use of innovative tools in this study illustrated that not asking questions does not reflect a lack of need for information but rather points to the lack of conducive social spaces for young people to ask questions.

The format that many support groups used, such as having a question and answer session toward the end of each support group meeting was constructive in encouraging young people to ask questions in a way that made them feel comfortable. Responding to the probe on what motivates him to attend the support group meetings Elias said;

“Just to ask questions, learn and play till we get dismissed when it’s time to go home... I enjoy asking questions because no one will know that this is Elias’ question... They will ask us to write our questions and put them in a box and they will read out the questions and respond to them all. They also ask us questions at the end of the meetings” (Elias, IDI 3).

Community-based support groups, appear to have provided a space for young people to discuss their innermost concerns regarding their HIV treatment. They also provided a platform where young people blended what they were learning during their monthly clinic visits with their own personal experiences of growing up with HIV. Young people would be given real-life scenarios to discuss and to learn from about living with HIV and adherence. The use of scenarios was rarely mentioned in the trial-run support groups.

Young people described this as particularly valuable as the scenarios recognised the structural challenges to adherence that young people faced as opposed to the idealised advice that they often received from the clinic. Similarly, the study also found that vignettes (hypothetical scenarios) provided a space that encouraged discussion around drug adherence (reported in Chapter 6). Tinotenda explained some of the practical scenarios they were given to discuss at her support group meeting:

“They start by giving us scenarios, like they once said there was a child who wanted to go for a clinic appointment but did not have bus fare and then she started asking us what we were going to do if it was us who did not have the bus fare and when you try to borrow and all the relatives say they do not have the money” (Tinotenda, IDI 1).

Tinotenda felt that brainstorming on possible challenges and solutions was helpful in prompting young people to problem solve. Some of the scenarios discussed resonated with

the children's lived experiences and made it easier for young people to get help and advice from their peers and facilitators without having to disclose their personal problems.

Challenges with taking treatment may be difficult to fix from within the clinic, but acknowledging this and discussing using realistic scenarios allowed young people to be honest about their adherence challenges. Crucially, these exercises acknowledged that despite understanding that it was important to take drugs, it was not necessarily easy for young people to do so. Legitimising the reasons that young people cite for not taking their treatment was a useful approach that provided space for children, with the help of the facilitators, to come up with situation specific solutions to address and overcome the social challenges to adherence.

7.3.4 Adherence information

Consistent across our sample was the perception amongst the young people (both support group attendees and non-attendees) that support groups taught them about the importance of taking pills. In some groups, drug adherence messages acknowledged that there were social situations which made it harder for young people to take their drugs exactly as recommended by the clinicians. They focused on how best to get around the social issues that might disrupt good adherence. All the young people stated that the main role of a support group was to teach young people to take the correct drugs daily and on time. Support group attendees confirmed that they were told that the drugs they were taking "boost their body protecting cells" and if they did not take their drugs as directed, their "immunity system becomes weak and drugs will stop working in their bodies and they will die". This complemented the messages the young people were getting from their carers and/or other grown-ups in their households. Sekai mentioned that:

"She [facilitator] taught us that the drugs are the ones making us healthy and to live and if we don't take them as we are told at the clinic the HIV will multiply in our bodies and we will end up sick and die" (IDI 1)

Some young people found that support groups explained the importance of adherence and the effects of non-adherence in a more comprehensible and helpful way than in the clinics and at home. The young people reported finding adherence messages easier to understand and to implement when messages were combined with real experiences of taking drugs and learning about how the drugs actually worked in their bodies than when they were just given at the clinics. Mixing drug adherence messages with real-life experiences not only appeared to cultivate a shared understanding among young people but also helped young people to personalise it with their own or other children's experiences. Young people also appreciated the platform to share experiences on what taking treatment actually did to their bodies. Garikai explained how the support group approach differed from that of nurse counsellors:

“Here (at the clinic) they may be talking about pills, but at the support group young people will be talking about their experiences for example what is actually happening in their bodies when they take their pills and also what was happening when they used not to take their pills well...” (Garikai, IDI 3).

Talking about the drugs in the clinic setting and support groups was seen as significantly different from talking about the effect of drugs in their bodies. Young people found learning about the actual effects of drugs in their bodies helpful and informative. Not only did young people acknowledge that the main benefit to them was understanding more about their HIV treatment, they also perceived this to be the reason that other young people should attend support groups. In emphasising the importance of support groups, Brighton said:

“I would say to other young people who are not going to support groups, you must attend so that you are taught on taking medication well without missing because if you do not take the medication well, you will die” (IDI 1).

All the interviewed healthcare workers cited the important role of support groups in reinforcing adherence messages. Healthcare workers mentioned that for some children, adherence improved following referral to community- based support groups.

“A number have at some point expressed the fact that they are fed up of taking pills and then we have referred them to some support groups. We have always talked to them and we have also involved some, umm mm... what do you call them, some support groups which involve young people and we have seen a great improvement in their adherence. I guess being encouraged by other people who are not necessarily their clinicians and also the support of peers has helped and we are now referring almost all of them to support groups” (Doctor, 38 years).

“We encouraged them [trial participants] to join support groups so that they have continuous support because if one doesn't have support taking drugs everyday it becomes difficult. We never used to have adherence issues with those who were attending support groups, they adhered well maybe with a few exceptions but the majority adhered well” (Charge nurse, 35 years).

Similarly carers also cited support groups as a resource for adherence support. Most of the carers noted that young people were continually informed about the importance of taking treatment at their support groups.

“She always talks about how their facilitators emphasize the importance of taking treatment and this complements what the sisters [nurses] always tell us about setting

reminders and making sure that young people take their pills as recommended. I think that this is important, getting the same message from different sources such as the clinic, the support group and from us parents makes them realize that taking their pills is important” (Charity’s aunt, 45 years).

There were instances in which young people received locally tailored information to help them adapt to the particular conditions of their local environment. Adherence messages in most of the community-based support groups were tailored to suit the adherence challenges specific to the contexts in which they were being held. In some areas in Zimbabwe, there is a thriving ART black market and reports in local newspapers suggest that people are sharing ART. Given the heightened risk of treatment being misappropriated, Elias, who attends the Mbare community-based support group reported that they were taught to keep their drugs secure and not to share with relatives.

“They [support group facilitators] say you must keep your drugs safe and store them in a secure place as people are in the habit of stealing and selling ART. Aunt Elizabeth also said that we should not share them with anyone even our brothers and sisters but we must tell them [relatives] to go the clinic” (IDI 3).

The value of teaching young people to keep their drugs safe was limited by the reality that young people faced. Young people tended not to have responsibility for their own drugs. Although this message might have intended to prepare them for their future – when they were transitioned to independently take treatment on their own. It could also potentially highlight failure to recognise the limited control that young people had over many aspects of their situation.

Stigmatising non-adherence

Although young people admitted that they were taught about the importance of taking drugs consistently, both support group attendees and non-support group attendees still admitted encountering drug adherence challenges. Elias mentioned that some young people might be discouraged from attending support groups, which continually mentioned that “it’s bad” not to take pills. Young people reported that “bad” adherence behaviour would translate into them being considered “bad and irresponsible”. Being described as bad by their support group facilitators and or clinicians (for the trial-run support group) made the young people feel they were irresponsible and that they had failed and deserved to be reprimanded, potentially resulting in young people failing to disclose non-adherence.

The stigma perceived to surround non-adherence may therefore serve as a deterrent from attending support groups and disclosing non-adherence during support group meetings. During a focus group discussion one child stated:

“Maybe she does not take her drugs well so if they [support group facilitators] mention that to those who do not take their drugs its bad they get bored and refuse to go to the meetings” (Rudo, IDI 3).

Both the trial-run and community based support groups were represented as a form of governmentality, that is, as an extension to the delivery of biomedical intervention and clinical priority. Additionally, support groups were seen by some to have a kind of ‘disciplinary’ effect, ‘correcting’ those who were slipping up or somehow deficient in their treatment engagement. The discourse of moral value or failing surrounding exemplary adherence might be inadvertently excluding those that it aimed to support. The moral judgement was not limited to support groups alone but young people reported being “scolded, blamed and punished by their carers” for failing to take drugs as expected. Young people came to believe that other people (carers, sibling and clinicians) perceived those young people who had not adhered as irresponsible and deserving of punishment.

7.3.5 Being able to play

In addition to educating young people to a varying extent, about HIV knowledge and adherence practices, support groups provided young people with a vital space to play openly with other young people who were also HIV positive. Several young people spoke of support groups as providing a unique safe social space where they felt “normal” through being able to play and mix with other children, which was often been extremely difficult to do outside the support group. In the previous chapter, I have shown that physical interaction with friends is a valued normative practice of being a child. Similarly, many described being able to play with other young people without feeling different or discriminated against as fulfilling. The support groups made it easier for them to socialise and play with other young people who shared similar experiences and understood what it was like to grow up with HIV. They observed that this had represented a particularly important space which in part helped restore the ‘normalcy’ lost, when they were ill before being commenced on antiretroviral therapy.

My focus on different care environments enabled me to explore children’s experiences in the general community. The majority of the young people reported being able to play as an indicator of belonging and feeling ‘normal’. The majority of young people reported not having been able to play with other young people when they were sick for fear of stigma and due to other physical health constraints. However, this fear or reticence often continued to shape

their engagement with young people they perceived to be uninfected, even after they had returned to more robust health. Consequently, for some children, the space of the support group provided a rare opportunity to engage with their peers and to “fit in”. Fitting in was particularly pertinent for young people who bore physical scars or indicators of the illness, for example, Betty. She had skin lesions at the time she started attending the trial-run support group, and she described how, outside the support group, other young people did not want to play with her because of the distinguishing physical marks on her body. However, when she went to the support group, she felt comfortable interacting with other young people and she could play and eventually began to feel accepted and was able to make friends:

“So when I came here [support group] all those who had lesions we would just play together as a group. We did not mock each other because we all take drugs so we said let’s play together and it was fun and I felt good” (IDI 2).

When asked how she felt about participating in support groups Memory said:

“I do not feel shy because I will be among others who are just like me, we all have the same disease hence we cannot laugh at each other” (IDI 1).

Being around people who shared the same experiences created a form of citizenship in which they were able to make each other feel valued, loved and offered a unique common identity. This commonality was significant in part, making them less isolated and more accepted. Support group relationships are portrayed as playing an important role in the lives of HIV positive young people, influencing their overall psychological well-being as well as the way they managed their HIV and visual markers of HIV such as lesions, rash and speckles.

7.3.6 Restoration of confidence

Like Betty and Memory, many other young people had lost their confidence, had become shy, withdrawn and highly unsociable when they learnt about their HIV status. However, there was a strong pattern that this was ameliorated when they joined the support groups. Importantly for some young people, this experience influenced the way they engaged with young people outside support groups too, making them feel “strong” and restoring their confidence to play “in the streets” with other young people.

Talent mentioned that when he developed swollen lymph nodes and was diagnosed with HIV and TB, he became an indoor person and did not want to go outdoors and to show himself to other people or even play with other young people in his community. The internalized shame associated with HIV resulted in Talent withdrawing from public life. This, however, began to

change once he started attending the trial-run support group. His story indicated that, having been accepted by those in the peer-support group, his subsequent improved level of self-acceptance encouraged him to try to start playing with those in his community again. Describing the events after he began attending the support group, Talent said:

“That’s when we became friends. I just said ah let me play with them ... because in the past I used to stay indoors and I did not want to walk around or play with other young people in my road so the support group helped me to be united with others and to learn to play with others young people who stay in my neighbourhood” (IDI 1).

Carers whose young people were participating in community-based support groups echoed these sentiments and spoke of how their children’s participation in the support groups helped improve their interaction with other young people both within and outside the support groups. Elias’s stepmother considered this to be a critical contribution that support groups made to the lives of young people living with HIV. She recounted that, after being told about his HIV status, Elias became a very unsociable child who did not have any friends and would stay indoors even when other young people were playing but after joining a support group, he began to interact better with other children. Elias managed to make friends from the community support group and this helped him overcome his fear of being labelled and stigmatised. Elias confirmed his carer’s observation when he narrated how he now went out to pick his neighbourhood friends from their houses to go and play.

“...I know their homes and I go and pick them up, some of my friends will also come and pick me up so we can go and play on the open space near the vegetable market” (IDI 3).

Young people mentioned that support groups were particularly useful in helping them realise that they were not the only young people living with HIV and this helped them gain confidence. From the children’s accounts, it was clear that much of their experiences prior to getting involved in support groups were characterised by loneliness and a sense of isolation, which related to the silence and secrecy surrounding their condition.

“That’s when I became strong and first openly talked about my status that’s when I gained courage when I realized that they were so many young people who have HIV” (Shelton, IDI 1).

For many of the young people attending support groups, this was the primary opportunity to meet and get an opportunity to socialise with other HIV positive children, despite regularly attending an HIV clinic with other trial participants. The accounts suggested that, despite being a paediatric HIV clinic, the ARROW clinic space was not very interactive and young people continued to experience loneliness and isolation.

7.3.7 Role models

As was mentioned towards the beginning of this chapter, both the young people and carers' accounts showed that there was little discussion about HIV within the household environment. Many carers chose to keep their own status a secret from their children. An example is Allela who stays with her biological parents but claims that she is the only one who take pills in her household.

Zivai: Alright, so at your house how many people do you stay with?

Allela: We are five.

Zivai: You and who else?

Allela: Me, mum, dad, my sister and my cousin.

.....

Zivai: Ok. Is there anyone else from your house who is on treatment?

Allela: There is not.

ZM: Okay, so you are the only one on treatment?

Allela: Yes.

Carer's secrecy about their own HIV status made it difficult for young people to appreciate their HIV positive carers as role models and increases young people's sense of isolation and difference even within their own home. Despite the inherited nature of the illness, many young people experienced it in isolation. Young people therefore really appreciated being able to learn and hear from other HIV positive young people through support groups. In the support groups, status disclosure was expected so one of the first things they learnt about each other was their HIV positive statuses. As they got to know each other, they also learnt more about how they were managing their HIV status.

The trial-run support groups facilitated outings and meetings with older HIV infected young people in tertiary institutions in Zimbabwe and regionally through the Champions for Life programme. As a result, study participants described meeting HIV positive university students, who were perinatally infected and who had, by definition, survived with HIV longer than themselves. They described such encounters as transformative and inspiring. Through sharing testimonies, young people learnt that it was possible to live longer with HIV and all that they needed was to adhere well to their medication.

They also learnt that it was possible to realise their career aspirations.

"When we went to Mukuvisi woodlands we were happy, we played different games then we went to see animals, we also got inspired learning from the stories of other

HIV infected young people who were coming from different colleges I can't remember the names of the colleges but they invited young people who are now in colleges to share their stories with us. They took turns to share their stories and I got motivated to take my pills.... I want to be a nurse and from what they told us I learnt that nothing can stop us if we continue to get our pills" (Betty, IDI 3).

"At the Champions for life outing they taught and encouraged us to work hard at school. They said we must not let HIV stop us from becoming doctors or nurses or teachers. We had other young people who were saying that they are now training to be teachers and nurses but they were also born with the disease, some even started taking treatment when they were much old" (Elias, FGD).

Charity: They [healthcare workers] must continue to organize outing for young people like when we went to Mukuvisi, they were so many young people from different places and some just came to share with us their experiences.

Zivai: What sort of experiences did they share with you if you can remember?

Charity: Some said they almost died as they were always sick but when they started taking pills they got well and were now in colleges.

Zivai: Do you think that was helpful?

Charity: Yes we had fun and we played and having other young people talk to you and answer our question because when the sisters say you can live longer and become a doctor you think they are just saying that to comfort you but when you actually see other young people saying you can live and become a nurse then you are assured and it's easy to believe it (IDI 3).

Meeting older HIV perinatally infected young people who had gone on to universities restored their confidence in ART and many felt motivated to adhere to their medication. The value that young people placed on having role models underlined the importance of support groups in being able to facilitate peer interaction. Role models helped HIV-infected young people address their concerns about what it might mean in the future to grow up with HIV.

The majority of narratives cited in the discussion above show that support groups play a critical role, especially in providing a platform for learning, generating capacity to socialise, and to be loved and accepted as well as a space to talk away from the clinic, home and school. However, given the limited support available to young people living with HIV in Zimbabwe, there might be a tendency to not overly criticise the little support opportunities that exist, thereby portraying

support groups as being very supportive. This is not to suggest that support groups were not supportive but to highlight some of the social expectations that might make it difficult for young people to acknowledge the shortcomings of support groups. More so because it might have been difficult for young people to have an expectation of how best to use the existing opportunities.

7.4 Structural and physical barriers

Although the majority of children, both attendees and non-attendees, acknowledged the usefulness of support groups as a source of information about HIV, ART and adherence, some failed to attend or to continue participating in support groups. The next section outlines two key structural limitations that either hinder participation in support groups or limit the effectiveness of support groups.

7.4.1 Inadvertent disclosure and confidentiality challenges

Although for some young people attendance became an opportunity to restore a sense of normalcy through play and belonging by knowing that everyone attending had a positive HIV status in common, for a few exceptional cases, the threat of accidental and deductive disclosure was considered a substantial risk. Fear of being seen and recognised as an HIV infected child was substantial. Many described investing considerable effort into being considered “normal” in their neighbourhoods and by their non-HIV-infected peers through actively avoiding HIV-related activities. The strong compulsion to try to keep one’s status a secret, at virtually all costs, led some of the young people to refuse to participate in support groups.

It was clear that for some participants this was a prevalent concern when it came to accessing any HIV-related services. When the ARROW trial ended, some young people refused to be transferred to their local clinics and community based support groups, opting instead to receive their treatment and care through referral hospitals, for fear of being seen by their “neighbours and friends at the opportunistic infection waiting areas”. Garikai was one child who refused to attend his local clinic in an effort to ensure that his status remained a secret in his neighbourhood.

Garikai: Ah I do not want to go to my local clinic or even a local support group because everyone else will see me going there and they will eventually know that I have HIV.

Zivai: How are they going to know about your status?

Garikai: People will know because they will meet me on the way. The clinic is close by so I will go on foot and they can ask where I am going or they will see me in the queue

and will know that he goes to the opportunistic infection clinic so he has HIV. That why I don't want to go there [local clinic]

Zivai: What about the support group?

Garikai: the community hall used for the meetings [support group venue] is not very far from the clinic and people will still see me going there and they will know that 'ah he [Garikai] is coming for the support group for people with AIDS' (IDI 3).

Garikai insisted that he was never going to attend his local support group and would prefer to go to other distant communities where he was not known. Garikai was even prepared to commute to and from the support group. Strategies young people used to try to overcome concerns about confidentiality and inadvertent disclosure could create further barriers to support group attendance, for example, by increasing the distance people chose to travel for support which had a knock on effect on cost of transport which will be discussed below.

For those who chose to attend support groups, young people tended to be required to share some background information such as how they got to know about their HIV status, which clinics they go to, when they were initiated on ART as a way of introducing themselves to group members. This was expected immediately after joining the support groups and each time new members joined the group. This was however, contrary to what they were taught at home where they were instructed to conceal their HIV-information. Disclosing status involved ensuring that there was trust amongst the group that their status would not be disclosed outside the group. Young people were asked not to divulge information that other members discussed or shared during support group meetings with outsiders especially any identifying information such as names, schools, addresses and family members. Protecting this confidentiality was often challenging, and support group facilitators had to put strict measures in place to protect other support group members, such as expelling those who did not keep the secrets shared within the support group.

"I almost got removed from a support group because they thought that I was responsible for publicizing Anna's status. Her mother called auntie E [Support group facilitator] and told her that Charity was going around telling people that Anna has AIDS, then the auntie said if Charity can't keep secrets then we are taking her out of the support group" (Charity, IDI 1).

"They told us that we were not supposed to tell anyone what other people tell us at the support group. We even signed some papers as a promise that we will not share other people's stories at home but we can just talk about what auntie [Support group facilitator] would have taught us" (Elias, IDI 1).

The quotes above highlights some of the concerns and distrust that adults have about young people's ability to handle knowledge of someone else's status. This is demonstrated in the advice that they give to young people around friendships and the argument that disclosure was delayed because young people would unthinkably disclose. This anxiety circulate and is even manifested in support groups, where adults are concerned that other children's status will leak out of the support groups and therefore they have to put stern measures in place to control for it. Such anxiety underestimated children's agency in managing other people and their own HIV status. As with Charity's case, they later found out that it was not Charity who disclosed Anna's status to other people in the community but it was Anna's auntie (who lived in the same household with Anna and had been disclosed to).

"I explained that it was not me but no one believed me. Other young people were angry with me and also wanted me to be removed out of the group but I kept telling them that it was not me. After a few days Anna's mother called auntie E and asked her to apologize to me as they later found out that it was her auntie who went around telling people about it and it was not me. The whole group apologized to me..." (Charity, IDI 1).

Although carers were putting measures at home to ensure that their children's status remain unknown in their communities, their accounts did not perceive attending community- based support groups as a threat to their secret. The majority wanted their young people to attend and benefit from community support groups.

7.4.2 Peer-led support groups meetings

There were other aspects of support groups, which young people found unappealing. Five out of the nine young people exposed to the community-based support groups found constant peer led/facilitated support group meetings boring and less informative than if facilitated by a more skilled facilitator. Despite the increasing push for peer-led support groups by some funders, the young people themselves were not all appreciative of this approach. Elias recounted how, after having walked to the support group, he would expect to learn from the adults whom he presumed to be more knowledgeable experts, but instead found that he was attending consecutive peer-led meetings which he felt was a waste of his time.

"They [support group attendees] would have wasted their time walking on foot to the support group and they will be saying when we get there [support group] it will be someone like us talking. What is the difference when young people like us are the ones talking?" (Elias, IDI 3).

Charity also mentioned that she was less motivated to attend a peer facilitated support group meeting. She described peer led sessions as mostly play and songs which to her was less useful. Being less appreciative of peer facilitated sessions might imply that some young people

were more used and comfortable with hierarchy. However, this was not a uniformly held view. When asked during a focus group discussion on how support groups could be improved, some young people emphasised that they would appreciate a balance between the groups being led by adults as facilitators and those led by peers. The majority wanted the balance between peer led and adult led meetings to be increased in favour of adults.

7.4.3 Transport costs

Both carers and young people commonly mentioned transport costs as an important barrier to support group attendance. Given the relatively high cost of transport (US\$2 each round trip), and the fluidity of the caring arrangements for orphans, children's on-going attendance was vulnerable to changing financial circumstances or care arrangements within the household. Faith reported having to stop attending support group when she relocated to live with another carer:

“I could no longer attend because when I moved here I could not afford the five rand [South African – approximately US\$0.50] to get to the support group, it will actually be a \$1[US] gone in total so Granny said she does not have the money” (Faith, IDI 1).

The challenges in finding the resources to cover the transport costs were exacerbated by both the distance that some young people needed to travel to attend the support groups and the fact that some of the support groups were not consistently run due to funding constraints and low participation. This mutually reinforcing cycle of factors was summarised by Farai, who expressed his disappointment that it was not worthwhile for him to attend:

“My heart wants to go but the support groups are far away. The child protection society support groups are not reliable. Sometimes when I go there, they won't be anyone so my mother said it's better not to go rather than waste money [bus fare] going when there is no one” (Farai, IDI 3).

Carers also acknowledged that they were failing to meet the transport costs for their young people to participate consistently. All the carers whose young people were not participating in support groups mentioned that they would have liked their young people to be able to participate but they were finding it difficult to raise the bus fares; the lack of bus fare acted as a major hindrance to children's access to and participation in support groups.

Some carers also complained about the inconsistency in the way support groups were run in general. They shared their frustration for financing the trip only to be told that the group did not meet.

“She used to go to the one at the school but, she went twice and there was no one and she didn’t go again” (Sekai’s grandmother 66 years).

Healthcare workers confirmed the financial constraints that some carers were experiencing, some carers were unable to bring young people for clinic appointments despite being given bus fare reimbursements. In addition, they found it difficult to provide adequate food and clothing for young people under their care.

“I think some carers need material support because you find some of them like this cold season, you find the child coming to the clinic putting on a summer dress or a short with slippers and it’s very cold and when you look at the carer you can actually tell that she cannot afford warm clothing. Some even struggle to come for the scheduled clinic visits because of bus fares this is despite the fact that we give them reimbursements” (Counsellor, 48 years).

Given this difficult economic reality, paying for bus fare to attend support groups might appear more of a luxury than a need in some of the households. Economic insecurity is likely to increase given the country’s worsening economic status ([ZimSitRep_W. 2015](#)).

7.4.4 Carer’s perception- Failing of young people

Although young people cited the factors outlined above as reasons why they dropped out of support groups, most of the carers thought non-attendance was to do with the young people being too lazy and not wanting to walk to support groups.

Some carers thought that young people were seeing themselves as grown-ups no longer needing support groups, despite the support groups being there for young people aged 7-18 years.

“Maybe she is saying I am grown up or she is now getting bored with them [support group meetings] I don’t know because she no longer attends, she always come up with an excuse not to attend” (Charity’s aunt, 45 years).

“... She doesn’t like going to support groups, she likes playing around and reading her books. If you tell her that, the support group facilitator said you must come to the support group’, she will say, ‘I will go’ but you have to shout at her or even force her to go otherwise she will not go. She doesn’t want to walk even though the community hall is not very far from our place” (Rudo’s mother, 42 years).

A few young people cited carers’ non-attendance of carer support group as the reason why they also got tired of attending the meetings. The majority of providers ran concurrent support

groups for young people and carers. Carers cited lack of time as the main reason for not attending the carer support groups. This fatigue might have been silently passed on to the children. Charity confided in her friend why she no longer felt the need to regularly attend her support group.

“Her aunt always says she doesn’t have the time so she would just say, 'If aunt does not want to go, then I won’t go'. What would I go there for when they [support group facilitators] keep asking about my aunt?” (Charity’s friend, 37 years).

For some children, poor carer participation in carer support groups was understood to mean that it was not important to attend regularly hence they became less motivated. Young people might have underestimated their carer’s busy schedules and taken irregular and non-attendance to mean that regular attendance was unimportant. This compromised the information they could acquire as they missed some of the sessions.

7.4.5 Support groups as educational opportunities

Both the trial-run and the community based support groups were being used by providers as opportunities to fill in the gaps in children’s knowledge. When asked whether or not the clinics were giving adequate HIV information, the healthcare workers responded by saying:

“We can’t say it’s adequate because our role is to make sure that the young people are clinically well but we encourage them to join support groups in their respective areas so that they are taught about HIV. We understand those run by Africaid have a lot of materials that they can benefit from” (Charge nurse, 35 years).

This was not limited to healthcare workers only but carers also took support group as teaching spaces.

“Yes support groups are very helpful because they teach them about HIV and how to take their drugs well. I am sure young people are benefitting, they are taught many things” (Rudo’s mother, 42 years)

“Here, [trial-run support group] they taught them about how to take pills well and about the [HIV] virus for example and to protect other household members from getting the infection for example when they are using razor blades or pins and needles” (Faith’s father 46 years).

The healthcare workers and carers construct support groups as education opportunities where young people are taught about HIV. This challenges the ultimate purpose of support groups, which is to help young people cope with being diagnosed with a life-threatening condition and growing up with HIV. The teaching approach runs the risk of making support groups less

participatory. This might act as a barrier for some young people who might be looking for a less threatening social space to socialize, play and have fun.

7.5 Conclusion

The chapter explored the views of children, carers and their healthcare workers regarding support groups. The findings suggest that support groups are important for restoring lost confidence and in providing a safe social space for young people to play and to acquire HIV information. However, children's attendance had an influence on how much information they absorbed. Although peer support groups for HIV infected young people are universally perceived to be helpful, the study found that structural barriers hinder children's participation in these peer support groups. The thesis made a distinction between structural limitations shaping the effects that support groups have through children's participation and structural limitations shaping the forms that support groups themselves might take.

8.1 Chapter overview

Participatory research tools have been used with young people in resources rich settings (Jorgenson and Sullivan 2009, Fargas-Malet, McSherry et al. 2010) but as shown by the literature search (Chapter 3) very little research has been done using audio diaries in resource limited settings. This chapter explores how children's stories evolved, not so much by looking at the authenticity of their accounts, but how the use of different participatory research tools facilitated the ways young people expressed their lived realities and what this might tell us about those experiences. The analysis focused on exploring the opportunities for using participatory research tools, the feasibility and additional value of these participatory tools as well as the ethical dilemmas raised by the use of these tools.

The findings are presented in three sections: the longitudinal design, participatory tools and the ethical challenges. The chapter begins by discussing the usefulness of repeat in-depth interviews in exploring sensitive issues among young research-naïve children. This does not mean to say one off interviews would necessarily have been less valid but the chapter highlights the additional value of repeat in-depth interviews with young children. The second section addresses the usefulness of participatory tools in enhancing children's capacity to articulate their stories. I also reflect on the use of audio diaries with young children. Lastly, I discuss some of the challenges and ethical dilemmas of using such innovative tools with young people in this setting. This chapter highlights that throughout the waves of data collection, young people constantly negotiated ways of sharing their knowledge and experiences of living with HIV, demonstrating substantial agency.

In order to give the reader a guide to the purpose and focus of this chapter, I restate the secondary research objectives pertinent to this methodologically focused chapter:

- To assess the potential benefits of using longitudinal interviews to explore HIV experiences among young people.
- To assess the feasibility of using audio diaries with young people (11-13 years) in resource stretched settings.

8.2 Longitudinal approach

As highlighted in the methods chapter, the study adopted a longitudinal design. I conducted three waves of in-depth interviews and focus group discussions with young people over the course of 15 months (October 2011- December 2012). In the first section, I demonstrate how the young people stories evolved from being thin generalised accounts to rich detailed personalised accounts. As mentioned in Chapter 5, phase 1 interviews were used to build rapport and nurture a trusting researcher / participant relationship. Building good rapport and

trust is critical in all research, but particularly so when exploring the sensitive lived experiences of HIV among qualitative research-naïve children. It was always important to establish rapport in both the singular as well as those that were followed up and all the interviews were approached with this aim.

8.2.1 The approach

Although carers and healthcare workers had confirmed that young people were aware of their HIV status prior to recruitment into the study, phase 1 interviews started by establishing if participants were aware of their status. Awareness of HIV status was indirectly explored through asking young people to narrate their previous day. This worked well as all the young people talked about taking drugs in their narratives. However, their willingness to explicitly talk about HIV varied with the majority not wanting to explicitly talk about HIV.

8.2.2 Negotiating how to share personal accounts

When probed on the reasons for taking pills, three groups of young people emerged; those young people who openly talked about their HIV status (8/26), those who chose to indirectly reveal their HIV status (13/26) and those who actively chose not to disclose their status to the researcher and pretended not to know their status (5/26).

Explicitly disclosed HIV status

Eight young people explicitly revealed their HIV diagnosis in the first in-depth interview and were very comfortable talking about their diagnosis by name. Their accounts were mainly framed around living with HIV.

“I am taking drugs because they told me I am HIV positive” (Shelton, IDI 1).

“It’s for HIV and they said it’s meant to heal my body protecting cells” (Sekai, IDI 1).

“They [pills] are to reduce the spread of the HIV virus in my body, I was diagnosed with HIV in 2007 or 2008 I can’t remember.... And because I have HIV I take them twice a day...” (Grace, IDI 1).

These eight participants were not different from the other young people in terms of age, gender, knowledge of HIV, age at which they were disclosed to and all came from poor households where HIV talk was taboo. The only difference between them and the rest of the group was that they reported consistently attending community support groups. Six of the eight young people had attended several meetings run by the ‘champion for life’ programme. Champions for life is a regional programme within the Celebration International Church whose vision is to empower young people living with HIV to find their identity and hope in Christ (<http://celebrate.org/champions-for-life>). The increased participation and exposure to community based support groups and the ‘champion for life’ activities s likely contributed to accepting and adjusting to living with HIV. Throughout the interview, they consistently referred

to “being HIV positive”, demonstrating their willingness and comfort to openly talk about their status.

Implicitly disclosed HIV status

Half of the young people (13/26) chose to describe their status as an unnamed immunological illness. This group was less familiar with talking about HIV than the group described above. They chose to indirectly talk about their HIV status and used words such as “disease”, “illness” or gave descriptions of their illnesses which led them to take drugs without actually naming it.

“My mother told me that I have the disease so if I don’t take them [drugs] my body protecting soldiers [cells] becomes weak and I will eventually die...” (Tinotenda, IDI 1)

“I was ever sick with all kinds of illnesses and didn’t know what was causing the sickness and I had ringworms all over my body even on my head. I took all sorts of medication, the doctors tried different drugs and it didn’t work then I was taken by my maternal grandmother she is the one who brought me here [ARROW clinic], ... I was put on drugs and was told to come every month and the ringworms cleared off but I am still taking the drugs” (Betty, IDI 1).

“...because I have this disease... It’s a disease that gets into one’s body and it doesn’t get cured for life” (Moses, IDI 1).

Although most of the young people described their condition as an unnamed immunological condition and acknowledged it, they became more reserved in discussing their experiences of HIV. It was difficult with this group to probe for personal experiences of HIV or explicitly talk about HIV and the discussion centred on their experiences of “illness” and how this illness was shaping their identities. Within in this group, there was no personalised detailed talk about HIV.

The majority of young people resorted to using long silences, or “I don’t know/remember”, “I have forgotten” and “nothing” revealing very little about the direct lived experiences of HIV. Despite some of them having been aware of their status for more than three years, they chose not to talk about it and avoided mentioning it by name.

When asked about their illness, the majority of young people responded by saying “I was told about the disease but I have forgotten what they told me”. Forgetting things was selectively used throughout the interviews. They all seemed to remember their various pill combinations by name, how the drugs work in their bodies and other technical issues such as the meaning of a CD4 count and viral load testing, the ramifications of their “illness” and had no intentions of disclosing it to their friends. They all had a sound understanding that disclosing their illness to friends and neighbours would lead to stigma and discrimination but they seemed not to

know anything particular of 'this disease'. Forgetting was only apparent when talking about personal experiences of the 'unnamed illnesses'.

The strategy of pretending not to know their HIV status was so pronounced in discussions around who told them about their illness and what they felt when they became aware of their illness. When asked non-threatening or non-clinical questions about their illness dating back to when they were very young or about social events that had happened at enrolment into the clinical trial, young people were forthcoming. All the young people seemed to have good recollection of events including the unhappiest events, for example, parental illness and deaths, household disruption and previous illnesses but they described forgetting experiences that were directly linked to their own HIV diagnosis. Although young people pretended to know about their diagnosis, the subsequent phases painted a different story. For example in phase 4 when young people were completing the timeline exercise, detailed information around the HIV diagnosis including when they were diagnosed and who disclosed to them were revealed. This to some extent demonstrates the value of adopting a longitudinal approach when interviewing on sensitive topics such as lived experiences of HIV

The consistent use of "I have forgotten / don't remember" and the silence could be interpreted as a strategic negotiation of choosing what and how to share their lived experiences of HIV. This could demonstrate considerable agency in negotiating what they wanted and did not want to share. However, given the contextual background highlighted earlier in this study, describing how HIV is shrouded in secrecy and has often only been talked about during the one off disclosure event, the silence could also mean that young people had not conquered the fear that comes from living with a positive HIV diagnosis and were too distressed to talk about it.

Pretending not to know

The third group of young people was made up of young people who chose to pretend not to know why they were taking drugs or about their diagnosis. I present two case studies from young people among this group. The two case studies demonstrate how other social factors such as previous experiences of stigma and discrimination, prior experience (or lack) of experience talking about their own HIV status and relational influences shaped whether young people felt safe to disclose their status to the researcher. They also demonstrated the value of establishing rapport when dealing with sensitive topics especially those ordinarily defined by silence.

Box 8.1 Elias' case study

Elias is an 11 year old boy. Elias became aware of his status in 2009 when his foster parents disclosed to him. The counsellors verified that Elias was disclosed to and knew his diagnosis by name. Elias participated in the trial-run support group before the group was prematurely terminated due to lack of funding. Additionally, he consistently attend the community based support group.

During the first interview, Elias chose to pretend not to know his status, why he was taking pills and why he was participating in the community based support group. He was very reserved and gave very short answers throughout the interview. He brought up HIV three times in the interview and avoided personalised talk about his illness and HIV in general.

After the first interview I got the impression that Elias was not aware of his status and reflecting in my field notes I wrote:

Elias struck me as a very quiet and reserved young boy, even though his foster mother said he is very talkative. Each time I tried to probe why he was taking drugs he was quick to slip in the "I don't know" mode. His stepmother and the counsellors confirmed that he was disclosed to in 2009 and is aware of his status. Elias talked about his community support group and acknowledged that it's a support group for young people who take drugs to reduce HIV infection". What is surprising is that he doesn't know why he attends the support group and doesn't seem to realize what he has in common with other support group members. Could it be that he doesn't trust me with his status, is it that he is not disclosed or he is just using pretence to avoid talking about HIV and his status? Why is it that he doesn't want his friends to know that he takes drugs and more so his illness?

After the interview, I verified with his carer and the trial counsellors and they both confirmed that he was disclosed to and knew his illness by name. During the second interview Elias intuitively opened up saying that he knew his status and had made the decision to partially disclose to his friends that he took pills. When asked if his friends knew that he was taking pills, Elias responded:

Elias: I told them that I take drugs at 6:30

Zivai: didn't they ask what the drugs are for?

Elias: they didn't

Zivai: if they had asked, were you going to tell them?

Elias: yes.

Zivai: what were you going to say to them?

Elias: that they are for HIV.

Zivai: who told you about HIV?

Elias: it's my mum [foster mother].

Zivai: what did she say to you? I want you to explain to me what happened that day when your mum told you about HIV.

Elias: she asked me if I knew why I was taking drugs and I said I didn't know and she said you take them because you have HIV so if you don't take your drugs well you will end up sick and you won't be able to play or go to school and in the end you will die".

Zivai: Do you still remember when this happened?

Elias: ah it's a long time ago when I was discharged from hospital and I was not taking my drugs well, ah I can't remember the year but it must have been in 2008, ah it was in 2009 it's a long time ago....

When the first interview was conducted, Elias had already partially disclosed his status to his friends. His classmates inadvertently got to know about his HIV status when his mother brought the morning drugs he had forgotten to take to school. By the time of the first interview, Elias had recovered from that episode and managed to restore his friendship ties and had lots of friends both at home and at school.

Box 8.2 Faith's case study

Faith is an 11 year old maternal orphan who at first was staying with her father, sister and her stepbrother. She changed households and went to stay with her maternal grandmother in the same residential area. When I first met her, she had completed Grade 5 (10-11 years) and was about to start Grade 6. Her father was unemployed and the family relied on her elder sister who worked as a housemaid. Faith's father was on ART and TB treatment. In the first interview in her narration of her previous day, Faith talked about taking pills and when I probed about the pills she had this to say:

Zivai you talked about taking pills do you know why you take pills?

Faith: I don't know.

Zivai: did you ever ask your father why you take pills?

Faith: I didn't ask him.

Zivai: don't you want to know why you take pills?

Faith: silence

Zivai: silence

Faith: I don't know why I take them but my father knows he is the one who brings me here [ARROW clinic] all I know is if I don't take them I will fall sick and die.

Zivai: were you ever sick before you were commenced on pills?

Faith: yes

Zivai: what were you suffering from?

Faith: I had stomach pains and ... I was always sick [long pause], I don't know much but my father knows my other ailments, you can ask him.

I recruited Faith for the second interview after I had double checked with her father and trial counsellors and they all confirmed that she was disclosed to. After the second interview I jotted in my journal:

The first half of the interview was very difficult to manage as Faith seems to be reserved and used a lot more 'I don't knows', nothings; long pauses and silence than the first time I met her. She referred almost all the personal questions to her father but talked at length when discussing general issues, for example, when she was talking about her two sisters and her new teacher. Could this mean that Faith did not want to openly talk about her HIV status or that she was exercising her capacity for silence, negotiating what she wanted to talk about and not talking about things she didn't want to talk about. The use of 'I don't knows' could have been her polite way of saying I would rather not talk about HIV but ask me about my sister and my teacher and I can tell you everything you want to know. The silence and the 'I don't knows' were more frequent whenever HIV was mentioned. Faith seemed unsure of whether to disclose her status to me or to not to disclose. In the first interview she insisted that she didn't know why she was taking pills.

Interestingly, her attitude changed after the tea break and she began to slowly open up and the use of emotion maps and the drawing helped to facilitate talk. Faith acknowledged that she was disclosed to when she was in Grade 4 (9-10 years). She had also disclosed her status to her best friend. However, the trusted friend publicized her status to all her classmates and the whole school eventually got to know about her status. Could it be that her previous experience made her not to trust people or realized that her secret is only safe when undisclosed?

Elias and Faith's case studies demonstrate the amount of work that some young people put in to maintaining their secret. It took Elias and Faith more than one interview to openly admit that they were aware of their HIV status and later alone to share their personal experiences of HIV.

The case studies demonstrated how young people strategically used pretence as they tested how much information to disclose during phase 1 interviews. Pretending not to know their status gave young people the much needed time to decide whether or not to tell me about their status and eventually their personal experiences. They reflected on whether or not the interview was a safe space to talk about HIV, given that HIV-infected young people rarely talk about HIV in other care environments including the clinic. However, as the data collection progressed, young people gained trust and became comfortable with the interview setting and perceived it to be a safe space to talk and openly discuss their personal experiences of HIV. By the end of the second interview, all the five young people had explicitly acknowledged being aware of their status before participating in phase 1 interviews.

This group was, however, different from the rest of the cohort in that they had previous experiences of enacted stigma as a result of status disclosure. In the follow up interviews (15 children), I learnt that young people who chose to adopt the pretence strategy had previously

suffered betrayal when their trusted friends and relatives disclosed their HIV status to other people whom the young people had no intention of sharing with and without their consent.

“I told her [friend] in confidence that I have HIV and I take pills and days later she said ‘I want to tell people that you takes pills so do not play with her she might infect you with what she have’. She went ahead and told the whole class and people laughed at me and I told teacher and he asked me to name the people who were laughing at me and I told him the names and he asked why they were laughing at me and I told him that they were laughing at me because I take pills. So I gave him the names and he reprimanded them and told them not to laugh at someone who takes pills. After that I had no friends, people did not want to come near me. During break time I would go to my cousin’s class and talk to her but I would go home alone as we were in different classes and would finish school at different times” (Faith, IDI 2).

Moses is an example of someone who suffered from social isolation after had his status publicized without his consent.

Zivai: ok last time you said you didn’t want your friends at school to know, W and others do you now want them to know

Moses: yes

Zivai: why do you now want them to know?

Moses: Silence

Zivai: why do you want them to know?

Moses: because it’s now known

Zivai: known by whom

Moses: by everyone at school even those people who are not in my school

Zivai: who told them, when I last spoke to you; you didn’t want anyone to know

Moses: Silence

Zivai: who told them?

Moses: my friend told them, silence, I told him that I take pills

Zivai: uh

Moses: so don’t tell your peers but he told them

Zivai: okay and what did he say

Moses: then he went and told his friends and everyone got to know about it

Zivai: so how did you feel when J found out that W and the other were told about it?

Silence

Zivai: which card best among these ones described what you felt?

Moses: I was angry and most people did not want to talk to me or even greet me.

Such experiences resulted in these young people being protective about their status, wanting to avoid being stigmatised or shunned. Lack of willingness to disclose status was discussed in more detail in Chapter 6.

Elias and Faith's accounts illustrate that building good rapport is a process which might not be achieved in one interview. Rapport building is not solely dependent on the researcher's ability but is also shaped by the relational influences (carer and relatives), context (post disclosure silence) and previous experiences (experiences of enacted stigma and discrimination). In this case adopting a longitudinal approach helped to create a trusting relationship, where young people eventually got used to the researcher and began to open up including those who had made a conscious decision not to disclose their status or talk about their lived experiences of HIV.

In the methods chapter, I noted that young people were required to have known about their HIV status for a minimum of six months before recruitment into the study. The fact that the majority of young people chose to implicitly talk about their HIV status, with some pretending not to know regardless of how long they had been disclosed to, points to the challenges of setting a timeframe after which it would be alright for young people to talk about their HIV status. The study assumed that six months post disclosure would be a reasonable timeframe for young people to feel comfortable enough to talk about their diagnosis but some young people opted not to. This demonstrated that there are a number of social and contextual factors that influence children's ability to explicitly talk about their HIV status. As mentioned in chapter 3, young people are living under different cultural and socioeconomic contexts, have different emotional, informational and social support networks hence they are at different stages regarding making the decision to talk about their HIV status.

Most importantly, there was relatively limited talk about HIV post disclosure, except within support groups, HIV is still a highly stigmatised condition, so time since disclosure was not an adequate marker of whether a person had started to feel comfortable talking about HIV. For some young people they had no opportunities to talk about their status since disclosure. Some children, regardless of the social, cultural and relational factors persistent in their contexts, may still choose not to talk about it. This however, must not be interpreted as a sign that they are not coping well with their diagnosis but they are simply choosing not to talk about it.

During the interviews, I gave these young people the space and assurance that they were free to talk about issues, they should feel comfortable sharing and should not feel pressured to talk about things they were not emotionally prepared to share.

8.2.3 Confidentiality assurance

Besides providing a platform where young people could get used to the researcher, thereby gaining confidence to share their experiences, the longitudinal approach gave me an opportunity to prove to the participants that I was upholding confidentiality and not disclosing their stories to their carers and clinicians. The majority of the young people mentioned that during the first interview, they did not trust that I was not going to share their stories with their carers and healthcare workers. Fear of being punished by their carers and being reprimanded by their healthcare workers compounded the unwillingness to share.

Almost all of the young people commented that their carers and healthcare workers did not appear to have learnt anything from their first interview. Being able to maintain confidentiality facilitated their trust, which apparently overcame the initial decision of participants, described as being in groups 2 and 3 above, not to share their stories.

When asked how they felt being invited for the second interview, most young people talked about feeling confident and happy and the majority cited confidentiality assurance as the reason why they wanted to participate in the second interview:

“I was happy to come because after the first interview I didn’t hear her [my aunt] asking me about it saying you told the sister [researcher] that I am very short tempered” (Betty, IDI 2).

Confidence to share

Garikai also talked about how the interview environment made him comfortable to talk about things he had vowed not to share with anyone.

Zivai: how did you feel after the first interview, when you were going home?

Garikai: I was happy

Zivai: why did you go home feeling happy?

Garikai: because there are some things that I don’t want to disclose to anyone but I ended up talking about them here. You asked me some questions which I did not want to respond to or some information that I wanted to hide but I ended up responding...

Both laughing

Zivai: you don’t want to disclose to whom?

Garikai: some things cannot be disclosed to mum

Zivai: like what, can you give me an example?

Garikai: for example, when I go to church and I cannot tell her that I will be beating drums she will say how can you beat drum when you once had a broken hand, you risk having another fracture?... (IDI 2).

Most of the young people had never shared their detailed experiences (discussed in the following chapters) with anyone. Among all fifteen young people that were followed up, more private as opposed to generalised accounts, emerged. Meeting for the second and third interviews and finally in focus groups discussions proved useful in accessing the children's perceptions of support and friendship that might otherwise not have not emerged if I had conducted only one round of interviews.

Space to talk

Participants described HIV talk as very limited in most of the care environments. The majority of young people were openly sharing their experiences of HIV for the first time since they became aware of their status. Healthcare worker and carer interviews confirmed that HIV talk was almost non-existent at home. The focus of the talk at home was on drugs and young people were denied opportunities to share their feelings and inner thoughts of living with HIV. The carers avoided open discussion around HIV and even instructed other household members not to talk about HIV except when reminding the child to take pills.

“I don't talk about it and I don't want anyone in the house to talk about HIV... I think if I continue to talk about it she would constantly think about it and it will make her depressed or get more worried...” (Rudo's mother, 42 years).

Most of the clinic reviews and counselling sessions I observed for young people under the age of 14 years were conducted in the presence of the carers. Almost all the questions asked by the clinicians were directed at the carers and young people appeared to be invisible. In the sessions that I requested to sit in on, the counselling focussed on the carers and young people had little input and they would leave the room without saying a word. There was little room for children's voices to be heard besides responding to medical questions about their health.

As such, in most of the care environments, especially at home and in the clinic, young people were not accorded enough space to share their experiences and / or have adults listen to what they have to say. This is, however, not surprising considering that in the African contexts, as discussed previously in Chapter 4, young people occupy the lowest position and their voices remain largely silenced even in matters that concern them. However, the repeat in-depth

interviews provided an unusual opportunity for young people to feel comfortable to talk about their experiences.

Being able to adapt each interview to suit the pace and willingness of the child to share their accounts in their own way contributed to building good rapport and trust. This was commented on by the majority of children. Kumbirayi for example, mentioned this towards the end of the second interview “I was feeling happy because you have time to talk and listen to me and what you will be saying makes me happy” (boy, 13 years). Repeat in-depth interviews allowed me to tailor make follow up interviews to suit each participant’s context. Asking them about their friends and family members by name as well as following up what they told me in the first interviews reassured them of my interest in their stories; they became more than willing to open up and share their accounts.

In this first section, I have demonstrated the value of conducting repeat in-depth interviews with children, especially when investigating highly sensitive topics. Rapport was highlighted as an evolving process but crucial in facilitating children’s story telling. In the next section, I turn to discussing the value of using flexible innovative tools when conducting research with children.

8.3 The use of participatory tools with young people in resource limited setting

In this next section, I discuss how the use of participatory research methods and the audio diaries may have potentially facilitated intuitive discussion of HIV experiences.

The use of task-based activities which engage young young people as active participants in the research process are often cited as enhancing children’s story telling and are generally believed to capture children's lives as they are lived (Fargas-Malet, McSherry et al. 2010, Angell, Alexander et al. 2015). In this study, a number of participatory research tools were introduced at various stages in the data collection process, as and when a child appeared to need more support to enable them to express and or discuss their feelings and experiences. All the tools, with the exception of the audio diaries, were used as complementary tools during in-depth interviews.

A triangulation of these methods was intended to create a methodological strategy that not only enhanced access to children’s social worlds but added rigour, breadth and richness to the data collected with young children. In this section, I reflect on how participatory methods were used and whether and how they may have had an influence on the children’s engagement in the study and the data that I was able to collect. These tools are discussed in turn as summarised in a table 8.1 below.

Tool	Phase when used
Drawing	2
Emotion cards	1, 2, 4
Hypothetical scenario	2 and 4
Timelines	4
Audio diaries	Post phase 2 (8), phase 4 (4)

Table 8.1: Participatory tools and Audio diaries

Draw and tell technique

As noted in the first section, the use of silence and forgetting characterised the bulk of the phase 1 and part of phase 2 interviews. Phase 2 interviews explored HIV knowledge, experiences as well as access to social support. After the ice breakers and recap, young people were asked, “Can you tell me what you know about HIV?” The majority stated that they did not know anything about HIV.

The draw and tell exercise was used to elicit responses around children’s knowledge on HIV. I have used this approach successfully in my previous studies with young people as the ‘draw and write’ (Campbell, Skovdal et al. 2010, Campbell, Skovdal et al. 2012). Thirteen young people out of the fifteen that were followed up drew a child with HIV while two said that they were unable to draw and were exempted from the exercise. After completing their drawings, young people were asked to go through the drawing from head to toe. The drawings were, however, not used as primary documents for analysis, only the stories that came after the drawings were analysed.

The drawing exercise prompted rich discussions around HIV being an incurable debilitating infection. Almost all young people understood HIV in terms of sickness, poor growth, inability to walk and being inherently different from other children. Simbarashe’s response to the question, “Can you tell me what you know about HIV?” moved from the long silences to a rich discussion when he was going through his drawing.

Zivai: Okay let’s start from the head to the toes, what shows that this child has HIV?

Simbarashe: Because of his hair or mouth, he has thinning hair and his mouth is red and he has diarrhoea.

Zivai: Oh so is this why he is clutching his tummy?

Simbarashe: Yes and he is very weak and he has lost weight and he is not able to walk or feed himself... (IDI 2).

Lucia who had previously responded with an “I don’t know” described her drawing:

Lucia: She is very skinny and is always sick.

Zivai: Why is she bald headed?

Lucia: I had forgotten to put the hair, let me put it but she has thinning and pale hair.

Zivai: What else is on the child that shows that she has HIV?

Lucia: She has kwashiorkor and she is short.

Zivai: Why is she short?

Lucia: She was born short and disabled.

Zivai: Okay does being short have anything to do with HIV?

Lucia: Yes she was born very small and she is not gaining any weight and is not growing and she looks like a baby (IDI 2).

The exercise also elicited personal experiences of HIV before ART initiation. When Betty was discussing her drawing, the talk generated into her personal experience before she was initiated on ART:

“I used to be like this girl [referring to the drawing] when I was in Grade 5 (10-11 years). I used to have ringworms and it had spread all over my body, my hands, and legs and on my face and it was very itchy. I would always scratch my body” (IDI 2).

This prompted discussions around what HIV was, what their drugs did and did not do, for example, not heal nor cure, how long they would need to take their drugs and how they became infected with HIV. The drawings provided a mirror into children’s representation of HIV, all the thirteen young people drew an HIV infected child not on treatment. All the young people talked about the physical symptoms of HIV and its disfiguring potential. These included skin rashes, lesions, wasting appearance, diarrhoea and stunting. Physical markers were important in this context because of the social reaction and gossip that it prompted in the community, leading to stigma and discrimination.

“They might be seeing the thinning hair and say, 'Ah, this one has HIV'. Some might be seeing that the person is skinny and wasted and they will say, 'This one has HIV' and then there will be others with skin rashes all over their bodies including the face so they will be saying, 'This one has HIV let us not play with her'” (Charity, IDI 2).

The restorative effect of the drugs was also highlighted when young people were asked to tell if there were any differences between their drawing and a child who is on treatment. Being on

treatment was represented as being healthy and strong, not having thinning hair or red lips as well as being able to play.

“The one on drugs will look just like the one who does not have HIV but the one not taking any drugs will be sickly and people will feed her and she will not go out to play with her friends and that’s when people will begin to gossip about saying that child has HIV” (Kennedy, IDI 2).

“A child who is taking drugs will be able to eat and the amount of virus in her body will be reduced if she was unable to play she will now be able to play with others” (Rudo, IDI 2).

Although this question, “Can you tell me what you know about HIV?” appears simple, young people might have presumed it to require a medical response hence they lacked confidence to respond to the questions and resorted to the use of silence and “I don’t know”. Conducting the interviews in a medical setting might have contributed to how young people interpreted the question. They could have been worried about what they did not know rather than simply responding with what they knew.

Although language per se might not have been a barrier, and the question was very open ended, framing the question in a typical one-on-one interview format could have limited children’s ability to confidently respond to the question. The framing of the question might have worked well with adults who have better strategies for recalling but it did not work well with young people in this study.

However, when the question was framed differently and young people were asked to draw and discuss their drawing in detail, young people appeared comfortable to state what they understood HIV meant without basing it on medical knowledge. Thirteen out of the 15 young people were able to explain what HIV was in their own terms going through their drawings from what they had heard and understood in the trial and in their communities.

Each and every interview ended with a reflection on the interviews as a whole and the different participatory tools used during the interview. The rationale for asking young people to reflect on the interviews as well as on the different participatory tools that were used was to capture their views on using the different participatory tools. Thirteen out of the 15 young people that were followed up mentioned that they enjoyed using the participatory tools. The tools that were cited most as interesting were the drawing and tell exercise, emotion cards as well as completing the timeline.

Reflecting on the draw and tell exercise almost all the young people with the exception of 2 who could not draw mentioned that they enjoyed the draw and tell exercise most.

Zivai: Can you explain to me how you felt during the first and second interviews

Charity: I can say all of them were interesting but I enjoyed today's interview most.

Zivai: Why do you say so?

Charity: I say so because today you were not only asking about my family or school but at one time you asked me to draw and we also talked about that girl [hypothetical scenario], which I did not do in the first interview.

Zivai: What was interesting about the drawing or talking about that girl

Charity: Uh because uh uh although I am not good at drawing I enjoyed it. You gave me time to draw and you then we talked about my drawing and it was easier to talk through my drawing unlike in the first interview when you were asking me questions.

Zivai: Is there anything else that was interesting in today's interview

Charity: that's all

Zivai: Do you have any questions or anything that you want to tell me?

Charity: I will ask you when we meet for the last interview

Zivai: thank you

Reflecting on how the drawing method worked in my field notes I wrote

"This method worked well with 13 out of the 15 children. Young people felt comfortable and confident in drawing a child with HIV. The method gave young people time to think, reflect and organise their stories. When I came to ask them to explain to me their drawing, they were prepared to talk about their drawing with little probing" (FN1).

The 'draw and tell' exercise gave the young people the confirmation that they did not need to talk in medical terms, but rather about how HIV was manifested in everyday terms and everyday images.

Emotion cards

After young people had shared their understanding of HIV and openly described their personal experiences of HIV before and after ART initiation, it became easier to explore their disclosure experiences. Emotion cards were specifically used to explore children's feelings around HIV disclosure. Knowing one's HIV status was recognized as a prerequisite for accessing social support hence it was important to explore disclosure experiences before asking young people

about their perceptions and views of social support. The majority of the young people struggled to explicitly express their feelings around HIV status disclosure.

When asked how they felt when they were told of their HIV status, almost all the young people mentioned that they didn't feel anything. As discussed in Chapter 4, a range of emotion cards developed by a Zimbabwean artist were used to try and elicit information on the disclosure processes as experienced by children. All the young people were able to pick emotion cards that portrayed different feelings as they experienced them during the different disclosure events. In many instances, young people were able to pick more than one emotion card expressing their post disclosure feelings.

Zivai: How did you feel when you first learnt about your HIV status?

Charity: Nothing.

Zivai: I want you to remember the day when your aunt said, 'Charity you take these drugs because the doctors said you have HIV', how did you feel when she told you about your HIV status?

Charity: ah I did not feel anything

Zivai: okay, I have a range of cards here which show different emotions.

Long silence, noise of cards be put on the table

Zivai: which card among all these cards best describes your feelings when you were told of your HIV status? Take your time and go through all of them. I would like you to pick the card that best described your feelings that day.

Silence

Charity: oh I... silence... this one... and that one.

Zivai: scared and confused, what made you feel scared let's start with scared?



Charity: of my status and to think that for the rest of my life I will be like this and will not be cured.

Zivai: okay and is there anything else that you were scared of?

Charity: they [healthcare workers] told me that I will be taking pills for the rest of my life and I was worried to say, 'Will I be able to take them well?', 'What if I fail to take them?', 'Doesn't it mean I will die?', 'What if the pills make me sick?', 'What if I get worse?', 'What, ah...?' There was a woman who used to stay a few houses away from ours, people say she got worse and died when she started taking pills so I was scared of taking the pills.

Zivai: Uh.

Charity: and some people were saying the pills were too big and are many so I was afraid of mixing them up and not taking them well.

Zivai: were you not already taking ARVs when you were told about your status?

Charity: I was only taking Cotrimoxazole. That time we had gone to Harare Hospital before I even started coming here [ARROW trial]. I started taking ARVs when I came here.

Zivai: okay is there anything else that you were scared of?

Charity: ah no.

Zivai: okay, what about confused why did you pick confused?

Charity: that will I be able to live with the disease and more so I didn't know much about it. I thought I was going to die but they [healthcare workers] kept saying you will get better so I was a bit worried and confused (girl, IDI 2).

Being asked to choose an emotion(s) prompted Charity to reflect on how her aunt disclosed to her. She successfully expressed how scared and confused she was when she was disclosed to almost seven years before. Charity imagined her life beyond the HIV diagnosis, having an incurable potentially life threatening infection and having to start ART at some point against a background of myths and misconceptions regarding the pills and taking pills. Although at the time of disclosure Charity was only taking Cotrimoxazole, the emotion maps elicited her feelings around taking ART for the rest of her life. Charity had little information regarding HIV and this brought some confusion. The use of emotion maps added depth and richness to her story from the simple "I did not feel anything" response.

Young people were able to elaborate on significant events around disclosure, for example, Rudo gave a sad story of how she discovered that she was HIV positive after reading an ARROW trial assent form to participate in the 'stop or continue Cotrimoxazole' ARROW sub study. When she confronted her mother, she learnt that she was living with HIV and that the ARROW trial was for HIV positive children. She felt very sad and angry at her mother for not telling her the truth earlier. Her description of the sad and angry emotions not only provided contextual information regarding the disclosure event but it also gave insight into her own perceptions of how disclosure should be handled.

In the first interview, Rudo did not express this depth of emotions so the range of emotion cards facilitated recollections of how she felt when she learnt about her HIV status through reading by default. Throughout this interview and during her phase 3 interview, Rudo continued to express her anger and frustration about her disclosure experiences.

Emotion cards were also used to explore feelings around experiences and the interactions leading to disclosure of own status to their friends. Five young people had disclosed their status to their friends. Grace's emotions captured the social and emotional trauma that young people go through when hiding their status from their friends

Grace: This one

Zivai: Happy,

Grace: I felt happy after telling her [friend] because she would ask me, it troubled me for a long time that I was not telling her the truth. I did not know how to tell her, so when I finally told her the truth I felt happy and now she knows and I don't have to hide it anymore" (girl, IDI 2).

Even though I had a range of different emotion cards (22) some young people could not find cards that expressed their feelings. Although Sekai could not find an emotion card(s) to express her feeling, looking at the cards made her to reflect on her disclosure experience.

Sekai: There is no card ah I can't find the right one

Zivai: How did you feel when your grandmother told you about your status?

Sekai: I felt numb and didn't know what to think of and I was silent for some time then she [grandmother] asked me if I had understood and I just nodded my head and didn't say a word. I could not speak for a while I felt as if I was going to die that very minute. I kept staring at her in disbelief, I could not believe it and I questioned myself. I wondered where I got the infection from... (IDI 2).

The use of emotion cards created room for me to seek clarity on circumstances and experiences of disclosure, after young people had opened up regarding their emotions which was not possible when response such as "I did not feel anything" were given.

It is well documented that social cultural norms and notions play a key role in influencing display of emotions and that Africans preserve different norms of expressing emotions and disclosing personal information compared to people in the global North (Thomas 2007). Africans have also been shown not to articulate their emotions in the same way as in the global North. The work of Evans and Thomas (2009:22) has also shown how people can regulate their emotions and 'manage their presentation of self' as a way of protecting other family members. However, for most children, regulating their emotions was a way of protecting their status and themselves from further rebuke by carers and gossip from their peers. This shows how emotions are sometimes bound by identity and social relationships, making it difficult to access emotions using traditional qualitative methods. Public display of negative emotions can be very restricted; people may not always show or talk about their emotions easily (Evans and Thomas 2009).

The majority of the narratives demonstrate that young people believed in hiding their emotions. Most of the young people noted that it was not beneficial to openly share emotions as this could result in hurtful gossip or might offend non-biological carers. This next extract shows us how young people came to contain the expression of their feelings.

“When I cry I don’t do it in the presence of people because they are going to want to know why I am crying and when you tell them you never know what they are going to do with the information. They might gossip about why you are crying so it’s better to cry where you are not seen and don’t tell anyone why you are crying” (Charity, IDI 3).

In the first interview, Charity mentioned that she had a good relationship with her aunt and was very happy. However, subsequent discussions after the use of emotion cards highlighted how she was advised by her friend to hide painful emotions from her aunt.

“Tendai’s mother [friend] said that if I am having deep thoughts and I am distressed I must go onto the veranda and think about it and only come back to the house when I have wiped all the tears and when I am feeling better. She said that I mustn’t show my aunt that I am angry or distressed but I must look happy all the times because if she [aunt] saw me crying she might shout at me and ask me why I am crying and she might think that I am rude. Whatever she says to me, I am not supposed to show it to her even if it annoys me I must just keep my feelings to myself” (Charity, IDI 3).

“When something is bothering me or I am worried especially about my status, I don’t put on a sad or worried face especially when I am with my friends because I don’t want them to question why I am sad or worried lest they know that I have HIV. I don’t want any of them to know that I have HIV so I pretend to be happy as if everything is okay with me”(Rudo, IDI 2).

Coming from a background where it is considered normal to suppress negative feelings make it difficult for most young people to openly acknowledge and discuss what they felt after status disclosure in the in-depth interviews. Using the emotion cards appeared to have made it easier for young people to share and talk about their repressed emotions. I was able to learn about household dynamics and how young people were supposed to engage, relate and interact with their carers and other significant adults in their lives.

Reflecting on the use of emotion cards during phase 2 interviews most of the young people mentioned that the emotion cards made it easier for them to talk about their feelings. Sekai could not find a card that described how she felt when she was disclosed to.

Sekai: When you asked the question first I did not know how to express myself but as I was looking at the cards it prompted me to think about the day when my grandmother told me that I had HIV. At first I wanted to pick confused but then I realised that it was not confusion, I cannot say I was confused or angry or anything but my whole body became numb. I remembered just staring at granny as if my brains froze for a moment

and I could not say anything. I could not even cry it was as if I was in a state of shock ...

Zivai: okay I want to take you back to my earlier question on being asked to pick a card: How did feel when you were looking at the cards?

Sekai: I think the cards were very helpful even though I could not find the right card but they prompted me to think about the event and made it easier for me to remember exactly what happened when I was told about my status (IDI 2).

Rudo is another example who mentioned that picking emotion cards made it easier for her to talk about how angry and sad she was when she learnt about her HIV status by default.

“When you asked the question first I could not remember what happened that day but as I was going through the cards looking at each card I remembered that it was after my clinic visit and I was reading on of the forms we were given here [ARROW clinic]. I remembered how angry and sad I was when my mother confirmed that I was HIV positive. I can say the cards gave me time to put my thoughts together and after picking the two cards I was able to express myself better. That’s I why I said that I enjoyed today’s interview because we had to do a lot of things like drawing, choosing cards and talking about that girl who was failing to take her pills...”(IDI 2).

As has been shown by the quotes above emotion cards were very helpful in providing young people with the much needed time and space to reflect on when they were either disclosed to or when they disclosed their status to their friends. Young people were able to give detailed information regarding how they felt after picking the emotion cards.

Hypothetical scenarios

During the phase 1 in-depth interviews, young people reported very good adherence when asked “Have you ever forgotten to take your drugs or skipped a dose?” Young people were not forthcoming about their experiences of adherence slippage and it was difficult to explore the social support they required to improve drug adherence.

I reflected in the field notes about whether young people were revealing their actual lived experiences of taking drugs or were simply giving publicly acceptable representations influenced by the dominant adult discourses of coping and doing well, thereby not needing adherence support. The majority of the young people said:

“I have never missed my drugs and I take them well everyday” (Elias, IDI 1)

“It’s very difficult for me to throw them away so I just take them” (Bernard, IDI 1)

Hypothetical scenarios were used as an elicitation tool during the phase 2 in-depth interviews to capture information around drug adherence. Young people were given hypothetical scenarios that corresponded with their real life experiences captured in phase 1 interviews. Young people were asked to comment on the reasons for non-adherence. If the stated reasons matched their own experiences, they were asked how they would act if they were the ones experiencing adherence challenges.

The hypothetical scenario provided a less stigmatising platform to talk about non-adherence experiences. As young people discussed hypothetical reasons for non-adherence, they also negotiated ways and means of introducing their own adherence slippage experiences. Elias and Charity's narratives below highlight how the majority of young people slowly drifted into talking about their own personal experiences.

Elias: He might say if I take the morning drugs they might have a bitter taste in my mouth and I might fail to play well so it's better to take them in the evenings only and they throw away the morning pills...

Zivai: Have any of the reasons you talked about ever happened to you?

Elias: Ah uh when I was five years old I used to throw them in the sink or behind the fridge because they were very sour and I would spend the whole day with the bitter taste in my mouth and could not enjoy any meals because of the bitterness and didn't like it. I was also not able to swallow them so they could cause me pain in the neck (IDI 2).

The hypothetical girl/boy set up the platform to explore associations between actual everyday experiences and hypothetical reasons for non-adherence. In many instances, there was a close link between the reason young people gave for the hypothetical scenario and their own lived experiences. In the quote above, Elias cited sourness of drugs as the reason why the hypothetical boy would not take his drugs well, but his account revealed that when he was initiated on drugs he used to throw drugs behind the fridge as well as putting them in the sink because he did not like the sour taste.

Zivai: Do you think that she will be able to tell anyone that she wasn't taking her drugs well?

Charity: She might tell her mother but she might also have second thoughts saying if I tell her she might, [pause] ah like I when I was first commenced on pills, I used to miss doses I did not know the importance of taking the drugs so I would get carried away playing and would go to sleep without taking them but I would say if I tell her [aunt] she

will scold or beat me and at some point I wanted to get rid of the all drugs but my conscience would not allow me (IDI 2).

When this question of drug adherence was asked directly during phase 1 interviews very few young people mentioned experiencing adherence challenges. However, after talking about the hypothetical scenarios, the majority acknowledged experiencing adherence challenges when they were initiated on ART. Almost all the young people revealed personal experiences of throwing pills in the “flower beds”, “sink”, and “toilet” as well as hiding them between “the base and the mattress”.

Encouragingly, almost all the adherence slippages were talked about in the past especially around the time when they were just starting ART and not yet used to taking drugs daily. Even among the young people who maintained positive accounts of good adherence throughout the three phases, talking about the hypothetical scenarios elicited discussions about more complex adherence support needs which were not revealed when direct questions about adherence were asked in phase 1. Although Faith was adhering well, her account highlighted the possible disadvantages of having someone else taking treatment in the household as they may forget or give poor instructions. Faith and her grandmother were both on ART, taking their drugs at the same time at 7 o'clock in the morning and evening. When asked if she was encountering similar challenges with those being faced by the hypothetical girl, Faith's narrative raised some of the disadvantages of being cared for by elderly guardians:

“I might say ah granny is it 7 already like if it's a Saturday or Sunday isn't news is at 7 o'clock in the morning on ZTV 1 [the most common TV channel in Zimbabwean], so it was on a Saturday and I asked granny if it was 7 already and she said it was not yet 7. I said its ok I am going to play at Varaidzo's house and I went and we played. After a while when I asked for time and they said it was past 7 already and I went back home and told granny that it was already past 7 o'clock. She said it was not yet 7 and I said I am taking my pills and she questioned the time and could not believe that it was already past 7. She questioned why there were not reading the news and I ignored her and took my pills” (IDI 2).

Having an adult taking drugs in the house is normally considered to be good for the social support of children. They are regarded as treatment buddies who will remind the young people and offer moral support as well act as role models for good adherence. In Faith's case, the grandmother was not very reliable. Her account also suggested the challenges of keeping to time for children, if they did not have independent means of checking the time or if their carer was not reliable. The use of the hypothetical scenarios led young people to reveal more about

themselves, their context and how perceived social support may not always result in good adherence.

Timelines

The study also used timelines towards the end of phase 4 interviews as a winding up technique to get young people to give personal accounts of their life histories from birth, present and their future, paying particular attention to what they remembered as important times - both happy and sad. As mentioned in Chapter 5, young people were given a piece of paper with three marked events: birth, now and future and they were asked to reflect and talk through the different events.

Young people reported that the timeline exercise was relatively easy to complete. The timelines captured cross-cutting lived experiences and aspirations including: parental deaths, household disruption, and initiation on ART, restoration of health, exiting ARROW trial and marriage aspirations. Falling sick was the most noteworthy event and was quite distinct on the timelines. This event marked a significant negative transformation in their lives as in most cases it resulted in loss of friendships, loneliness and being isolated. Being constantly admitted to hospital and being bedridden was seen as a major limitation to accessing social support. Charity's timeline figure 8.1 below shows when she was initiated on ART, disclosed to and when she joined the community-based and trial run support groups.

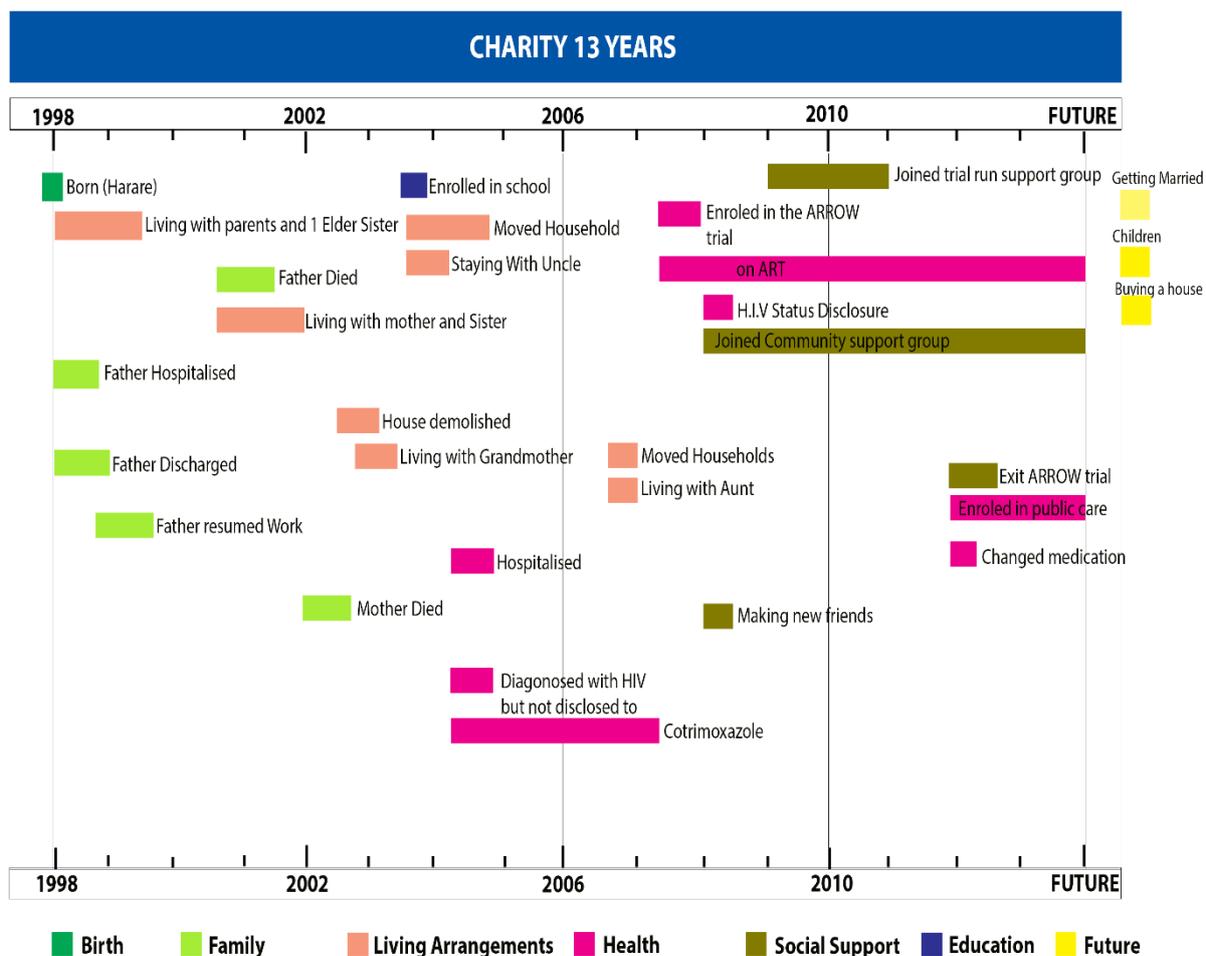


Figure 8.1: Charity's timeline 1

Lucia's timeline described how her past was marred with illness:

"I was born in 2000 and my mother said I was well the first 2 years of my life. I don't remember a time when I was not sick, I was always in and out of hospital. Sometime back I was admitted for 2 months then I was transferred to the provincial hospital and stayed there for a month. In 2007 I had TB and was put on treatment and was cured then I had asthma. I was always sick and was unable to walk or feed myself for a long time. I suffered from many illnesses. In 2008 that is when I joined the ARROW trial and I was put on treatment. Soon after joining ARROW I got sick and I was admitted at Harare hospital for close to two months" (Lucia, IDI 3).

Another significant event was parental sickness and death resulting instable carer lives, leaving young people to become highly nomadic, losing contact with friends and other significant people in their lives. Four young people (3 followed up) moved households more

than three times during the course of the study the study. Young people who moved households three times or more differed in their experiences of living with HIV with young people who never moved or who moved two times or less. Their timelines revealed that they were having difficulties in establishing lasting social relationships as they were constantly negotiating new homes and school environments. The four young people expressed their frustration arising from the many uncertainties in their lives. For example, not knowing when they would be moving households, transferring schools and where they would be moving to. Such uncertainties had implication on HIV status disclosure to peers (discussed in detail in Chapter 6).

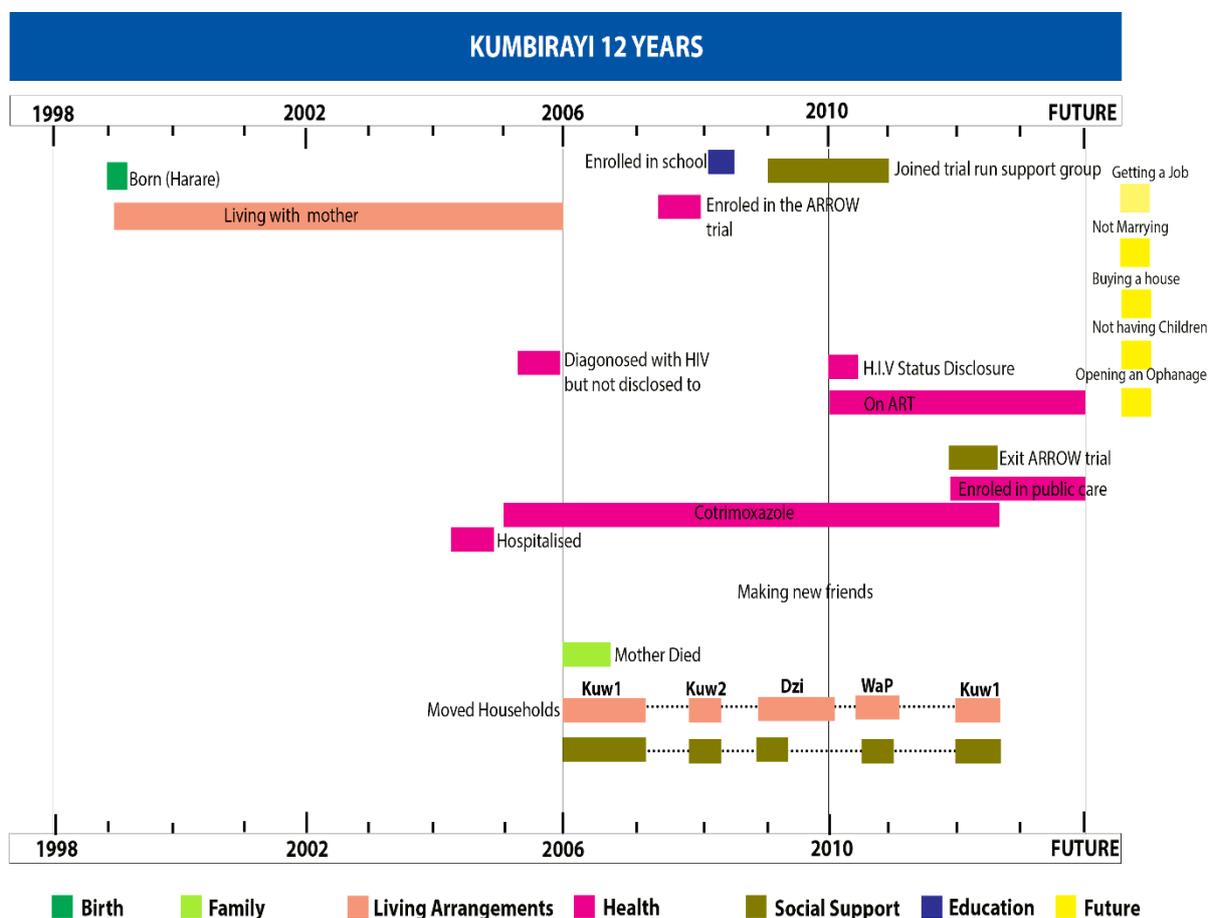


Figure 8.2: Kumbirayi's timeline 1

Kumbirayi is one example, having born out of wedlock his maternal relatives convened a family meeting and decided to take turns in looking after him. His timeline below shows how he had stayed in four of Harare residential suburbs with his maternal relatives six year after his mother's death. Kumbirayi's timeline figure 8.2 above shows how he was being constantly

moved from one household to the other as his maternal relatives decided to take turns in looking after him.

Kumbirayi also narrated how he suffered from stigma and social exclusion under her maternal aunt's care in Dzivarasekwa (Dzi). He was stigmatised because of his HIV status and he eventually got to know about his HIV status through the stigma and discrimination he experienced. He was given his own plate and spoon and he was not allowed to watch television with others or to sit on the sofas. His laundry and crockery was washed separately.

Most of the participants who stayed with non-biological carers also cited being treated differently from the way their carers treated their own children. In some cases when young people were accused of being ungrateful if they questioned the discrimination and the ill-treatment.

Kumbirayi's greatest pain was trauma came when he was admitted in hospital for four months and his aunt whom he was staying with at the time didn't visit him until he got discharged from hospital.

"I woke up very sick and my aunt took me to the clinic. I was transferred and admitted to hospital on the same day. I stayed in hospital for four months but my aunt from Dzivarasekwa never visited me at the hospital even though I was still under her care. Only my uncle from Kuwadzana would visit me with his family. When I got discharged I did not want to go back to Dzivarasekwa but my uncle took me there. My aunt was very surprised to see me, I think she thought that I was going to die" (Kumbirayi, IDI 3).

Another major frustration among young people who constantly changed households was the lack of communication regarding their moves. In most cases, young people were not forewarned or consulted when decision about their care were made, for example changing households and / or school. They were often excluded from such family meetings. Kumbirayi's and many other narratives showed that young people were not consulted when care and living arrangements were made on their behalf.

Kumbirayi: I moved here [Warren Park (WaP)] beginning of this year because my uncle did not have money to send me to school so my cousin sister came and said, 'Pack your clothes I am taking you to Warren Park'.

Zivai: So how long will you be staying in Warren Park?

Kumbirayi: I am not sure, they [maternal relatives] usually do not tell me but I think I will be going back to Kuwadzana end of December because I heard my niece [carer's child] saying I might be moving back to Kuwadzana in December ...” (Kumbirayi, IDI 3).

Such uncertainties affected children's decision to disclose their HIV status to friends [discussed in Chapter 5] as they were not sure how long they would stay in the neighbourhood and / or school. Timelines were useful for enabling young people to reflect on how important events such as parental deaths impacted on their lived experiences. Not involving young people in communication and important decisions about their care had significant implications for their experiences of social support and peer friendships.

The timelines also captured how young people project themselves into the future. Although this was not the primary focus of this research, future projections for example regarding future relationships and status disclosure plan are presumed to influence their current relationships. For example 2 out of the 15 young people that were followed up mentioned that they did not want to get married or have children.

“I do not think I am going to marry in future, I would rather stay single but I want to have my own home and look after orphans” (Kumbirayi, IDI 3).

“I do not want to get married or have young people but I want to get a good job, I want to be a nurse...” (Sekai, IDI3).

Although the majority of young people desired to get married and have families, they were all very fretful and sceptical about dating and getting partners with their positive HIV status. Their main worry was about disclosing their status to their future partners. They worried that they would be rejected, ridiculed and have their status publicized. These fears however, were never talked about in the early interviews.

“I am also worried when I think of who will marry me. Will I be able to find someone who will accept me as I am”? (Rudo, IDI 3).

“I am not sure if I am ever going to disclose my status in future, it's not easy say you have a boyfriend to just tell that that I have HIV. I don't know but it was difficult for me to disclose to my siblings or my friends at school, talking about my status is just difficult and I try by all means to avoid talking or telling people about it” (Memory, IDI 3).

Young people were also worried about living with HIV and the uncertainties concerning future availability of ARVs and other HIV commodities in the public facilities. Many young people

worried that they were not going to get the drug combinations they were receiving in the clinical trial and were anxious about the possibility of changing regimens and the possible side effects that might come with adjusting to new regimens. Their fears were intensified by increased media reports on drug stock outs in public facilities. The use of timelines revealed that young people thought and worried about taking treatment even though they may not talk about it or admit they thought about it much.

Carers also shared the same views, they were worried and sceptical about their children's transition to public care. For example they were concerned and unhappy about the quality of care and the lack of availability of some of the drugs their young people were receiving in the trial.

"Maybe it's the hospital or that's what is common across the country I don't know. The care given is different in fact this and the previous month we went to the hospital for her routine check-up as she already had the pills at home, the trial gave us three months' supply of drugs. I was not happy with the services at the hospital, it is not good at all. The healthcare workers are not so caring they would just sit not working and one patient collapsed in the queue and they said they will attend to him after tea, the treatment is just different from what we used to get here. On that day we spent the whole day there at the hospital, they are very slow and intolerant to an extent that one becomes afraid of asking questions" (Garikai's mother, 51 years).

"Here [ARROW clinic] we never had problems with the pills but when I went to the hospital to order her pills in advance as she was still taking the ones we got from here, when I went back to check on them they still have not ordered them. They wrote me a prescription and I could not find them in our local pharmacies so I went back to the hospital and they told me that they do not supply that type of pills but that there is another type which is combined and then they sent me back here [ARROW clinic]. When I asked them the type of pill I can buy as an alternative they were irritated and started to ask me where I used to get my pills. I told them that I used to get them in ARROW from the UZ Research team and they said I should go back there to get the pills since they do not supply such pills" (Betty's aunt, 43 years).

Similarly, healthcare workers were certain that quality of care would change and that some drugs would be unavailable in the public care.

Counsellor: Yah they could be because in ARROW we had about 400 young people whom we would spread throughout a 6 week period and we would have time to talk to them and discuss unlike when they are on the national programme they are many

clients there and they will not be enough time to talk to each and every participant, to attend to each participant and this would affect them in one way or the other

Zivai: Okay and in the HIV management do you think they will be major changes?

Counsellor: the other major change would be in the drugs that the drugs we were using might not be easily available in the national programme so they might have to be changed

Zivai: Can you give examples of such drugs that may not be available in the national program.

Counsellor: drugs such as kivexa and abacavar because in the national guidelines abacavar is reserved for the second line and yet in ARROW we were using it as a first line drug so we just hope that they will get good enough substitutes.

After discussing the past, present and the future, the drawn timelines were also used to reflect on what was missing in terms of support. Young people identified gaps in terms of sexual and reproductive health messages. Almost all the young people mentioned that they lacked reproductive health information. This lack of information exacerbated their fears around possibilities of having HIV negative young people and whether they would live long enough to raise their own children. It was evident from the accounts that these young people would at some point consider child bearing and they needed sexual reproductive health information to make informed choices. Having limited access to sexual reproductive health information in a context where it was taboo to ask for such information suggested that these young people would continue to live with many unanswered questions regarding their sexual and reproductive prospects.

8.4 Audio diaries

One of the secondary objectives of the study was to assess the feasibility of using audio diaries with young people in a resource limited setting. Twelve out of the fifteen young people that were followed up chose to keep audio diaries for two weeks. Eight young people kept diaries between phase 2 and 4 while four had to keep the dairies after phase 4, before the focus group discussions. Young people were asked to record whatever they felt relevant in characterizing their experiences of lifelong HIV and ART. Key to this method was for young people to select and prioritize what they thought was important. Details of how these were used were presented in Chapter 4.

8.4.1 Feasibility of using audio diaries with young people.

The study found that all the 12 young people who were offered / opted to use audio diaries were comfortable with the technology of audio recording and were able to record audio diaries.

All the young people acknowledged that the audio recorders were simple to use with only one child reporting getting stuck when the recorder could not turn on. I had forgotten to replace the batteries when I issued it. This was rectified and she was given new batteries. Reflections on keeping the audio diaries at home showed that almost all the young people enjoyed keeping diaries and did not encounter any challenges in using them.

“It was easy to use them and I didn’t even have to ask for assistance in using the recorder. The instructions you gave us were straightforward and I enjoyed using the recorder. I used it during the day or when I was alone at home. I would play it and listen to my voice and I would laugh at myself... I only deleted one recording because I felt that it was similar to the one I had recorded previously” (Faith, IDI 3).

“I only had challenges when the recorder could not switch on but when you changed the batteries everything was fine and it was easy to record, play and rewind. What I enjoyed most was to listen to my recordings and being able to delete some files which I thought were not so good. I deleted two files that were not audible, there was so much noise in the background, my sister was laughing and commuter omnibuses were hooting. Our house is close to the taxi rank so on that day the commuter omnibus operators were demonstrating against the police and there was so much noise at the taxi rank”(Kumbirayi IDI 3).

All the recordings were audible and the majority of young people recorded daily while others chose to record at unspecified intervals. The majority of the recordings were soliloquies with a few young people recording their interaction with other household members and their friends. The majority of girls recorded themselves singing church related songs while some boys recorded their scuffles with their friends among other things.

Out of the 15 young people who were asked to keep audio diaries only three opted not to. The three who refused cited lack of privacy at home. They felt that the audio recordings would pose a confidentiality risk as they had not disclosed to some of the relatives they were staying with. On the other hand, the 12 participants who took the opportunity reported that the diaries did not pose any risks at home.

I did not encounter any logistical challenges in giving out and collecting the recorders. All 12 diaries were collected and returned to the clinic on time. The recordings varied in terms of files recorded and when they were recorded. However, there were delays in transcribing the audio files in time to give out the recorders to the next participants before phase 4 interviews. As mentioned earlier, the recorders did not have the option of downloading the files to a computer

hence they had to be transcribed directly from the recorder. This meant that four participants kept their diaries after phase 4 interviews. This minor challenge can be rectified by allocating enough resources towards transcribing or having enough recorders for the intended participants.

The study however, found that the use of audio diaries has the potential to cause some distress in participants. Recording and reflecting on events caused emotional distress in some young people. Two out of the 12 young people cried when using the recorders. These two are discussed in detail under the ethics section below. Regardless of the stated challenges, the study found out that using audio diaries is a feasible and novel method to use with young people in resource stretched settings.

8.4.2 Data captured by audio diaries

In assessing the feasibility of using audio diaries with young people, I was also interested in finding out what kind of data using this method would produce. Secondly, whether the data was going to be different from what I was able to capture during the in-depth interviews and focus group discussions. The study found out that the audio diaries added depth and a different perspectives and views from those produced by the interviews and focus group discussions.

The audio diaries successfully captured reflections on household experiences in real time and provided a medium for young people to express their day to day encounters in relation to growing up with HIV and taking treatment. The majority of diary accounts echoed negative experiences regarding care arrangements, HIV and ART and these painful reflections were often hidden from other household members including the primary carers. Garikai used the diary as an opportunity to talk about his fading relationship with his elder brother. He reflected on the negative changes that had occurred in the house as a result of his brother's recent marriage.

“Before my brother got married, we used to be very close and we would talk a lot and he would accompany me to the ARROW clinic but since he got married, he no longer wants to go with me to Parirenyatwa (treatment centre). He now always has an excuse and says to mum, 'Go with your child'. Dambudzo doesn't want his wife to be told that I have HIV. I want to tell his wife about my status because I might fall sick when it's just the two of us at home and she wouldn't know how to help me. He [brother] doesn't want me or mum to tell his wife. He even said to mum that we shouldn't talk about HIV when his wife is around. Staying at home with his wife not knowing my status is not good because we are no longer free to talk about my drugs at home because

Dambudzo will become very furious or even ask, 'What do you want to talk about?' in an angry manner. This worries me to say why doesn't he want us to tell his wife even mum has not yet told her about her status because she realised that Dambudzo doesn't want his wife to know. My fear is what will happen if mum and granny die. Who will accompany me to the clinic if she [brother's wife] doesn't know my status?" (Garikai, AD).

Garikai shared his emotional distress which he had not been able to share in the interviews. During the in-depth interviews, Garikai's relationship with his brother had not been specifically explored as the explorations focused more on the primary carer. He mentioned in passing that his brother used to accompany him to the clinic but he did not give such a detailed explanation of the nature of their relationship. During the interviews, Garikai might not have had enough time to reflect on his relationship with his brother and how it was distressing him. However, having the diary at home and seeing these events happening allowed him to reflect on them and to record them in his diary. The diary recording was located within Garikai's everyday life and was totally immersed and integrated with daily life activities.

For Garikai, his brother's marriage meant fragmented support, limited drug talk and that he was no longer accompanied to the clinic by his brother. This weakened adherence support as other household members could not openly supervise and check on him. His diary revealed his inner perceptions and feelings which were intimately bounded up with personal relations. In Garikai's case, his diary illuminated the relationship between how social events, in this case, his brother's marriage, affected his treatment taking behaviour, his adherence support and his confidence in the security of his clinic attendance. I had not been able to see these connections in the interviews. Young people were able to guide the diary conversation, they were able to bring up these hitherto unexplored perceptions on family relationships and other issues.

Keeping the audio diaries at home enhanced the immediacy of the reflections, allowing for more detailed reflections. The majority of the diaries were recorded as reflections on events and response to their own experiences, thoughts and emotions, perhaps promoting new insights into their views and perceptions of their own everyday lives. Charity and many other young people recorded the agony of losing parents as well as their fears, denial and pain of living with HIV which they had not discussed in the previous interviews.

"Today I am alone, Marcia has gone out to visit her aunt and my aunt has gone to work. My friend, Tendai's mother has gone to see her sister who is not feeling well in Ruwa. Every time I get lonely, I can't help thinking about my status and the thing that worries me most is, 'Is it really true that they said I have HIV or they lied to me?' Where

did the HIV come from? When I was born well and healthy and I completed grade 1 and 2 walking and looking healthy? Why is it that I am the only one with HIV and my sister is not sick? Will this HIV ever get cured Zivai or for the rest of my life I will be regarded as a person with AIDS. For how long am I going to take the drugs without knowing whether I am going to be cured? Sometimes I cry on my own but when Tendai's mother is around, I cannot cry because she doesn't want to see me crying so I pretend to be happy. She said that if I cry, my late parents will 'see' me crying and they will come and take me..." (Charity, AD).

There was a noticeable disparity between Charity's first interview and her diary. In the first interview, Charity talked about how happy she was at her aunt's house. However, in her diary, she talked about being wrongly accused of stealing. She was even contemplating running away from home to join her elder sister in South Africa. Highlighting these different accounts was not to suggest that some narratives were more legitimate or authentic than others. Instead, I am highlighting the breadth of different data generated and the different frames within which this data was generated. The context was different for some of the methods, resulting in different levels of engagement with each method.

Inconsistencies in data generated were followed up in phase 3 interviews and / or before the focus group discussion. The inconsistencies in children's narratives highlighted how sometimes in-depth interviews may encourage stereotypical representations of coping and doing fine living with HIV rather than depict actual experiences and perceptions. The inconsistencies might also highlight how young people learn to talk, guided by adult reaction or responses to events. The study had to identify these common scripts and find ways to move away from them. With adherence, the common script was 'I always adhere' and with support and coping the script was "I am doing fine" and "I do not need extra support".

The study needed to define different spaces for young people to feel comfortable to communicate alternative stories. The majority of young people adopted these common adult scripts and presented a positive picture of coping and adhering well to drugs which was a different picture in the diaries. The diary accounts may also have disrupted the solidity of 'I am doing fine' and the 'support is enough' revealing support gaps. The extract below highlights how the diaries may have provided the space that young people needed to be able to move away from the script of 'being okay with HIV' to talk about alternative experiences and feelings.

Rudo portrayed a bold character - coping and being strong during the interviews but her diary tells a story of hurt and challenges in accepting her status:

“Ah, I don’t like this disease and this [having HIV] pains me a lot, I am not happy at all living with this disease... I have changed my mind and I am now being honest in this diary. All along, I was just talking to give advice to you but I am now being very honest concerning my life and what’s deep down in my heart is what I am going to say out now through these words that I don’t want this disease and taking pills. Sometimes I have devil’s thoughts to say let me throw the drugs away but I just realise that I will be wasting my life. If it was possible for the disease to be cured I would be the first person to advocate for it to be cured for sure because I don’t want this disease” (AD).

In the interviews, some young people might have been compelled by their carers and or interview setting to provide socially desirable responses of coping and having adequate social support. Such stereotypical representations limit children’s ability to give real life experiences. Phase 1 and 2 interviews gave a very positive picture of resilience and coping with a few notable exceptions. However, audio diaries painted a picture of pain and agony showing fractures in their coping. Diary accounts revealed that young people needed information regarding perinatal infection and to be constantly reminded that HIV is incurable.

The participant-led nature of the diaries also proved useful in raising potentially difficult issues that had not been explored in the interviews. Rudo, for example, in talking about her agony, anger and frustration of being HIV positive, raised the blame perspective when she said:

“Personally living with HIV is very distressing for me and makes me sad each time I think of my status. Even my taking of pills, I don’t take them wholeheartedly but I force myself, I just take them to make my mother happy. It makes me very unhappy to think that my eldest sister is not HIV positive my other sister is also not HIV positive and it’s me the last born infected with HIV. This probably means that my father didn’t die of HIV. These are some of the things that distress me to say mothers are the ones harvesting this disease for us because the majority of people you find in beer halls are women spreading and contracting this disease and passing it on to their children” (AD).

Rudo blamed her mother for infecting her with HIV. Although perinatal infection was discussed in the interviews, the framing and the focus of the question limited the discussion of knowledge of perinatal infection. It was only in the diary discussions that perceptions illuminated the blame discourse where women were portrayed as potential sources of infection through high-risk sexual behaviours such as prostitution. This idea of “mothers harvesting the infection” was discussed in the follow up interview. Rudo’s anger and frustration regarding her perinatal infection had subsided when I interviewed her in phase 4:

“I guess I was angry at my mother when I said that but I am not saying that my mother is the one who brought this disease but I don’t know who brought it between my mother and my father and this distresses me a lot that no one explained to me what happened or how my father died” (AD).

Although she had toned down her rhetoric, her diary clip revealed some of the hidden anger, sadness and frustration that she was not prepared to talk about in a one-on-one interview. Rudo’s diary clip revealed the anger and frustration that young people repress especially when they are not given adequate information regarding their circumstances. Rudo had an opportunity to air her anger and frustration regarding the silence around her perinatal infection. Had it not been for the diary, it would have been difficult for Rudo to acknowledge and talk about her emotions.

Rudo’s audio diary provides an example of how young people sometimes regulate and manage presentation of their emotions as a way of protecting others, discussed earlier under emotion cards. When she was in her own space (using the audio diary) she managed to express her emotions but during the follow up interview she tried to manage her emotions and not to show her anger as a way of protecting her mother’s identity.

In the Zimbabwean context, it is often difficult for young people to raise issues that may be interpreted as disrespectful because of the weaker position they occupy in the household. Being aware and attentive to the cultural context and household dynamics informed our understanding of why there were absences in the interview data and particular discussion in the audio diaries. Arguably, this was revealing about the voice that young people have in this context. There were social hierarchies which limited expression and communication. Even though children’s interviews were conducted within a neutral space, there was substantial evidence of bounded agency of what they could share. Audio diaries provided a more private setting for children, giving them the much needed flexibility of what they were able to share.

Wanting to know the circumstances surrounding perinatal infection came out in almost all the diaries. Most young people questioned how they became infected and their reflections demonstrated the confusion and inadequacy of the information they had been given regarding perinatal infection. The diaries gave young people time to think through, define and prioritize experiences and issues that were important to them and were able to raise them.

The audio diaries provided the opportunity for the recording of events and emotions in their social context. A particular benefit is that these social contexts were not accessible to researchers. The qualitative study was confined to the trial clinic as carers and their young people did not want their participation in an HIV trial to be known in their communities. Taking the audio diaries to the household setting resulted in narratives that were very individualised

and grounded in children's daily realities. The findings presented here highlight that using audio diaries with young people was feasible and the method produced rich data as a standalone research tool.

As highlighted in the section, participatory research tools was very useful in shifting the power relations and provided participants with greater control over their involvement in the study. Negotiating what to tell, when to tell it and how to present it using different methods created an enabling environment for young people to actively participate in the study. Young people have different needs and skills and having a multi-method approach worked well in enabling most of the young people to express their experiences.

Although innovative tools were helpful in enhancing access to children's social worlds, they raised a lot of ethical considerations. Even though I fully subscribe to the fact that researchers should uphold ethical guidelines, I believe that applying the guidelines must be enmeshed with a reflexive appreciation of the social contexts, relational influences in which the research is being conducted. In the next section I present ethical reflections on the use of innovative tools with young people in resource stretched settings.

8.5 Ethical issues that might arise from using participatory research tools

This previous section described how different methods and contexts can determine how young people tell their stories. Ethical issues arise in all research studies involving human subjects. However, researching young people together with the use of innovative tools raises specific ethical dilemmas that warrant special attention. In this section I focus on the principle of not doing harm and lastly, the ethical implications of raising the children's expectations posing the dilemma that often arises - now the young people have talked what's next? I chose to write about these ethical reflections, not aiming to provide answers but to bring some of these challenges to the fore and to promote thoughtfulness when using participatory tools with children.

8.5.1. Doing good and avoiding harm

Globally, there is the recognition that ethical research pertains to beneficence- doing good and non-maleficence- to do no harm to research participants (Jamieson, Simpson et al. 2011, NSPCC 2016). This study aimed to explore experiences of HIV and ART and how these experiences influenced young people's engagement with social support. Experiences of HIV and ART were potentially upsetting as they invoked memories of illness, parental illness and death and other disturbing living/care arrangements. Some of the interview questions resulted in a few young people getting emotionally distressed. Four girls out of the twenty-six young people that were interviewed in phase 1 became emotional and cried during phase 1 interviews. Reflecting in my field notes I wrote:

Lydia looked cheerful when we started the interview and during the interview she responded well and seemed to be enjoying the interview. This changed when I probed to find out what the pills she was taking was for. Lydia became very emotional and cried. When I asked her if we could reschedule the interview, she insisted on carrying on. I stopped the interview and gave her time to cry and when she was composed we carried on. I felt very uncomfortable during the interview and for one moment I didn't know what to do which question to ask and what probes to avoid. I decided to be let her guide the discussions. This interview prompted me to reflect on my role as the researcher. I wondered what was it about taking pills that made Lydia become so emotional, could this mean that the discussion provoked hidden or suppressed feelings and memories about her diagnosis. Was it because she was not ready to talk about her diagnosis. Throughout the interview she is avoiding mentioning HIV (FN 1).

Given the sensitive nature of this research study, I tried to be cautious and to give young people the space and time they needed to talk but being there listening and seeing Lydia and the other three young people becoming so emotional and crying made me very uncomfortable. Although the interviews were paused and young people were given time to cry and to make a decision either to continue or terminate the interview, I was more concerned about whether the emotional distress was ethically justifiable. It is the researcher's responsibility not to cause harm to research participants especially young people with a chronic condition who are by definition considered a vulnerable group.

There is ample literature on the therapeutic nature of research interviews (Kavanaugh and Ayres 1998, Birch and Miller 2000, Jamieson, Simpson et al. 2011, Rossetto 2014) that argues that talking about painful experiences helps but one questions whether the extent of unhappiness during interviews is justifiable. Talking about lifelong HIV and ART stirred painful memories and led to the disclosure of personal information which most of the young people were not emotionally prepared to share in the first interview. Probes such as 'what are the pills for?' or 'do you know why you take pills?' which worked well with most of the young people did not work so well with the four young girls referred to above. The probes and questions could have triggered hidden or suppressed memories regarding HIV status disclosure or circumstances in which they were disclosed to which were not prepared to share.

Such emotionally upsetting questions or probes undermined the attempts to avoid harm and raised a lot of questions around defining harm and what levels of harm were deemed acceptable and/or unacceptable. I reflected on my rationale for choosing young people (11-13 years) to participate in such a sensitive study and the methods that were used and wondered if the distress experienced by participants would have been lessened if I had

interviewed adolescents or young adults. Young people who showed signs of emotional distress during the interviews were given support immediately after the interviews.

Managing emotion distress was however difficult during the two weeks of audio diaries recording. Two young people cried when they were using the audio diaries.

“I don’t know how to thank my mother for looking after me. It pains me to say how can I thank her? (*Crying*). My mother oh I don’t know how to thank her (*crying*) ...How can I thank her? God bless her with more days to live here on earth Jehovah how can I thank my mother? If it wasn’t for her mercy I wouldn’t be alive today if she was some other woman who isn’t caring she would have dumped me at my paternal relatives and instructed them to look after their own relative’s child. She could have easily said, 'I am now a widow and I can’t look after your young brother’s sick child’” (*crying*) (Rudo, AD).

Rudo became emotionally distressed when she reflected on how her mother had supported her when she was sick. Her paternal relatives deserted her after testing positive. The clip was dated 14/04/12 and was recorded when her mother had gone for her piece jobs and Rudo was at home with her sister’s young people (aged 7 and 3 years). Rudo did not seek support from the trial counsellors. Unlike the interview where young people who showed signs of emotional distress were given support immediately after interviews, young people who got emotionally upset during audio diary recording did not receive any immediate support. This was despite putting in place support systems to accommodate such children. It was through listening to the diaries that I was able to pick the emotional distress and it was highly likely that this emotional distress was hidden from carer and other household members as most of the diaries were recorded in the absence of other household members.

Although young people were informed about the availability of support, this depended on them being proactive in seeking support. In the same way, they were asked to ensure that their dairies were kept confidential at home. This, however, did not work as I had anticipated because the majority of accounts depicted agony, anger and so much sadness yet no one sought emotional support from the counsellors.

Although the aim was to give young people a less confrontational space to capture experiences they felt important, children’s decision not to seek support when I assumed they needed it most might have, to some extent, undermined the intention to do good and not harm. It could have been that young people chose not to seek support from the counsellors because they did not need it. Narrating some of their painful stories as well as reflecting on their experiences, editing (deciding which experiences to keep or delete from the diaries) might

have been therapeutic for some children. It may have been alright for young people to cry as a way of letting it out, reflecting upon it and thereby taking steps towards healing.

Contrary to the picture painted in the accounts of sorrow and suffering most young people stated that they enjoyed keeping audio dairies and confirmed that they would want to keep them again in future. Debriefing meetings were conducted with each child to explore their feelings and experiences of taking part in the audio diary interviews. The rationale for having the debriefing session was to provide space to young people to express their feelings so that appropriate support could be given to young people who could have found the process distressing before it was too late. But again young people gave very positive feedback. The positive experiences were reiterated in the phase 4 interviews for the 8 young people who kept their diaries before phase 4. Below are some of the responses to the question “what was it like for you to keep an audio diary?”

“Rudo: I liked it

Zivai: What is it that you really liked?

Rudo: I enjoyed talking about things that are in my heart without anyone asking me or listening to what I was saying. If I talk about the things in my heart I will not think about them all the time

Zivai: Things like what if you can give me an example

Rudo: If I talk about my late father or if someone asked where my father is and if I say he died I will not think about it too much or if I talk about my aunt who refused to help my mother when I was sick, it will not bother me again...” (IDI 3).

Memory: I enjoyed it because I was recording things on my mind and what I would have talked about would stop worrying me and I would forget about it and would not think about it

Zivai: Uh

Memory: such thought will just stop upsetting me after talking about them so I enjoyed it. It is good it makes me not to think too much

Zivai: When I said to you I want you to go and record things at home what came to your mind

Memory: when you said you wanted me to record anything I thought I should talk about my status and I started to think that maybe she wants to know about my living conditions.

Zivai: Uh

Memory: to say is everything ok at home and at school and if I am having any worries

Zivai: uh ok and how did you find it talking about your status on your own?

Memory: ah it was alright

Zivai: wasn't it difficult for you

Memory: it was not

Zivai: why wasn't it difficult for you?

Memory: it was not difficult because some of the audio I recorded with my mother and young brother the one who was also in the ARROW.

Zivai: Uh anything else

Memory: and because you told me that you were not going to tell it to people in Zimbabwe so that made it easy for me and I was happy because I know that no one will know about what I have said except you

Zivai: is there anything else that you liked

Memory: nothing

It was only during transcription that I discovered that some young people experienced emotional distress. I tried to follow this up during the phase 4 interviews with young people and just before the focus group discussion (4 who got diaries after phase 4 interviews) when we were going through their diary extracts. Although the tone of their voices, crying and the anger of their narrative vividly portrayed emotional distress, not one child acknowledged being emotionally distressed when they kept audio diaries at home. This raises the question of the definition of harm and who defines harm. Was crying a reflection of emotional distress or was it therapeutic? Should the young people have been able to express and unpack their often hidden feelings during data collection? All the young people whose audio diary showed signs of emotional distress were referred to the counsellors soon after the interview. This was done in order to give the young people a chance to personally disclose their deep emotions regarding living with HIV to the counsellors. Prior to the diary extract discussion young people

were complaining of being given limited time to engage and talk to the clinicians in the new facilities they were attending. It is important to note that when the audio diaries were returned all the young people were exited from the trial and were attending the public health service.

When using the audio diaries researchers need to be conscious of its potential to cause emotional distress and that the audio diary is time consuming. The emotional distress reported above could have been compounded by the structural barriers that limit children's capacity to seek help without going via their carers. Not having access to the phone might have limited their ability to seek help when they needed it, taking into consideration that most of the diary accounts were recorded when the young people were alone or in private.

Responding to views about the research process as a whole shows that young people enjoyed participating in the study and showed eagerness to continue participation in research. Towards the end of phase 4, almost all the young people expressed their dissatisfaction that the research was coming to an end. They were very thankful for the opportunity to share their stories and to be listened to. I became convinced that the research provided some form of emotional release as well as opening other avenues for young people to seek social support.

8.5.2 Managing participant's expectations.

One of the major ethical considerations was in managing participant expectations of the research process. Phases 2 and 4 when young people finally managed to break away from the silence and talked about their experiences this raised a lot expectations in them. The question that participants had was that now that we have talked then what? A number of young people asked toward the end of phase 4 how the interviews were going to benefit them:

“At the end of this interview session, are you going to tell me what you are going to do? How are you going to assist me or you will simply tell me that there is nothing that will be done and you were just asking so that you know our lives?” (Betty, IDI 3).

“... You asked me things that happens in my life, the way we live at home but I don't know whether you will solve our problems or you just wanted to know and do nothing about it” (Farai, IDI 3).

As part of the informed assenting process, attention was paid to managing participants' expectations of the research process. I clearly explained that the research was unlikely going to benefit them directly and that the study aimed to guide further interventions as well as improve treatment, care and support for young people living with HIV. Despite the ongoing assenting process where I explained what the research could and could not do, children's expectations were raised as they shared their experiences. Explaining that there were no direct benefits seemed insufficient.

8.6 Conclusion

This chapter has presented some of the methodological and ethical reflections regarding interviewing young children. Repeat in-depth interviews allowed establishment of rapport, resulting in young people feeling comfortable to talk about their lived experiences of growing up with HIV. I have tried to demonstrate the additional value of innovative tools in creating safe spaces for young people and in legitimising HIV talk. Framing questions in child friendly ways was very useful in building the confidence of young people to share their knowledge on their own terms.

Although this study demonstrated some of the shortcomings of standalone interviews in accessing children's social world, innovative tools also have their own ethical shortcomings. It was therefore critical to be mindful of the ethical challenges associated with interviewing children. I have highlighted the need to go beyond looking at the co-production of social knowledge to include reflections on the ethical process of conducting research with young children. Researchers must constantly engage and reflect on the social contexts, hierarchical power imbalances and other arising ethical issues.

9.0 Chapter overview

This chapter discusses the implications of the study findings for how we understand children's experiences of growing up with HIV and their support needs. In the previous chapters, I demonstrated how HIV is lived through silence and secrecy. In this discussion chapter, I draw on this core themes of agency and stigma and demonstrate how this PhD research is an empirical illustration of bounded agency. This chapter will also demonstrate the complexity of the levels of stigma and how the confusion and lack of understanding around perinatal infection exacerbate the stigma experienced by young people. This thesis discusses the impact of HIV stigma on children's experiences of formal and informal support. Additionally, the chapter reflects on the methodological challenges of engaging with a research topic which is defined by silence. I discuss whether or not the design and methods I have used were the best and explore if I could have used more informative methods. I integrate my recommendations within the discussion and conclude by outlining some of the strengths and weaknesses of the study design.

9.1 Experiences of informal peer friendship

This study was based on an assumption that childhood friendship is a potential source of support for young people growing up with HIV. The study found out that young people valued peer friendship. Peer friendship was conceptualised as source of happiness and social completeness. In the context of HIV infected children, play was important in reconnecting young people with peer social networks.

9.1.1 Conformity with peers

A core theme running through the data chapters is children's desire to fit in and wanting to be like every 'normal' child. These findings confirm what has been found in resource rich settings where young people desired to be physically similar with friends and were very cautious of appearances or actions that would make them look different from their peers (Philbin 2013, Persson, Newman et al. 2014). In some studies, the strong compulsion for conformity with peers led to poor drug adherence (Calabrese, Martin et al. 2012, Rydström, Ygge et al. 2013, Bernays, Jarrett et al. 2014, Persson, Newman et al. 2014). Although this study found relatively good drug adherence, a few young people interrupted drugs for fear of being seen by friends. This desire for conformity was not limited to drug adherence alone; some young people compromised their health by engaging in activities they had been discouraged from doing by their healthcare workers or carers, for example, participating in sports. For many, not conforming to medical advice had negative effects on their health, however for the young people the desire to be like their friends superseded the health benefits. This created a

constant tension in their lives as they struggled to balance the consequences of having a lifelong condition with the need for maintaining a peer valued and acceptable self-image. Children's desire to conform to clinical expectations are sometimes undermined by their desire to manage their HIV within their social lives outside the clinic environment and this creates constant tension in their lives.

In agreement with findings from the US, young people developed strategies to ensure that they appeared healthy and did not conform to the biomedical and social expectations of how HIV infected people should look (Philbin 2013, Bernays, Seeley et al. 2015). Participating in sports and in school chores, looking energetic and putting on a brave face even when they were ill were some of the strategies adopted by children. Looking healthy and participating in sports and other school related activities were considered to be characteristics of uninfected, healthy individuals. The strategies highlight the capacity that these young people have for shaping their circumstances. By resisting expectations of how HIV infected people should look young people are demonstrating that they do not passively accepting societal notions of HIV but actively engaging with the notions and adopting behaviours that resist negative identities of being HIV positive.

Being marked out as different was undesired and difficult to deal with (Philbin 2013, Bernays, Jarrett et al. 2014). HIV was depicted as having the potential to significantly limit access to social relationships for example through absences from the different care environments in which they ordinarily access friendships. As noted by Hogwood and others, young people were anxious about being identified with 'a condition that was associated with shame' (Hogwood, Campbell et al. 2013) and had the potential to steal their normalcy (Persson, Newman et al. 2014). The majority of young people chose an identity which had nothing to do with HIV. Peer acceptance and conformity was prioritized over other health benefits associated with, for example, status disclosure (Hogwood, Campbell et al. 2013).

A number of studies have documented how the need for conformity with peers is a strong characteristic of childhood and adolescence and therefore, very common at this life stage (Eccles 1999, Teunissen, Spijkerman et al. 2012, Leung, Toumbourou et al. 2014). The desire for conformity with peers is unchanged by being HIV positive and young people appeared to be more defined by adolescence than by their illness. The findings have shown that although having HIV complicates the normal process of growing up, it does not fundamentally alter it as young people constantly negotiated ways of resisting images that marked out their differences.

The quest for belonging, peer approval and need for desirable social images accounted for most of the pretence, secrecy and silence that were reported within these peer friendship. However this pretence and secrecy has been found to have profound negative impacts on young children's identity formation, how they view their abilities and aspirations as young people growing up with HIV. Studies have shown that living with a chronic condition in pretence and silence negatively impacts the sense of self, health, well-being and quality of life (Calabrese, Martin et al. 2012, Bernays, Jarrett et al. 2014, Daniel 2015).

Goffman explained how individuals with less visible attributes can sometimes hide their undesirable conditions or pass off as normal (Goffman 1963). He made a distinction between the discredited, those with visible markers that cannot be hidden from the public and the discreditable, those with no visible markers who can successfully hide their undesirable condition from the public. Young people who were successfully initiated on, and responded well to, treatment (the discreditable) had a comparative advantage in that they managed the biological aspect of HIV and successfully concealed HIV. However the risk did not simply go away as medical aspects of HIV such as taking medication and attending routine clinic visits and support groups were difficult to conceal. Young people worried about the possibility of their friends finding out their HIV status from other sources. This risk of being seen was always there making it difficult to fit them in into Goffman's discreditable category.

Although some young people successfully 'passed' for normal, a few struggled to hide their status as a result of the physical markers of HIV (Daniel 2011, Parsons 2012, Bernays, Jarrett et al. 2014). These unfortunate young people whose HIV status was written all over their bodies fall into Goffman's (1963) discredited category. Late diagnosis and late initiation on ART meant that some young people were already wasted. They could not fully recover, neither could they successfully conceal their diagnosis (Daniel 2011, Bernays, Jarrett et al. 2014). Examples were given in Chapter 5 of young people who were isolated and or gossiped about as a result of their inherent difference from peers and those who had lied to their friends that they had asthma, heart diseases and chest infections. To avoid the risk of being seen to be different from their friends, a few pretended to be healthy while some chose to avoid public spaces and withdrew themselves for interacting and playing with other children.

9.1.2 The decision making process- to tell or not to tell

One key aim of this study was to unpack young children's engagement with the status disclosure decision making process in their informal networks. As shown in Chapter 5, multiple factors influenced the decision to tell or not to tell their friends about their HIV infection. These included establishing the trustworthiness of the friend, friend's ability to keep secrets, anxiety about what will happen after disclosure and longevity of friendship.

Disclosing to friends was perceived as a great social risk because these relationships were viewed as non-family and less stable. This confirms existing findings from Zambia where many adolescents who had disclosed within family circles were very reluctant to disclose to their friends (Hodgson, Ross et al. 2012). Zambian and many adolescents across the world do not trust their friends well enough to disclose their status (Hodgson, Ross et al. 2012, Hogwood, Campbell et al. 2013, Nöstlinger, Bakeera-Kitaka et al. 2015). Disclosing to siblings and other relatives was however contrary to my findings were young people were less willing to disclose their status to their own close relatives because they viewed were afraid that family members would fail to protect their secret. This was so because the majority were staying with non-biological parents. Only a few young people were staying with their parents and siblings.

Many of the young people outlined in Chapter 5 had repeatedly changed households and were staying in households that were not necessarily 'family' making it difficult for them to bond sufficiently to feel confident about disclosing their status. In most instances, stigma and discrimination was located within the 'family' rather than outside. Examples have been cited where young people were even stigmatised and ostracised by their carers and other relatives they were living with. This was mainly because the family was the only space in which HIV is known and therefore the only space in which the experiences of stigma were located.

Although the distinction between biological and non-biological families was not the focus of this research study, I must point out that there was a noticeable difference between families that were defined by kin and non-biological families in terms of the quality of care and support provided to young people living with HIV. Biological families were portrayed as being more caring and supportive than non-biological families. Family experiences presented in this study therefore must be considered within this background. This important area is well described in an ethnographic study on the experiences of growing up with HIV in eastern Zimbabwe (Parsons 2012).

The construction of friendship as inherently fragile indicates a number of important issues that characterize the experiences of young people growing up with HIV. Firstly, it demonstrates that young people think about friendship. They are conscious of the essence and form of their friendships and how their friends treat them appears to constitute important elements of how they view themselves and the quality of their daily lives. This reveals a great deal about how young people view their HIV status and what they 'understand' about it. Young people have come to understand that HIV has the power to alienate and change the way they are viewed by their peers. They understand the social meanings attached to HIV and that individuals diagnosed with HIV face various forms of stigma, isolation and powerlessness regardless of

how they got infected (Fielden, Chapman et al. 2011). In the same way, young people have come to understand the need to navigate between conflicting moralities of disclosure to peers normally encouraged by healthcare workers and the need for social acceptance and social inclusion. Such understanding significantly informs their decision not to tell their friends about their HIV status.

Although secrecy reduced the risk of social exclusion from peers and preserved them from being judged for being HIV positive, it presented challenges to them in adhering to treatment such as not being excused for missing school. It also impacted on their normality in that they did not feel normal as they had to consistently lie to their friends about their illness and treatment (Rydström, Ygge et al. 2013). Having to consistently lie to their close friends about their health is just one example of the countless social challenges that HIV infected young people grapple with outside the clinic settings but which have the potential to undermine how well they conform to clinical guidance and expectations. The study noted that the lived experiences of young people were constructed around ongoing fear of what might happen in the event of an inadvertent disclosure. Keeping the secret requires a lot of work which includes increased self-surveillance and information management (Calabrese, Martin et al. 2012).

Secrecy subtly shapes children's interaction with their friends as well as their lived experiences of HIV. Secrecy has the potential to cut off sources of social support in terms of empathy, medication reminders and love from friends (Evans and Becker 2009, Fielden, Chapman et al. 2011, Daniel 2015), undermine psychosocial well-being and mental health (Frijns and Finkenauer 2009). The impact of living in secrecy is unlikely to be limited to their current experiences but to significantly impact how they handle disclosure later in life. As noted in the literature, being told to keep HIV status a secret for many years can turn disclosure to future sexual partners into an extremely difficult thing (Fair and Albright 2012,, Persson, Newman et al. 2014).

There is a growing concern that young people growing up with HIV in an environment of secrecy will develop poor self-worth and psychological distress. Studies have shown that some HIV positive young people isolate themselves from others and are full of shame (Fielden, Chapman et al. 2011, Mupambireyi, Bernays et al. 2014). This secrecy and lack of openness regarding their status limits children's understanding of their condition. Instead of young people developing better coping strategies and more efficacious sense of self, secrecy and silence often feed into their identity making, intensifying self-stigmatisation thereby undermining their capacity to develop resilience and positive self-images and self-worth.

Understanding children's disclosure decision making pathway is important for a number of reasons. Firstly it allows for the identification of children's fears including the sources of their

fear and concerns around disclosure. Understanding how young people come to know that HIV should be silenced and should be feared is important in informing the design of intervention that aims to promote disclosure. For example if the fear is emanating from myths and misconceptions around HIV, addressing these myths and misconceptions with the correct information might go a long way in building the confidence that young people need to be able to disclose their status. This can also be useful in informing the kinds of communication that carers and healthcare workers need to have with their young people regarding disclosure.

Secondly it is imperative in helping us understand whether young people think that their status needs to be a permanent secret or whether they can imagine a time or circumstances when they would disclose. If for example young people anticipate being able to disclose at some point, it will be crucial to identify areas they require support. On the other hand, if the child thinks that their secret is permanent or cannot envisage a time or circumstance in which they would tell, then they need to be supported to live with secrecy. Interventions must be designed to best support young people regardless of the decisions they make.

While there is a common approach to overcome secrecy and stigma because of the challenges this presents, (discussed above) there is need to recognize and respect that these young people are making their own decisions to live with secrecy. Although they should not need to live with secrecy, but if the structural barriers compels them to, that is their prerogative. There are structural, cultural and contextual factors (highlighted in the data chapters) that make it imperative for them to live with secrecy. There is an understanding within the literature that stigma is complicated and this thesis provides examples of this complexity. Young people growing up with HIV are not perceived as a being a distinct 'innocent' group within the HIV group due to limited understanding or awareness of perinatal infection. Chapter 7, has shown how young people are carrying confusion of what happened in the past regarding their infection. Lack of knowledge around perinatal infection within the community and by their peers that if you are an adolescent you could have been born with the infection and that you could be surviving, makes it difficult for young people to disclose their status thereby compelling them to live in silence and secrecy.

The stigma that young people experience or anticipate is shaped by the history of the paediatric epidemic during which young people often got sick and died before they were diagnosed or initiated on ART. Therefore, young people suffer double stigma that in addition to being HIV infected their peers and the community at larger assume that they were infected sexually. What is more significant is how the young people conceive it when they are not sure about how they got infected themselves. This means that the stigma that young people experience is made worse by this prevailing confusion. As has been shown in the thesis this

confusion is perpetuated by the lack of post HIV disclosure talk. Young people are not given the chance to ask questions or seek further clarity by their carers. There is therefore need for interventions that target carers and educate them on how best they can engage and communicate with young people when disclose their status. Additionally carers of HIV perinatally infected young people need to be made aware of the prevailing confusion that young people carry around perinatal transmission so that they provide greater clarity when disclosing to their children.

The prevailing confusion around perinatal infection among this cohort, which has been participating in a clinical trial for five years was one of the surprises of this research. I expected young people to have sound HIV information considering that they had the best possible care available at the time and had had access and time to talk and engage with the clinicians, had been exposed to a number of educational outings, had access to resources. One wonders what is happening to young people who are accessing their services at a primary care facility, which are manned by less qualified and poorly resourced staff and where it is likely that the opportunity for one on one counselling is limited.

Young people's perception of stigma is also still being influenced by the prevailing attitudes and the strong beliefs that their peers and the community at large have towards HIV infected people. The historical conceptualisation of HIV as deadly and infectious disease still continues to inform current experience of HIV. One would have thought young people would appreciate that HIV is not spread by playing or sharing food and that instrumental stigma would have lessened. However, the fact that some young people continued to see their HIV infected peers as infectious for example as described in the cases of Faith and Moses (chapter 5) is unfortunate.

The guilty and innocent rhetoric is also problematic; people should not be stigmatised regardless of how they got infected. It is therefore crucial for healthcare workers, carers and policy makers to understand this background and the need for the social circumstances and broader environment of young people living with HIV to change. This might lessen the need for secrecy. Young people must however, be trusted to make their own decisions. In the next section, I highlight the need to respect children's agency to live with secrecy.

9.1.3 Children's ability to exercise agency

Although young people do not seem to have a lot of agency as they are to some extent being forced to live in secrecy, the findings have shown that they are not passive beings but they are active agents as they directly engage with the decision to tell or not to tell. By not telling anybody young people are exercising their agency and at the same time, trying as much as they can to limit the implications of their lack of power within the domestic space. Having

weighed the benefits and the costs of HIV status disclosure to peers, the majority of young people opted for non-disclosure in almost all the social spaces in which they informally interacted with their friends. This resonates with much of the literature among this cohort in both resource rich and stretched settings where the majority of young people chose not to disclose their status to other people including their close friends (Siu, Bakeera-Kitaka et al. 2012, Hogwood, Campbell et al. 2013, Philbin 2013, Rydström, Ygge et al. 2013). Fear of stigma and social exclusion is cited in most of the studies as the central concern for young people growing up with HIV (Fielden, Chapman et al. 2011).

Children's accounts discussed in chapters 5 and 6 have shown that they are successfully managing information regarding their status in their peer networks. This therefore consolidates much of the sociology of childhood literature, which argues for the agency of young people to be more sincerely acknowledged (Mayall 2002, Wyness 2012, Brady, Lowe et al. 2015). Whilst carers, and to a lesser extent arguably, healthcare workers, may interpret the silence that young people keep around HIV as a reliable indicator that they do not think about it too much and so are not 'too affected' by it, this assumption might be challenged if we take into account how young people consider and manage the risks of disclosure to friends.

This is an example of how young people are negotiating their experiences of growing up with HIV through a framework of bounded agency. Although young people have agency it is severely curtailed by social, physical and relational circumstances. For example, even though young people are making the decision to live in silence and not to disclose their status this does not guarantee that their status will not be disclosed another way. The data chapters have shown how adults sometimes inadvertently disclosed children's status and also how the visual markers of HIV made it difficult for young people to conceal their HIV. Even when young people seem not to be in control this is not because of passivity but it shows that their agency is overwhelmed by circumstances. Arguably this is the same even with adults but when young people show lack of control it is often defined as having no agency at all.

The thesis has shown that young people are engaging all the time, making decisions about what they want to do even though what they want is not always what happens. Young people are portrayed as not always accepting their parents' decisions but they filter the information and make their own independent decisions. For example the thesis have shown how some young people disclosed their status behind their carer's backs.

Cultural beliefs prevalent in a context also severely limit children's agency. For example, there is a deep-rooted cultural belief in Zimbabwe (Parsons 2012) which maybe similar across Southern Africa (Sengendo and Nambi 1997, Daniel 2005, Snipstad, Lie et al. 2005) that young people do not understand emotionally disturbing issues and therefore they will not be

affected by them. An example is death, many young people in sub-Saharan Africa lost their parents due to HIV related illnesses before ART roll out. The majority of these young people were not allowed to attend their parent's burial nor did they receive answers or explanations regarding their parent's death (Daniel 2011, Thwala 2013, Kheswa 2014).

In this study, we can see how such practices continue to shape how adults interact with the young participants, for example, young people were encouraged to silence the emotional challenges of their own HIV by constantly being told not to cry in public (presented in Chapter 5), having limited opportunities to ask questions and through the absence of talk or acknowledgement of HIV within the domestic spaces (chapters 5-7). Even though children's health is more robust, they get to understand about their own HIV infection through their parent's death. There is limited communication regarding the circumstances of their own HIV infection. Although such cultural beliefs are meant to protect young people from the trauma, they in turn limit opportunities for young people to talk about their emotional problems. They also further marginalize young people from accessing help and this may hinder positive adaptation (Daniel 2011).

The findings have shown that young people think a great deal about HIV, they have many questions about HIV but may not talk about how they are feeling. One reason for the silence being that they are not given the social space to express themselves, they have been exposed to a culture of silence and this makes it difficult for young people to express their emotional problems (Daniel 2011). Even though they are very young, they are already worrying about their future, for example, whether or not they can have families or will be able to have families, even though they do not openly talk about it or acknowledge that they think about it much. There is therefore need to educate carers and to some extent healthcare workers, that young people do worry and are affected by HIV. Adults need to be encouraged to open avenues for communication with young people if they are to provide the psychosocial support required. Post disclosure talk is vital especially as evidence continues to show that young people have many unanswered questions and want to understand what it is like to grow up with HIV now and for the future.

Many studies from resource stretched settings have shown that carers justify postponing disclosure arguing that young people are young and incapable of keeping secrets (Alemu, Berhanu et al. 2013, Motshome and Madiba 2014, Mweemba, Musheke et al. 2015). As my findings have shown a number of young people cannot even envisage a time that they will ever tell their friends, even those they are closest to, this seems an unlikely risk and an unjustified reason. Rather, this indicates a lack of recognition that adults have for children's comprehension about the social risks of HIV. This assumption that young people do not

appreciate the social risks inherent in disclosing an HIV status may both serve to justify the postponement of disclosure, but also mean that adults do not engage with how these social risks can be managed, alleviated or challenged. Instead young people worry about HIV, and they have real concerns that they want to discuss with their carers but are denied the opportunity (Fielden, Chapman et al. 2011, Bernays, Papparini et al. 2015). They also worry about their uncertain future but these concerns are neither adequately recognized nor addressed by most adults. This again curtails young people's agency.

The thought that some young people invest in assessing the trustworthiness of their friends to keep their secret and the refusal by most young people to entertain the idea that they might be able to tell their friends in the near future suggests that the carers' reasoning is misjudged. Possibly this reflects carers' misunderstanding about the scope and extent of children's social awareness. In a few cases where the carers have told their young people about their own (i.e. the child's) HIV status, these same carers have kept their own (i.e. carer's) status a secret from the child. Carers withhold this information and justify it using the same rationale: the child doesn't understand and so may unthinkingly tell others. Young people are disadvantaged by the wider social and cultural contexts in which they are not heard but understood as a minority social group, subordinated to adults notably carers and healthcare workers. This socially constructed dependency on adults grounded in social norms and practices blindfolds carers from appreciating children's ability to robustly understand and comprehend several issues including those relating to HIV.

This huge disconnect between what carers think young people would do and what actually happens on the ground reveals two key dynamic issues: lack of open communication and fear of disclosure aftermath. Firstly, the data points to a lack of open communication between carers and young people about HIV. Once disclosure has occurred, HIV ceases to be talked about (Parsons 2012, Kajubi, Bagger et al. 2014, Kajubi, Whyte et al. 2014, Bernays, Seeley et al. 2015, Daniel 2015). This insistence on secrecy is however misplaced considering how young people assert their agency by closely guarding their 'secret' and are very strategic about whom they disclose to. Secondly, it also reflects the carers' fear of the other consequences of telling the child. The literature has shown that most carers believe that disclosure could prompt uncomfortable and painful questions about transmission, sexual behaviour, illness and vulnerability (Kidia, Mupambireyi et al. 2014). Carers worry that young people will question how they got infected and parents would be eventually blamed for passing on the infection to their children.

In many cases young people are reported to have no say over who gets told about their HIV status (Calabrese, Martin et al. 2012), for example in the household, and they bear the consequences of this disclosure by carers and others adults (Mburu, Ram et al. 2014,

Nöstlinger, Bakeera-Kitaka et al. 2015). It is important to consider that carers' experience of HIV in its historical context and how what has gone before in terms of how HIV used to be considered will affect how HIV is lived now for these young people (Parsons 2012). Young people are not trusted to safeguard such a tabooed and sensitive issue. Although to some extent young people are bounded by relational influences, my findings have shown that they tend to be in control over whether, when and how they tell their friends. Disclosing to their friends is something that they are fearful of and give a lot of thought to (Michaud, Suris et al. 2009, Hogwood, Campbell et al. 2013).

9.2 Self-disclosure of HIV status to friends

Despite the complexities around children's status disclosure to peers, a few young people who intentionally or unintentionally disclosed their HIV status shared both negative and positive experiences.

9.2.1 Negative experiences post disclosure

Two main issues were raised: experiences of enacted stigma and status getting publicized to people they had no intention of telling. As discussed in Chapter 5, a few young people (only 2, Faith and Moses) reported experiencing stigma which included being laughed at and gossiped about and felt discriminated against when friends refused to play with them. Although these two cases were exceptional, in that they were the only ones who got negative responses from their peers amongst those who did tell, their experiences serve to rationalize and reinforce the concerns that the majority of young people have around status disclosure.

A greatest concern amongst the majority of young people was the need to protect their status from being disclosed to other people. A limited number had their HIV status leaked and publicized to others. This lack of confidentiality eroded the trust they had in their peers. The findings have shown that children's concerns were not just limited to reaction of their close friends but also at the wider community. For example, they worried about what their neighbours, fellow classmates / schoolmates and church mates would treat them post disclosure. Young people worried about having a negative identity and publicity beyond their circle of friends. Such negative experiences confirm the strong conviction among young people that their friends, and other adults, were "rumour mongers" who could not be trusted because they would spread stories about their HIV to everyone else or "the whole school" as they described it. Telling one was seen as telling the whole nation; confiding in peers was fraught with risk.

The findings therefore underpin the importance of avoiding generic approaches that advocates for blanket disclosure without seriously engaging with children's fears and concerns. There is a need to understand the social contexts and the social fabric that holds children's peer networks before encouraging them to disclose their status to their friends. Findings from

Switzerland suggest some benefit in non-disclosure (Michaud, Suris et al. 2009). Failure to assess the costs and benefits of disclosure can result in some young people suffering stigma and social distress and having more devastating effects than when they do not disclose. There is need to give young people room to test the waters and establish if social support will exist before they make the decision to disclose to their peers.

Experiences of enacted stigma have implications for how young people handle disclosure in their subsequent encounters. As discussed in Chapter 8, some young people decided not to continue disclosing after experiencing stigma in their first disclosure encounters. Non-disclosure in subsequent encounters included even to healthcare workers, researchers and other professionals. I directly experienced this when young people were hesitant to disclose their status during phase I interviews despite them being fully aware of their HIV status. Similar findings were reported in Tanzania (Daniel 2015) and Switzerland (Michaud, Suris et al. 2009), where young people who have had direct experiences of stigma were hiding their status in their subsequent encounters. Fear of further stigmatization and rejection meant that they became less confident and more cautious with regards to whom, when and how they disclose their status. The findings confirm that young people need guidance for making decisions about whom it is beneficial to disclose to and for what purpose. For example, it will be beneficial that they disclose to healthcare workers say they are referred for other services by their usual healthcare workers.

9.2.2 Positive experiences

The majority of young people who had friends who knew their status described it as being a source of significant comfort and support. Young people who chose to disclose despite being instructed not to disclose their status by their carers reported getting medication reminders, assistance with school work when they missed school during ART refills and check-ups and being encouraged to take their medication during drug fatigue moments, receiving love and empathy during their “not so good days” from their close friends. Regional and international studies have shown similar findings for example from Tanzania (Midtbø, Shirima et al. 2012), Uganda and Kenya (Nöstlinger, Bakeera-Kitaka et al. 2015), United Kingdom (Hogwood, Campbell et al. 2013). In most of these studies, young people reported that their friends became very supportive and ‘stuck by them’ post disclosure (Hodgson, Ross et al. 2012, Fournier, Bridge et al. 2014). Talking to and sharing difficult situations with friends has been noted to be critical in the development of resilience (Sherman, Bonanno et al. 2000). The findings confirm the assumption that peers are a vital source of support though commonly underestimated by adults and to some extent, service providers who advocate for silence and secrecy.

Having a trusted friend to share difficult times with has been shown to yield better health outcomes (Sherman, Bonanno et al. 2000). Although many worried about social rejection, the few young people who voluntarily disclosed their status spoke of having positive caring relationships with their friends. Not having to worry about their friends finding out their status and risking being accused of keeping secrets was considered a protective factor in their lives. Data from other settings also suggest that young people who disclosed had higher peer self-competence and had better psychosocial outcomes (Battles and Weiner 2002, Wiener and Battles 2006, Hodgson, Ross et al. 2012).

Social support from disclosed friends was seen as a protective factor crucial in coping and adapting to living with HIV. Resiliency literature discussed in Chapter 4 has shown social support as an important ingredient in positive adaptation but this is however tied to individual's capacity to seek and access support. In this case, young people who took the step to disclose their status benefited from the support of their friends. Children's ability to engage with social support was beneficial in building their resilience (Shaikh and Kauppi 2010, Skovdal and Daniel 2012, Fournier, Bridge et al. 2014).

Since my findings suggest that many young people are aware of the benefits but are fearful of the disclosure aftermath, intervention needs to help support young people to disclose to their friends should they want to. Young people need to develop skills and have adequate information and have their questions answered to help them build the confidence they require to disclose their status. They need to fully weigh up the potential benefits and harms of disclosing given their circumstances and the context in which they live. Young people need to have access to other children's positive experiences of disclosure through books, magazines, short films and short stories. Sharing such positive stories might motivate young people to also want to disclose their status to their friends. Chapter 6, has shown how some young people were motivated and inspired to live positively with HIV after reading experiences of other young people in one of the Zvandiri books titled "Our story" (<http://www.africaid-zvandiri.org/portfolio/our-story>), that they were given during support group meetings. Having access to other children's experiences will reduce the level of uncertainty in their decision making process.

Additionally, access to other children's disclosure experiences will not only increase their knowledge and awareness of how other young people around them are handling disclosure but will also help them make informed decisions regarding their own status disclosure. Data from other regional settings have shown that stories, cartoons and books are effective tools in delivering important information to young people (Petersen, Mason et al. 2006, Bhana, Mellins et al. 2014). For example, a family based psychosocial intervention that used culturally tailored cartoons story lines was successful in improving drug adherence among young people living

with HIV in South Africa (Bhana, Mellins et al. 2014). In the same study, a story book character helped promote healthy positive self-identities among the young people who took part in the study (Bhana, Mellins et al. 2014). Having said that, it will be important to ensure that the books, short stories and other material are age specific, culturally sensitive, provide realistic examples and are provided in an accessible language and format.

9.3 Formal support networks

In the previous section, I looked at support from HIV negative peers but in this section, I now turn to support from other HIV positive peers. In this section, I reflect on children's perceptions and experiences of formal peer support discussed in Chapter 7. One of the aims of this work was to explore how young people access and benefit from formal peer support. As discussed in Chapter 2, receiving support from more formalised support networks has been found to promote positive psychosocial adjustment. As already mentioned in Chapter 7, formal peer support for young people in this study was mainly accessed through support groups hence the focus of my discussion is on community based and trial-run support groups.

9.3.1 Support group as a source of HIV and drug information

The findings illustrate support groups' potential in significantly transforming children's perception of HIV infection as a debilitating infection which they are experiencing in isolation to one in which they may begin to have more confidence in being able to live with it, alongside others, as a manageable condition. Support groups were portrayed as challenging the negative representations of HIV. However, I must mention that the negative representation of HIV for young people is perpetuated by the secrecy within which they are experiencing HIV. The findings have shown that they have limited sources of information about HIV and have a negative idea about it. The findings have shown that support groups play a significant role in providing HIV and drug information to HIV-infected children, confirming what was found in Botswana and Tanzania (Midtbø, Shirima et al. 2012), Zambia (Menon, Glazebrook et al. 2007), in France and Canada (Funck-Brentano, Dalban et al. 2005, Di Risio, Ballantyne et al. 2011). This is also very similar to findings from among adult population (Liamputtong, Haritavorn et al. 2009, Mburu, Ram et al. 2013, Paudel and Baral 2015).

As shown in chapter 7, young people who have been consistently attending support groups over a period of time tend to have better HIV knowledge. This suggests that consistent exposure to support groups is likely to be influential in children's capacity to absorb HIV-related knowledge and understand the nature of their HIV condition. However, the fact that a few regular support group attendees still had sub optimal overall knowledge of HIV and on-going and unresolved questions about being cured and the duration of taking pills points to the

inadequacy of relying solely on support groups to meet children's HIV and drug information needs. It also questions the sufficiency of the information given to young people as well as the framing, packaging and delivery of HIV information in other care environments such as the HIV clinics and also in the support groups. For example, some support groups engage young people across a wide age range (7–18 years old), presumably making it challenging to present information in a way that is relevant and accessible to all within one group. The number of community based support groups was inadequate for the number of children needing the services accounts for the oversubscription within some of the groups. The large groups was despite that fact awareness of HIV status was a pre-requisite for attending as mentioned in chapter 7. The need for improved access to HIV information in an accessible manner cannot be over-emphasised. It is important for support groups to have set standards of what constitute a support group. Getting young people together without clearly laid out structures might be less valuable. Support groups need to ensure that YPLHIV's information and skill gaps are properly addressed.

The assumption made by most carers that by attending support groups, young people get enough HIV information suggests that carers themselves, in overestimating the ability of support groups to fill all the gaps, may inadvertently use this to minimise their own role in contributing to the children's acquisition of HIV information or to use this as an excuse not to have to discuss difficult issues. Overall, carers' satisfaction with the learning their young people got through support groups, despite the evidence that many young people remained confused, suggests that carers may not even be aware of the gaps in their children's HIV knowledge. As has been shown elsewhere (Kouyoumdjian, Meyers, & Mtshizana, 2005; Madiba & Mokwena 2012), this may reflect the fact that carers themselves have inadequate HIV knowledge and are thus not in a position to identify their child's information and skills gaps.

This might also be perpetuated by the lack of openness regarding HIV within the homes where adults hide their own HIV infection from children. As has been shown by others (Letteney and Laporte 2004, Murphy, Austin et al. 2007), disclosure of parental HIV diagnosis often equates with disclosure of socially stigmatised behaviours such as prostitution or injection drug use. Preconceived notions regarding a positive HIV diagnosis and fear of being blamed limit adults' willingness to engage in HIV discussion at home. This again illustrates the need for a holistic approach to the provision of HIV information, which targets HIV infected children, their carers and the wider community including schools, churches and other spaces where young people hang out. As outlined earlier carers need to be supported with the correct information and communication skills especially when communicating with young people.

If we are to achieve desired levels of knowledge among young people growing up with HIV in future, there is need to engage with the carer to identify and address carer's own information gaps and then provide accurate and complete HIV information. Carers need to understand and appreciate the role of HIV information in shaping the experiences of young people and this will enable them to openly talk about it at home (Bernays, Jarrett et al. 2014, Bernays, Seeley et al. 2015). Carers need information on how best they can explain perinatal transmission to young people in a more comprehensible way especially around how they contracted the disease without having sex. Studies worldwide, have shown that carers encounter a number of challenges in discussing issues related to HIV/AIDS and sexuality in general (Baumrind 1991, Guilamo-Ramos, Jaccard et al. 2008, Bastien, Kajula et al. 2011). Carers appear to lack the knowledge, confidence and skills needed to engage young people in useful, and timely discussions about HIV. Thus, there is need to develop ways to teach carers to communicate effectively with their children.

The adherence messages young people were getting from the support groups as well as from the clinics, were based on what young people should do and therefore any behaviour that was less than exemplary was interpreted by young people to be considered a disappointment and a failing. This suggests the limits in how much support groups currently engage with the structural challenges young people encounter in being able or willing to adhere to their treatment. The discourse of blame, which young people perceive to centre on non-adherence, appears to silence non-adherence, making it more difficult for young people who may be struggling with adherence to access both the help and support they need in taking pills (Kawuma, Bernays et al. 2014, Bernays, Papparini et al. 2015, Bernays, Seeley et al. 2015). As Bernays (2015:107) noted, young people will end up using the silence as "tools for their social and cultural survival".

As discussed in Chapter 7, young people ended up controlling which information to tell and not to. Missed doses and periods of not taking treatment were not disclosed to either carers or healthcare workers for fear of being scolded. Support group facilitators and other healthcare workers need to embrace and validate reasons given by young people who may be struggling to maintain acceptable levels of adherence and try to help them without judging and ostracising them (Bernays, Papparini et al. 2015). Instead, they need to strategically use the reasons to motivate young people to change non adherent behaviours as well to make them come up with practical solutions to conquer non adherence. Expectations of perfect disclosure might lead to non-disclosure of drug slippages as well as demotivate young people from consistently attending support groups. By neglecting the social and cultural contexts that influence non-adherence, support groups may run the risk of becoming a duplicate of the HIV

clinics, thereby becoming less effective in providing the much needed emotional and psychosocial support for young people growing up with HIV.

The findings reaffirm the importance of considering the social and relational context in which young people are taking treatment as discussed in Chapter 4 at the same time challenging the value of integrating support groups within HIV clinics. Chapter 6, has highlighted how the format of the trial based support groups failed to acknowledge that mistakes can happen in terms of drug adherence and this therefore limits adherence support they are able to provide. Similar findings were also reported in Tanzania where the communication style of the support group facilitator changed from one that encouraged honesty to “subtle threats and authority” when two young people innocently acknowledged occasionally missing drugs (Mattes 2014:31). My findings and those from Tanzania demonstrate the interface between the clinic and the social, where the clinic represents a perfect strategy which sometimes may not be a realistic strategy.

This represents a much bigger problem; how should clinic-based support groups engage with YPLHIV to demonstrate that, for example, good adherence is not actually as straightforward as they say? It also presents challenges in terms of how the clinics would move towards encouraging YPLHIV to be feel more honest about the challenges they face and therefore, better able to access more effective support. YPLHIV might feel isolated or silenced because their own lived experiences of HIV may not be reflected in the narratives of the clinic. The wider literature on HIV adherence support recognises this limitation. Life- Steps for example, is an adherence programme devised for adults which uses problem solving and behavioural activation to encourage and support adherence within a clinical trial (Safren, W. Otto et al. 2001). More recently, the ‘Life-Steps’ have been used to increase adherence to pre-exposure prophylaxis (PrEP) among high risk sexual minority men (Taylor, Psaros et al.).

9.3.2 Support groups as safe social spaces

Chapter 6, has shown that young people valued support groups as providing a safe social space to play and mix with other children. Play therefore comes out as a vital component in reassuring HIV-infected young people that they are normal young people and that they can fit into the wider community. Play has significant value in children’s lives and has often been cited in other studies as a motivating factor for good paediatric antiretroviral therapy adherence (Weigel, Makwiza et al. 2009). In my study, it was common for young people to report having avoided public spaces and withdrawing themselves from interacting and playing with others following status disclosure and once they experienced an HIV-related illness. This corresponds with the significant literature on HIV stigma, which suggests that young people

withdraw from social groups or isolate themselves following their diagnosis (Campbell, Skovdal et al. 2010, Petersen, Bhana et al. 2010, Snyder, Wallace et al. 2014). As shown in Chapter 6, self-stigmatisation and self-isolation changed when they found companionship and mutual support after joining support groups.

Participating in support groups was conceptualised as vital to the restoration of the once lost confidence. As shown in Chapter 6, many young people described losing or never having developed confidence but support groups facilitated their reintegration into the public sphere through playing and mixing with other young people outside the confines of the support groups. This highlights that support groups are a useful resource for facilitating self-acceptance and restoring the confidence that may be lost once one is diagnosed. The findings resonate with findings from South Africa (Snyder, Wallace et al. 2014) and Uganda (Nöstlinger, Bakeera-Kitaka et al. 2015) where support groups provided health enabling safe spaces for young people living with HIV. Support groups were important in creating social bonds and networks for young people (Witte and de Ridder 1999). Being exposed to an accepting community of peers who also had HIV was described in Chapter 6, as comforting. Sharing their lived experiences of HIV with a supportive and caring audience in a relaxed environment in turn served to assure young people that it was possible to live with HIV. The important role played by the support group was that young people gained confidence, self-acceptance and learned to talk and share their experiences with other HIV infected children. This was not possible in other care environments where HIV talk was non-existent. Crucially, support groups also provide a rare space to feel normal for those young people who still feel reticent about interacting with other young people outside of the support group.

Specific to Zimbabwe, research has shown that support groups are a promising and viable intervention for meeting the emotional and psychosocial needs of young people living with HIV (Mavhu, Berwick et al. 2013, Kidia, Mupambireyi et al. 2014, Mupambireyi, Bernays et al. 2014). Given the consistently declining economy coupled with the shrinking HIV donor funding in Zimbabwe, it is important to consider less costly, simple interventions, which focus on play but help young people to build resilience. Simple interventions that use play and or sports have been shown to improve self-confidence and increased adherence among young people growing up with HIV in other Africa settings (Midtbø, Shirima et al. 2012, Strasser and Gibbons 2014).

9.4 Factors hindering access and attendance to support groups.

Although support groups are shown to be key in children's management of HIV, a limited number of young people in HIV high burden countries are accessing these services. Children's experiences of access to support groups, though not very dissimilar to adults, must be understood as a double challenge. Adults are often responsible for getting themselves to support groups whereas for children, adults are responsible for providing resources to facilitate young people to attend support groups (bus fares and availing time) while actual attendance is dependent on whether the child wants to attend. This thesis set out to explore the factors that hinder children's access and participation in support groups. Six barriers were identified and discussed in Chapter 6.

A big deterrent to children's willingness to attend support group was fear of being seen and recognised as an HIV infected child. The strong compulsion among young people to keep their status a secret compromised their participation in support groups. As shown at the beginning of Chapter 7, the majority of young people 24/26 attended the trial-run support group compared to 9/26 who attended the community based support groups. The trial support group might have been preferred by many because it offered more privacy and was convenient. The risk of being seen at the trial support group was minimal compared to community based support groups which were held mostly in public places such as community halls and churches. For those who chose to attend support groups, fear that other group members might fail to keep confidentiality was a substantial risk.

Fear of inadvertent disclosure is not limited to young people but also among the adult population (Heyer, Mabuza et al. 2010, Madiba and Canti-Sigaqa 2012). A study conducted in South Africa found that men were reluctant to attend support groups for fear of unintended disclosure (Madiba and Canti-Sigaqa 2012). Service providers need to understand the limitations to access among existing psychosocial services as well as how social environments influence YPLHIV's access to services. A better understanding and appreciation of the current access limitations and the impact of the social environments will inform the development of services that meet the needs of YPLHIV, thereby enhancing improved access.

Transport costs was also an important barrier as the majority of carers could not afford the relatively high transport costs (US\$2 each round trip) to the meetings. Most of the caregivers were unemployed and therefore could not afford transport costs to and from support group meetings. Studies that have explored barriers to uptake of HIV-related services have often cited transport costs as a major barrier (Skovdal, Campbell et al. 2011). Burden of transport costs could be lessened if all routine check-ups in paediatric HIV clinics are complemented

with peer support groups that run after the young people have been attended to by the healthcare workers. Most of the successfully documented adolescent support groups in resource poor settings were nested within the HIV clinics or adjacent to clinics (Midtbø, Shirima et al. 2012, Snyder, Wallace et al. 2014, Daniel 2015, Nöstlinger, Bakeera-Kitaka et al. 2015).

Although this approach makes support groups more accessible to young people by reducing the transport costs and the risk of accidental disclosure in their communities, it has its own limitations in terms of the quality and usefulness of the support young people will be able to receive discussed above. Studies found that trial-run support groups which were facilitated by doctors and nurses did not adequately address the key support needs of YPLHIV. This was mainly because the doctors and nurses were not necessarily the right people with the right skills to run the support groups. This contradiction in what clinic based support groups can offer and what is actually happening for YPLHIV highlights the challenges fundamental to why it's difficult to support YPLHIV in resource stretched settings because in supporting YPLHIV, it involves acknowledging imperfections around adherence and to some extent, disclosure. Clinic based support groups might work better if they are run by trained facilitators who use a structured approach as mentioned earlier.

Intermittent funding for children's support groups has seen a number of support groups being terminated in Zimbabwe, leaving young people with no social space to interact with other HIV positive children, let alone learn from other children's experiences. Stable funding for children's support groups would be more likely to ensure that young people attend reasonable number of meetings to complement the information gained during clinic visits. Carers and young people emphasised the importance of peer-support groups for reducing the HIV and drug information gaps, building self-esteem as well as creating a social space for HIV-infected young people to play and mix. For this age group, having community and clinic based support groups is important, because their friends outside very rarely know about their HIV status. Many feel alone and need help to come to terms with their status and to realise that they are not the only ones living with HIV. Support groups play a crucial role for many children. Long term commitment to funding support groups activities is vital as psychosocial health outcome are not short term (Greifinger and Dick 2011). Lack of long term funding commitments limits the ability of the few organisations that are providing psychosocial support services in Zimbabwe to provide a holistic package of support.

9.5 Methodological and ethical reflections

This section reflects on the methods and research design used for this study. It discusses the challenges around engaging methodologically with a research topic which is by definition not discussed. I discuss whether or not the methods that I used were the most appropriate methods. A brief comparison with the methodological approaches taken by other studies is given.

9.5.1 Longitudinal approach

A number of studies have highlighted the difficulties of researching experiences that are regarded as family secrets (Parsons 2012). One central theme throughout this research study and similar in other studies was that children's experiences of HIV were played out or rather lived and not talked about (Hejoaka 2009, Parsons 2012, Bernays, Seeley et al. 2015). Participants had relatively limited opportunities to talk about HIV within the different care environments where they lived and accessed care. One key methodological contribution of this study was in demonstrating the challenges of using methodological tools that are dependent on people talking in order to try and access experiences that are embedded in silence. During phase 1, the majority of the participants were unwilling to talk about their experiences. I was able to notice the discomfort, tension and anxiety that young people had. As outlined in chapters 5 and 8, the study used a longitudinal approach complimented by a range of innovative tools. Having repeat in-depth interviews with young people proved useful in establishing and sustaining rapport.

The longitudinal approach created a social space in which the young people felt comfortable to come out of their protected spaces to share their lived experiences. This was, however, an evolving process where feeling safe and becoming comfortable preceded the confidence to share. Using a range of innovative tools was also effective in creating a bridge which enabled young people to move from the 'lived and silenced' to the 'shared' stories. This methodological strategy stimulated young people to engage with the research process and added rigour, breadth and richness to the data I collected as shown in Chapter 8. Using a single method for example, interviews alone, would not have allowed me to sufficiently explore the lived experiences that I had set out to explore.

9.5.2 The audio diaries

Audio diaries were used as a methodological strategy to enhance access into children's social worlds. As outlined in chapters 5 and 8, audio diaries were piloted with children. One key concern highlighted in Chapter 5 was to explore whether or not young people were going to be comfortable using the audio diaries, given the sensitivity and silence regarding HIV talk. The insights gained from using the audio diaries were threefold: feasibility, acceptability and the increased access to potentially taboo topics.

A number of studies (Buchwald, Schantz-Laursen et al. 2009, Worth 2009) have used diary methods with young people in resources rich settings to explore various social issues but I could find no evidence that audio diaries had been used with young people in resource stretched settings. Comparatively whilst the audio diary method worked well in Zimbabwean they did not work very well in Uganda. Although the research presented here was limited to the data that I collected in Zimbabwe, team meetings and presentations gave me an opportunity to reflect and compare my findings with the other three sites in Uganda. It was reported that young people in Uganda were not comfortable keeping audio diaries in their homes. The discomfort implies a number of significant contextual differences between the Zimbabwean and Ugandan contexts.

Firstly, it may have been about the amount of space and the confidence that participants had in their ability to protect their possessions. If young people were living in crowded households with little privacy, as has been reported in other studies from Uganda (Villar and Alder 2011, Bernays, Jarrett et al. 2014), this could have potentially increased their fears and anxiety and account for the discomfort in keeping the diaries. This points to the challenges of keeping the audio diaries within confined spaces. Secondly, it could also indicate the lack of confidence that participants had in engaging with and keeping certain technologies (gadgets) in their homes. I must mention that in Zimbabwe, the participants were predominantly a Harare based cohort (mostly urban) which might have made them more familiar with technology and therefore comfortable keeping the audio diaries hence my learning suggests that they can work well in these settings. Future researches however need to bear in mind the specifics of this research environment and what kind of technology one could use.

In the Zimbabwe setting, the audio diaries were very useful in engaging with ordinarily unsayable topics. For example, the diary methods provided a multi-occasional window which captured children's experiences in real time (Bernays, Rhodes et al. 2014) and enhanced access to the children's hidden and suppressed emotions (include their anger) and feelings regarding the circumstance surrounding their perinatal infection. The diary method provided an opportunity to compare and see how young people engaged differently when talking about their experiences of HIV using different methods. A notable difference was in the experiences of coping with HIV. The interviews portrayed young people as being more resilient, optimistic and more able to cope with their diagnosis and taking treatment, while audio diaries painted a gloomy picture of anger, pain, sorrow and a lack of resilience.

As has been highlighted throughout this research study, the adult world cuts off opportunities for young people to talk about HIV or express the emotional challenges of their HIV. Understanding the children's experiences might therefore be increasingly difficult because of this cultural background of silence and secrecy. The silence and secrecy may be reproduced

during the interviews as shown in Chapter 6, making it increasingly difficult to access their social worlds. This can also be made worse by the power differentials between the researcher and the young participants. Earlier in the thesis, I talked about challenges that adult researchers face in engaging with young people, the diary method therefore becomes the effective medium to overcome the age/generation gap. It is impossible for adult researchers to get rid of the age difference, but the diary method provides an opportunity for young people to communicate with, without directly talking to, the researcher while maintain the distance and the proximity considered necessary.

Although the diary is an effective method for encouraging taboo topics to be discussed, the methods fundamental rests on young people's understanding of the method and what the method is intended to achieve. Although the majority of the diaries were of interest there were a few that were revealing but did not work as I intended. There were instances where young people recorded songs and television programmes that did not in any way reflect their lived experiences of HIV. If young people misunderstand the method there is very little that the researcher can do. Young people control the diary hence the researcher cannot ensure what they record. This therefore implies the need for investing time in setting up the process, putting checks and balances to see that the young people have understood the purpose of keeping the diaries at home before handing them out. One way of ensuring this would be to give out written guidelines on some of the possible areas they can record but at the same time emphasising that they are not limited to what is listed.

One ethical concern around the audio diary method is the challenge of maintaining confidentiality. There will always be concerns that the diaries may be found by other people. The technology that I used was in many ways cumbersome compared to opportunities increasingly available which might further enhance its applicability. In my future research with young people, I will consider embracing the evolving technology. For example making use of smart phones to design an application which is more similar to WhatsApp, where young people could record and straightaway send their recordings at the same time allowing for the files to be immediately deleted from the gadgets from which they were sent. This technology is becoming relatively accessible in resource stretched settings. The audio diary method has been shown to be useful but the execution of the method should move with technological advances which make participants less vulnerable. However, sending audio recording instantly comes with its own challenges for example, if a participant sends it straightaway they have less opportunity to reflect on whether they want to share it or edit it. Although sending it straightaway enhances their control (by the diary not being accessible within their home or outside their homes), it reduces their control through the lack of time for editing.

Good ethical practice is mainly about doing good and avoiding harm which includes, but is not limited to, ensuring the psychological and emotional safety of participants. One concern in using the diary method is the lack of opportunities to offer immediate support to participants who get psychologically or emotionally distressed while using the method. This however becomes difficult when using audio diaries where the responsibility to seek psychosocial support rests on the young children. A number of diary accounts depicted some form of emotional distress, some participants cried but I only got to know about this during the transcribing and translation exercise two weeks after the data were generated. The local IRBs make it mandatory to offer psychosocial support to participants who show signs of distress during or after interviews but this does not mean that it is taken up. This so especially when counselling within HIV context in Zimbabwe and elsewhere does not ordinarily mean emotional and psychosocial support but adherence support.

Although the aim was to give young people a less confrontational space to capture experiences they felt were important, children's decision not to seek support when I assumed they needed it might have, to some extent, undermined the intention to do good and not harm. It could have been that young people chose not to seek support from the counsellors because they did not need it. There is however, an extensive debate on whether it is justifiable and ethical to use research as a therapy (Jamieson, Simpson et al. 2011). Narrating some of their painful stories as well as reflecting on their experiences, editing (deciding which experiences to keep or delete from the diaries) might have been therapeutic for children. It may have been alright for young people to cry as a way of letting it out, reflecting upon it and thereby taking steps towards healing. Within this research there are many sides as to whether it was good or not to encourage young people to talk.

As I have shown throughout this discussion, the study adopted a wide range of methodological tools. In addition to the use of a wide range of methods, my data interpretation also relied heavily on other sources which included my clinic observations and informal discussion with carers and healthcare workers. The informal discussions were not just with carers whose young people were in the qualitative study but it included those who were only participating in the clinical trial. My use of the other sources was not in any way questioning the validity or reliability of the children's accounts but this was important in contextualising what the young people were saying.

9.5.3 Methodological approaches adopted by other studies

The value of an ethnographic approach in studying the lived experiences of young people growing up with HIV were shown in a book by Ross Parsons (2012). Interestingly, Parsons described how the ethnographic approach which entailed weekly meetings with young people in their homes and in clinics, enabled him to observe the silent exchange that constituted

communication between carers and young people about drug times, illness and HIV in general (Parsons 2012, Alberts 2013). Such communication signals are a critical component of their experience and serve to further perpetuate the culture of silence which informs how young people experience HIV. The book provided significant insights into the daily lived experiences of young people growing up with HIV especially on how young people interacted with their carers and other household members (Parsons 2012). Dominick Mattes also used participant observation in exploring the experiences of young people and adolescents living on antiretroviral treatment in Tanzania (Mattes 2014). This allowed him to observe how young people interacted with adults in the clinics, children's homes and in two orphanages (Mattes 2014). The ethnographic approach gave both researchers opportunity and space to observe, experience and interact with intimate every day practises. However, such signals could not have been easily accessed using the methodological tools that I used in my study as they are normally observed and not communicated.

A number of studies have successfully used emerging methodological approaches and techniques to capture the complexities of young people's diverse experiences. This includes the drawing techniques (Evans and Becker 2009, Campbell, Skovdal et al. 2010), photo voice (Skovdal 2011), digital story telling (Willis, Frewin et al. 2014), river of life (Mavhu, Berwick et al. 2013) with young people in Africa. I subscribe to the notion that there is no one best or most suitable methodological approach but that the use of a wide range of methods extend the reach of research to data that might be difficult to access (Jamieson, Simpson et al. 2011). It is therefore imperative to adopt research methods that recognise and support the different ways in which young people feel most able to share their lived experiences (James, Jenks et al. 1998, Christensen and James 2000, Christensen 2004). Punch (2002) argued for the adoption of a mid-way approach that takes into account the shortcomings of adult centred research methods and gives example of research techniques that she used in a classroom setting. The adoption of research a wide range of methods that are tailored to suit the needs of young people will increase access to children's lived experiences which might otherwise be difficult to access using one methodological approach.

9.5.4 The research design

While ethnographic and the other emerging approaches referred to above produced rich data in their own contexts, they could have presented some ethical challenges when I consider how this research study was designed. This study was nested within a clinical trial hence conducting observations within the homes or outside the ARROW clinic could have been quite exposing for these young people and their carers. Conducting observations in participant's homes could have potentially increased risk of accidental disclosure of the young people's HIV status within their households and in their communities. On the other hand, being limited

to the ARROW clinic setting gave me the opportunity to learn of the tacit clinic experiences which I could have missed had I conducted the interviews outside the clinic. For example, I was able to see the disconnect between what the clinic was advising in terms of drug adherence and disclosure and what the young people felt they were able to do. Parsons for example may not have got this dimension in his ethnographic study. Almost all qualitative research tends to be incomplete as lived experiences are so multi-dimensional. Nonetheless, I feel that the methodological tools that were available to me produced rich and novel data.

At the time of the study, the association with the clinical trial was one of the most effective ways to engage with young people and families without creating additional risks by interviewing young people within the community and recruiting them independently. The trial provided safe access to this population because at the time of the study paediatric HIV clinics were not yet established in Zimbabwe making this population invisible. The existence of stigma in the community could have added another layer making it difficult to recruit this population using community structures.

Although being nested within a clinical trial had its own benefits in terms of accessing the young people it has also limited the generalizability of this study. This case study is very specific to the circumstances in which young people found themselves, which is having to access care from an internationally funded clinic, which at the time was offering optimal care which was by definition better than the standard of care offered within the country (Bwakura-Dangarembizi, Musesengwa et al. 2012). The experiences discussed in this thesis might not give a true reflection of what is going on in other settings because of the specificity of this study. However, there are key learning points that can be drawn from this study that might be useful in other contexts.

9.6 Recommendations for policy and practice

Interventions that seek to encourage young people to disclose their status must consider the social and cultural contexts that compel young people into secrecy. As was shown many young people are keeping their status a secret in order for them to fit in and be accepted within their social networks given the high prevalence of stigma in the social context in which they are living. Young people exist and operate within social and cultural contexts that directly or indirectly influence the decisions they make. It is important for healthcare workers and policy makers to have an appreciation of the fears and concerns of young people before advocating for blanket disclosure campaigns.

The findings have shown that support groups play a crucial role for many young people and these need to be rolled out to primary care facilities where decentralisation of paediatric ART services have been implemented. The thesis has shown how young people have benefitted

from attending support groups through learning and sharing experiences with other HIV infected young people. Support groups need to be equipped with additional resources such as books, short films that young people can read or watch and learn from.

Even though this thesis recommends the establishment of support groups in all paediatric HIV clinics two questions remain unanswered, which is whether having support groups nested within clinics is going to be beneficial and adequate to meet the emotional and psychological needs of young people growing up with HIV. The study found clinic-based support groups run by clinic staff to be problematic. Routine care providers risk adopting a clinical focus when running support groups and thereby limit the usefulness of support groups in terms of meeting the varying needs of young people growing up with HIV. Support group facilitators need to handle the issue of adherence carefully, striking a balance between promoting the importance of adherence while at the same time affording young people who may be struggling with adherence an opportunity to get the psychosocial and emotional support they require. Secondly, many clinics have 3 monthly schedules for routine check-ups and having support groups tied to these visits is likely to be inadequate. The research presented here has shown the importance of having regularly and consistent meetings.

Support groups also need to strike a balance between peer led and adult led meetings so that they meet the expectations of young people. Some young people were less motivated to attend consecutively peer led meetings as they also valued learning from the adults. This thesis has shown some of the shortcomings of having unstructured support groups, where some support groups became repetitive and boring. Having a curriculum will go a long way in structuring the sessions in a way that minimizes repetition at the same time promoting diversity and coverage of important topics. Additionally have an outlined curriculum will allow for balanced facilitation from both young and adult facilitators.

Although support groups have been cited as mitigating some of the HIV information gaps for young people, carers should not rely on support groups to provide for all children's' psychosocial needs. Healthcare workers need to continuously encourage carers to take an active role in discussing HIV with their young people so as to complement the information that young people will be receiving from the clinics and support groups. The thesis has shown that young people still have many questions and want to understand what it is like to live with HIV now and for the future. Additionally carers need to be equipped with the basic HIV information to address the gaps, fears and concerns they might also be having regarding initiating HIV talk. Equipping them with the necessary information in the form of books, fliers and pamphlets will improve their confidence in talking about HIV with their children.

It is also critical that healthcare workers, carers and NGO workers and researchers who work with young people understand the need for investing time to build rapport. The findings have shown that young people will disclose their stories and experiences only to trusted person, when given enough time and a conducive social space. Demonstrating respect towards young people and not presuming to already understand is also important.

Researchers working with young people must make provision for referral to offer emotional support in between and after interviews. Allowing for debriefing sessions for both the researcher and the participants is vital and must be arranged for during the planning stages.

Lastly, the MoHCC need to develop national guidelines on provision of psychosocial support services for young people living with HIV so that psychosocial support interventions can be systematically evaluated for impact.

9.7. Dissemination and publication plan

On completion of this PhD study, findings were first disseminated to the young people and their carers. I held a successful dissemination event at UZ-CRC in Harare on the 21st August 2015. The event was attended by participants, their families, as well as representatives of local IRBS. At the end of the meeting I also distributed the 2 graphic novels that were produced, published collaboratively across research teams. We have also produced a series of desk calendars aimed at healthcare workers to make them aware of and/ or remind them of young people's priorities for how they interact with health services and staff. I am still disseminating the graphic novels as widely as possible in Zimbabwe with the help of clinical team, partners and in collaboration with NGOs such as Africaid Zvandiri to ensure that they are available within clinics and support groups across the country.

I was invited and presented at the TB/HIV partnership forum meetings on the 25th May 2016. The TB/HIV partnership forum meetings are organised monthly by the MoHCC and are attended by representatives of civil society, ministry of health, donors, clinical groups and researchers. The last dissemination meeting was at the UZ-CRC journal club meeting and findings were presented to the ARROW trial staff and other trial staff based at the clinical research centre.

Findings have also been disseminated at national, regional and international conferences. I have successfully published one paper in a peer-reviewed journal. The table below shows the presentations and publications to date. My future plans are to publish five more papers in peer-reviewed journals.

Conferences
Mupambireyi Z et al. An exploration of the structural barriers to support group attendance among HIV infected young children participating in the ARROW (ISCRTN24791884) clinical trial. <i>18th International conference on AIDS and STIs in Africa (ICASA).Harare, 2804th December 2015.</i>
Mupambireyi, Z. et al Complexities around friendships and HIV status disclosure among HIV perinatally infected children in Zimbabwe: Results from a longitudinal qualitative study. <i>3rd Structural Drivers HIV conference, Cape Town, 5-6 December 2013.</i>
Mupambireyi, Z. et al “I don’t feel shy because I will be among others who are just like me...” The role of support groups for children perinatally infected with HIV in Zimbabwe. <i>Growing up with HIV in Africa</i> , London School of Economics, UK, March 2013
Publications
Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, M. & Cowan, F. (2014) “I don’t feel shy because I will be among others who are just like me.” The role of support groups for children perinatally infected with HIV in Zimbabwe. <i>Children and Youth Services Review</i> . 45: 106–113.
Bernays, S., Seeley, J., Rhodes, T., & Mupambireyi, Z. (2015). “What am I ‘living’ with?” Growing up with HIV in Uganda and Zimbabwe. <i>Sociology of Health and Illness</i> . 371 (2): 270-283.

9.8 Conclusion

This case study has illustrated the lived experiences of young people growing up with HIV. It has highlighted available support systems, the gaps within the current support systems and their most felt needs. The thesis has highlighted the tension and disconnects that exist between the clinic and the young people and the challenges in providing support for this age group. The case study has also illustrated the methodological and ethical challenges of engaging with young people, sensitive topics and conducting research in resource stretched settings.

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APPENDICES

Appendix A: Children's guide

- Phase 1 topic guide
- Phase 2 topic guide
- Phase 3 topic guide
- Focus group discussion guide
- Audio diaries guidelines

Appendix B: Participant list

Appendix C: Healthcare workers topic guide

Appendix D: Carers topic guide

Appendix E: Publications and conference presentations related to case study

Phase 1 topic guide

Aim of phase 1: map care environments and explore their interaction to narrow the focus

The phase 1 interview will follow the interview diagram, tool 1a (in a clockwise direction, starting from the top). This tool is used in order to show the participants exactly where the interview is going and what it will cover.

1. Yesterday: Talk me through what happened yesterday?

a) Was this a fairly typical day?

2. Faces and important people: Whilst they are doing that start the exercise of getting them/ together drawing people mentioned- names, faces

a) Prompt for explanations of who they are (hope this will lead to understanding of household and family structure, without having to start with/ ask direct questioning about orphaning, family etc).

b) *Prompt for more important people.*

3. Day when you visit the clinic: Talk me through a day when you last went to the clinic.

a) At the clinic- Who you go with and who you see there (including prompting for any other HIV positive young people they know attending the clinic).

4. Mapping exercise of other care environments: go through each of the following care environment: household; school; friends/ community; religion; support groups.

a) Ask for general descriptions first before asking specific HIV-related questions. Avoid assuming the importance of HIV in each environment.

b) Explore how is HIV talked about and how it feels to be HIV positive in each setting

c) Prompt for other environments, including being alone

d) Explore ambiguities when it is not clear/ explicit that their HIV status is known about

e) Thinking about the transition/ journeys between spaces? Prompting for differences in how they feel in each of those. Is HIV something that you are thinking about in each environment? What are the main things (worries, issues, priorities)?

This is the main stage of the interview and the interviewer will adapt their order of questions, use of prompts and emotion cards depending on how comfortable the young person is in talking or how much they would like to talk through task based activities

- Use the map to graffiti ideas- to encourage them to brainstorm.
- Move from general to HIV specific
- Emotions and talk icons can be used at anytime to prompt further discussion

Environment	Key themes	Subtopics	Topics/ eg questions
Clinic	<ul style="list-style-type: none"> • Visit • Relationship with Clinical staff • Treatment experience, especially adherence • HIV talk • Peer support/ networks 	Feelings in being there. Worries Concerns Openness/ sense of being comfortable and oneself	Who do you go to the clinic with? Who do you see? Are there any other YPLHIV you know there? Tell me about what it's like taking HIV treatment everyday? How do you feel when you visit the clinic? When you are leaving the clinic?
Example linking question: When you came home from the clinic what were you thinking about?			
Household	<ul style="list-style-type: none"> • Disclosure and HIV status awareness of household members • Attitudes of household members towards young person • Adherence practices • HIV talk 	Feelings in being there. Worries Concerns Openness/ sense of being comfortable and oneself <i>Start with general then onto HIV specific</i>	Tell me about what it is like in your household? What normally happens when you come back from the clinic? Do you talk about HIV within the household? With whom?
Example linking question: The next day when you go to school, can you tell me a bit about what it is like?			
School	<ul style="list-style-type: none"> • Disclosure and awareness at school- teachers and peers 	Feelings in being there. Worries Concerns	Tell me about what it is like for you at your school? How do you feel about going to school each day? Does anyone know about your HIV status? What is it like keeping it a secret?

	<ul style="list-style-type: none"> • Inadvertent disclosure • HIV talk • Bullying • Worries around school attendance, ability and falling behind • Relationships 	<p>Openness/ sense of being comfortable and oneself</p> <p><i>Start with general then onto HIV specific</i></p>	<p>What do you think your friends' reaction would be if they knew?</p>
Community-friends, neighbours, area	<ul style="list-style-type: none"> • Disclosure and HIV status awareness • HIV talk • Care and support needs of young person and their family/ household 	<p>Feelings in being there. Worries Concerns Openness/ sense of being comfortable and oneself</p> <p><i>Start with general then onto HIV specific</i></p>	<p>Tell me about what activities you do in your community? Do you think anybody knows? Is this something that you think about?</p>
Religion/ Church	<ul style="list-style-type: none"> • Disclosure and HIV status awareness • Support/ anxiety • HIV talk • Care and support needs of young person and their family/ household 	<p>Feelings in being there. Worries Concerns Openness/ sense of being comfortable and oneself</p> <p><i>Start with general then onto HIV specific</i></p>	<p>How does your Church talk about HIV? Are there any people you know in your Church who are open about their HIV status? Do you think anybody knows? Is this something that you think about?</p>
Peer support groups	<ul style="list-style-type: none"> • Role of this form of support • HIV talk • Peer support • Role models 	<p>Feelings in being there. Worries Concerns Openness/ sense of being comfortable and oneself</p> <p><i>Start with general then onto HIV specific</i></p>	<p>Tell me about the support group that you attend Is it different between your friends here and those you know from school? How and why?</p>

5. **Emotion mapping of these environments-** exceptions? Where do you feel happiest? Safest? Most relaxed? Uncomfortable? To explore more in phase 2- for changes, development and depth.

6. **Prominence of HIV in their thoughts and experiences:**

- a) Which of these places do you talk about HIV- most? Least? In general and in relation to you personally? Silences/ talk/ communication.
- b) Where think about it less? What's that like?

7. **Having their say:**

- a) Three things that you'd like to say about living with HIV at your age?
- b) Three useful forms of support you have or would like to have?

Tools:

- Diagram plan of interview- adapted from FLP- Tool 1a
- People templates for drawing- Tool 1b
- Map: Clinic, household, school, community, religion, support groups- prompt for others? – *This will be a blank piece of paper which is drawn on.*
- Emotion cards- Tool 1c.
- Talk cards- Tool 1d
- Both 1c and 1d may be adapted to include other emotions or talk scenarios in line with the evolving analysis.

Phase 2 topic guide

Key area of investigation	Rationale	Themes	Task	Example questions
WARM UP - follow up on topics raised from last interview- primarily rapport building rather than investigative	One of the benefits of repeat interviews is to build trust and to demonstrate interest in each participant. So to start the interview the conversation will focus on individual's situations and catching up on what's happened since the last interview.	Drawing on FN and transcript- focus on their interests (e.g. football, reading); events that would have occurred (i.e. changing year group or moving school)- to create a space to talk openly and specifically about them since the last interview.	<p>If you have the people diagrams saved from the last interview, you could bring these out and discuss their favourite relationships/ friendships (as learnt from their previous interview).</p> <p>Recommend that this is recorded as part of the interview, rather than just done beforehand.</p>	<p>You were telling me last time about how you played for the school netball team, have you played any games recently? What was your favourite bit?</p> <p>So tell me what have you been enjoying doing since I last saw you? Are you still playing dodge ball with XX and XX?</p> <p>These questions can be asked before and at the start of the interview.</p>
HIV KNOWLEDGE	Rationale	Themes	Task	Example questions
	To investigate how much participants know and understand about the course and effects of HIV and ART, as well as their sources of information.	<p>Understanding of status- course and manageability of illness</p> <p>Role and limits of treatment</p> <p>HIV transmission routes</p> <p>Expectations around cure and treatment longevity</p> <p>Sources of information around HIV</p> <p>Attitude towards seeking/ learning more about HIV,</p>	<p>HIV talk cards may be helpful in exploring where certain aspects of HIV knowledge get discussed.</p> <p><i>NOTE:</i> It's very important that the child is clear is not a test. An open tone needs to be adopted.</p> <p><i>Portrait:</i> You could ask them to draw a picture of what someone with HIV looks like. You could then ask them if they think that they look the same. If yes, why? If not, why not?</p> <p>There are 3 options here-</p> <ul style="list-style-type: none"> • they draw; • you draw (with them describing and telling you what to draw); • and them describing and nobody drawing. 	<p>Can you tell me what you know about HIV?</p> <p>How can you tell if a child has HIV?</p> <p>What does someone living with HIV look like? Is that what you think that you look like?</p> <p>What does someone living with HIV who takes HIV treatment look like? <i>Make sure that you are exploring both living with HIV (without treatment) and living with HIV on ART.</i></p> <p>What do the drugs do?</p> <p>How long do you think you will have to take them for?</p> <p>What do you think are the different ways that you can get HIV?</p>

TREATMENT ADHERENCE	Rationale	Themes	Task	Example questions
	To access more talk about adherence slippages and impediments for continuous adherence.	<p>Adherence slippages</p> <p>Reasons for lax adherence (risk management: adherence vs. avoiding deductive disclosure)</p> <p>Responsibility for adherence</p> <p>Side effects of treatment</p> <p>Limited adherence talk- concerns around discussing adherence problems- so exploring the relationship between children and clinic staff in relation to what is talked about.</p>	<p>Start with open questions. Examples given in A) section.</p> <p>Scenario on barriers to ideal adherence- using drawing of the boy or girl and matching it to the age and gender (and similar circumstances) of the participant being interviewed.</p>	<p>A) Have there been any changes since you last met?</p> <p>Can you tell me all about what happens when it is time for you to take your treatment in the morning? And in the evening?</p> <p>Has there been anything going on that has made it harder / easier to take treatment every morning or evening?</p> <p>Is X still reminding you every day?</p> <p>B) Scenario</p> <p>What do you think might mean that he doesn't do exactly what the doctors have told him to?</p> <p>Sometimes he misses it in the evenings, what might be the reasons that he does that?</p> <p>Do you think that he would tell anyone?</p> <p>Why might he not want to tell his carer? The counsellor?</p> <p>Why might it be harder than the counsellor/ carer thinks to take your treatment in the morning and evening every day?</p> <p>Can you explain why we can talk about it now, but it is not easy talking in the clinic about it?</p>

				Can you think of any particular times that it might be hard to take your treatment? Etc.
DISCLOSING TO OTHERS	Rationale	Themes	Task	Example questions
	<p>Participants describe wanting to control the disclosure of their status, with many focusing their efforts on keeping their status a secret. Explore issues of control, who they would like to know/tell and why, as well as their expectations of disclosure in the future.</p> <p>This may be influenced by their own disclosure experiences and so will be explored.</p>	<p>Experience of and capacity to control disclosure</p> <p>Managing their secret (school, play, friends, household)</p> <p>Knowing about drugs but not HIV- why important difference?</p> <p>Disclosure decisions (to whom- why, why not; trust)</p> <p>Own disclosure story, including their suspicions beforehand (by whom, what was said, influence on own expectations)</p> <p>Expectations of disclosure in future (who to tell, under what circumstances, why, what support needed to be able to).</p>	<p>This needs to draw on FN and transcript to remind yourself of what they have already shared in the previous interview about disclosure to inform your personalised questions.</p> <p>If the people cards are available you could use these.</p>	<p>You told me last time that X was the first one that told you about your HIV positive status. Can you tell me more about that? Did you have any idea beforehand? How? <i>Emphasis here is on the details of the process.</i></p> <p>Who do you remember talking about it with after this? Have you talked about it with anyone else? Have you ever spoken about this with X (discloser) again?</p> <p>When X told you did they talk to you about telling anyone else? What did they say? Is that what you have done? Why?</p> <p>You told me that X didn't know and you don't want them to. Do you think that there ever will be a time when you might tell them? What would need to be happening? What do you think it would be like?</p> <p>Can you think of any circumstances in which you would need to tell someone ever in the future? <i>This is hinting towards relationships, sex, marriage etc and where appropriate we would like to explore their expectations around this.</i></p>
<p>These topics should come into each stage of the earlier topics but may also be discussed on their own during the interview.</p> <p>So remember to keep asking questions which relate to sources of fear around HIV and coping strategies</p>				

	Rationale	Themes	Task	Example questions
Sources of fear around discrimination	<p>Interlinked with above topics.</p> <p>If HIV talk is silent, how do they learn about HIV and stigma?</p> <p>How does silence of HIV talk in the different care environments influence this?</p>	<p>How are they influenced by the 'background talk' about HIV?</p> <p>Sources of fear around HIV</p> <p>Association of HIV with AIDS and death, promiscuity etc.</p>	<p>Examples:</p> <p>Possibly could draw out the care environments as in phase 1 and ask about each space to find out where they learnt about HIV and how HIV is thought about in each space.</p> <p><i>Portrait drawing</i> : Return to the portrait of someone living with HIV they drew (if done) ask them what other people think of those living with HIV. Why? Why does the child think that? Are there any other people who think differently?</p>	<p>How did you learn about what other people thought of those living with HIV? Do you ever see any adverts about HIV? Or on TV?</p> <p>Have you ever heard about a child being badly treated because they are HIV positive? Tell me about that. Who told you about them?</p> <p>Do you know anyone who has HIV in the community? How do people treat them?</p> <p><i>Moving from what people think of PLHIV generally in the community to what they may think of them specifically?</i></p>
Coping mechanisms- including sources of support, such as support groups.	<p>This is an over-riding issue that we are interested in. How do children manage their HIV treatment and growing up with HIV in everyday life.</p> <p>Throughout the interview we are interested in finding out what helps and what makes things harder. This may not always be addressed through direct questions- but bear in mind this area of interest throughout.</p>	<p>Care (food, trust, play)</p> <p>Support (adherence support, disclosure support or protection against disclosure, financial support)</p> <p>Support groups</p> <p>Challenges- insecurity within the household, grief and caring responsibilities.</p> <p>Positives too- what works, what helps, what makes things easier.</p>		<p>These questions will draw on the FN and interview of phase 1 and be adapted according to the direction of conversation during phase 2 interview.</p> <p>E.g. You mentioned last time that some other children were teasing you at school, how is that?</p> <p>Tell me what you have been doing in the support group? Has this influenced how you think about the other children teasing you at school? How? What do you do now?</p> <p>Children who do attend support groups</p> <p>Can you tell me about the last support group meeting you have attended?</p> <p>How have you benefited from attending support groups?</p>

				<p>If HIV came up which care environment would feel comfortable to talk about? And why?</p> <p>If you are selected to lead the next support group meeting which area would you talk about and what would you say?</p> <p>During the support group meetings do they teach you about ART?</p> <p>Do they teach you about disclosing to others? if yes what do they say</p> <p>Is there any way in which HIV is talked about differently</p> <p>Can you tell me three things that you would like a child who doesn't know about support groups to know?</p> <p>Children who do not attend support groups</p> <p>Have you heard about support groups?</p> <p>What kind of things do you think they talk about in support group meetings?</p> <p>Why have you not joined a support group?</p> <p>Would you like to? Why?</p>
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CLOSE

Although ARROW is closing explain that there will be one more interview, if they would like to meet again.

Thoughts about end of ARROW- gauge awareness of any arrangements for clinic transfer?

Ask what they enjoyed about ARROW? What they think that they will miss? Do they think that there will be any changes once they leave ARROW trial?

How has it been talking to me this time? How did they feel on the way home after the last interview?

Anything else would like to say?

Phase 3 Topic guide

<p>Pre-amble to set scene of final interview</p>	<p>Explain that this is the last interview and time we will probably meet. Thank them for all that they have shared in previous interviews.</p> <p>Explain that while we would like to continue to hear about their experiences this particular interview will focus on getting their advice. This study is about finding out what it is like growing up with HIV for children their age and therefore we want to find out from the experts what they think could be done to make it better and easier. So this interview will include questions about what they have been through and what they think and feel about their situations, but also be asking for their advice on what other children might be going through and what help they might need. So we will be asking about what they think is good, but also what is harder. The more you help us the more it might mean that this study is able to help other children too.</p> <p>Things to remember:</p> <ul style="list-style-type: none"> • Prepare for each interview by personalising the topic guide drawing on what you already know. • If their carer has been interviewed reassure them that nothing they have told you was passed onto their carer and be careful not to let anything that the carer told you creep into your questions. • There are a number of tasks available to use in this interview. They represent a bag of tricks and are devices to help the child talk through their experiences. But they do not need to be used in all cases and should be adapted to fit the individual you are talking with at the time. • Consider in advance for each individual, drawing on your experience from their first two interviews, which sections would be best to spend the most time on. This will help you to manage the time as it may be too long a topic guide if each section is done thoroughly. • For those from MRC and Harare who have changed clinics there is a lot we can learn from them about changes in care post-trial and this is going to be a significant part of their interviews. 				
<p>Key areas of investigation</p>	<p>Rationale</p>	<p>Themes</p>	<p>Tasks</p>	<p>Example questions</p>	<p>Explanatory notes</p>
<p>Opening discussion</p>	<p>Catching up – since last interview.</p> <p>Finding out about clinic and treatment experiences post-trial</p>	<p>- Update</p> <p>- Post trial experience</p>	<p>None- just talking things through</p>	<p>So, how have you been since I last saw you?</p> <p>Any changes in your household/ school/ class/ play time since we last saw each other?</p> <p><i>Tailor questions that you think would be appropriate to consolidate rapport from the previous interviews about how the last few months have been.</i></p>	<p>This is a simple section designed to start the child talking and to re-establish their trust and comfort in talking to you.</p> <p>There is an early opportunity to gauge what their experience of treatment and care has been like since they left the ARROW trial. We know that it is likely that for the MRC and Harare</p>

				<p>The last time I saw you were leaving the ARROW trial, where are you receiving care now?</p> <p>What is different about visiting the clinic now? <i>Depending on how much they want to talk about their experience in the new clinic some of the later post-trial section could be asked here.</i></p>	<p>participants this will have led to some significant changes.</p> <p>If it is clear from these early questions that there have been a number of changes, this is an opportunity for you to plan the interview to spend more time post-trial experience section. You will then need to take this into account when considering how long to spend on the other sections.</p> <p>You should not ask all the important questions highlighted as needing to be followed up in phase at the beginning of this interview. If we ask too many important or challenging questions at the beginning it is very likely that they won't answer them and the opportunity may be lost. Instead such questions need to be integrated into the relevant sections throughout the interview.</p>
Key areas of investigation	Rationale	Themes	Tasks	Example questions	Explanatory notes
Advice on non-adherence/ adherence slippages	This is the first in a series of questions around certain aspects of the HIV experience that we will explore using the hypothetical boy/ girl scenario.	<p>-Support in instances of non-adherence</p> <p>-Opportunities available, through offering child-appropriate support, to</p>	Explain how last time spoke about a boy/ girl like you who was having trouble taking drugs as they should. Imagine that he wasn't telling anyone about not taking his drugs, what	So we're going to go back to the girl/ boy that we spoke about last time, who was encountering adherence problems. This time I'd really like to get your opinion on what could help them.	Last time we focused on whether they could speak to their carer and/ or the healthcare worker. This time we are going to ask if there is anyone they could talk to. In many cases there

	<p>Two key things: As far as possible we want to use these hypothetical scenarios to encourage them to talk about themselves. We are only using the hypothetical scenarios as a way into them feeling more comfortable to talking about themselves. So as soon as this is achieved keep going with the 'you' rather than 'them'.</p> <p>We are interested to learn whether they think that any of these responses are gendered, i.e. differently experienced/ felt between boys and girls. Therefore the default hypothetical scenario to use if the participant is a boy is the boy (and a girl if it is a girl). However where appropriate we would like you to follow this with the other picture to explore whether this would be different in anyway if it wasn't a boy but a girl and vice versa.</p>	<p>improve communication around non-adherence</p> <p>-Role, relevance and influence of food availability in adherence, as well as the sources of information about the importance of food in facilitating adherence</p> <p>-Whether the above are influenced by gender</p>	<p>advice can you give him about who they could talk to?</p> <p>Second part of this exercise is if they can't think of someone is to use blank person (see explanatory notes) to construct the characteristics of what an ideal or accessible person might be like.</p>	<p>So if this boy/ girl was going through problems taking his drugs, who could he talk to?</p> <p>If you can't think of anyone, then imagine a person they would be able to talk to. What would they be like? How would they respond to the child? Explore differences in gender. Do you think that this would be any different if this was a girl/ boy?</p> <p>Do you think it would make any difference if they were taking the drugs with food? Why? How did you come to learn that taking drugs with food made a difference?</p>	<p>may be no one that the child feels that they can talk to.</p> <p>In such cases we would like them to imagine what the characteristics of the person would be if they could create someone they would feel comfortable to be.</p> <p>You would then use the cloud cards and fill in each card with a characteristic.</p> <p>Tip: It may be useful to have prepared some in advance, e.g. kindness, not get angry with me, try to understand why, come up with solutions. You should only bring these out if the child is not able to come up with any themselves.</p>
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Key areas of investigation	Rationale	Themes	Tasks	Example questions	Explanatory notes
Advice on disclosure	It's important that as part of your preparation for the interview that you familiarise yourself again with their disclosure story (and where available their carer's story of their disclosure). Importantly this exercise is not to get them to repeat their disclosure story but instead to explore how they would like to be disclosed to and the lessons that can be learnt from their disclosure experience.	-Child-led advice on better ways to disclose to children -Lessons learnt from their disclosure experience	Use the same scenario.	How would this person like to be told that they have HIV? How does this compare with the way that you were told about your HIV status? What do you think would be the key things that they would want to be told when they were disclosed to? (e.g. <i>transmission</i>) Afterwards it seems that for most children HIV is not really discussed again, what do you think about that? Would you like to have had the opportunity to talk about it? What would you like to have spoken about?	As always with the scenario we are using it as a device to encourage children to talk about their own experiences. So wherever possible this is where the direction of the conversation should be heading. Emphasise that this is really valuable topic for us to learn about from them.
Key areas of investigation	Rationale	Themes	Tasks	Example questions	Explanatory notes
Thoughts and questions about HIV	Discussion of their thoughts about HIV and the questions that they have should lead on naturally from the previous topic about HIV talk. Having heard from the carers that HIV talk is discouraged in the home because they are concerned that it is identifying but that it might also remind the child of their HIV status.	-HIV talk in the home, their preferences and opportunities -HIV thoughts: what are they, what do they do with them and how did they learn to do this -Questions that they have about HIV -For those living with non-biological carers exploring how their parents are spoken about within the household.	For the discussion about the HIV questions if the scenario is working well continue to use it. If the young person is talking in the first person about their own experiences stick with asking them direct questions. In using this task it is important to use it flexibly and to make sure you are using it, and where necessary adapting it, in the	We've spoke a bit about how much HIV is spoken about in the home, when people aren't speaking about it do you think about HIV? What thoughts do you think that he/ she (hypothetical) might have about HIV, if we can imagine we can see inside his head? In what circumstances do these come up? <i>Personalise this to draw on what they have already told you.</i>	Personalise you questions so that they are appropriate for the young person and your questions draw on and develop from what they have already told you. Adapt your use of the scenario to try and encourage them to talk and reveal as much as possible.

	<p>We want to hear from the children whether they do think about HIV, despite the silence.</p> <p>Secondly we have learnt from the carers that there is an expectation that if children had questions about HIV they would ask them. Therefore carers wait for the child to initiate conversations about HIV. It seems unlikely that children feel able to do this. We want to encourage them to talk to us about the questions that they may have about HIV, what they would like to know, and then to discuss why they might not feel comfortable asking them. Finally we want to find out from them who they think would be the best sources of information.</p>	<p>-Appropriate information sources about HIV- where would they like to get to get the answers to their questions</p> <p>-Their knowledge and questions they may have around sex, prevention and transmission as well as the possibility of having a healthy family.</p>	<p>most appropriate way for the young person in front of you.</p>	<p>What do you do with them? Why? How did you come to learn to do this?</p> <p>Going back to the boy/girl once they have been told their HIV status what questions do you think they would have about it? What questions might they have after having known for a few years, like you have? Would this be any different if they were a girl/ boy? <i>Reverse to explore gender differences.</i></p> <p>If you could have the power to ask questions, but silently and without any knowing that you are asking them, what would they be?</p> <p>What difference do you think it would make to this boy/girl if he felt that he could just talk freely?</p> <p>(For those living with non-biological carers) do you ever talk about your parent/s with anyone? Are they spoken about by your carer or others in the household? In what way? What do you think about that?</p> <p>Would this boy/ girl have any questions about whether they would be able to have children in the future who are not HIV positive? Would they have any other questions about HIV prevention and sex that they would like to know about? How would they like to get that info?</p>	<p>Asking about thoughts that they don't voice and questions that they don't feel they can ask is very challenging and reflects the ongoing silence which circulates around HIV. Therefore as they tend not to feel comfortable to say anything about their thoughts, we can instead ask what we would see if we could read his/ her mind might be a good way of trying to get to this. The parental question relates to what is coming up from the non-biological carers' interviews where it has been suggested that the child's parents are talked about in warning terms about what happens if you don't adhere or don't practice safe sex. This may be significant in shaping the way that these children think about HIV and themselves, especially given it is one of the rare things that is said. However as we cannot be asked about it directly, this may be a more appropriate place to ask.</p> <p>It may be that the scenario is particularly helpful in approaching any questions that they might have about sex, HIV transmission and</p>
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Key areas of investigation	Rationale	Themes	Tasks	Example questions	Explanatory notes
<p>Post-trial experience (including reflections on current support) and current assessment of health and social well-being.</p>	<p>This section will focus on their experiences post-trial.</p> <p>This section will also involve exploring the support that they have now that the trial has finished (using people cards).</p> <p>It will also involve asking them to describe how they think about their life now in terms of their physical health, social situations and access to support in comparison to a few years ago (emotion cards). This will help frame the discussion around current and future concerns and expectations, using the timeline.</p>	<ul style="list-style-type: none"> -Post trial experience -Key messages from their trial experience -Support available to them now, post-trial and also exploring changes since phase 1 -Comparison of how they feel physically, socially and in terms of support now and to a few years ago. 	<p>Post-trial experience does not involve any tasks.</p> <p>To explore the support available to them now remind them that in the first interview we used the people cards to discuss who was in their life. We'd like to use them now to discuss who they feel supports them (and how). So when they mention someone write it down (they can do this and decorate/ colour in the people cards as they would like).</p> <p>Ask about whether this has changed at all. Anyone new or who isn't any longer supporting them. This is an opportunity to explore how they are managing now that they are not seeing the healthcare workers etc in the trial, but is also a device to consider how fluid their support networks have been over the past couple of years (and why).</p> <p>Finally we would like to use the emotion cards to encourage them to describe how they are feeling about their physical state, their social situations and their access to support.</p>	<p>How has it been leaving the ARROW trial? Tell me about your most recent visit to your new clinic?</p> <p>Now that the ARROW trial is over and as you are helping us represent young people's voice and views, would there be anything that you would like to be different if you were in another trial? Or anything that you would like to have been done differently in this trial?</p> <p>What would you like the healthcare workers to understand about what it is like living with HIV at home?</p> <p>What would you like your treatment to look like in the future?</p> <p>Using the people cards, who are the people who are supporting you in your life right now? <i>Prompt for those outside of their household too.</i> In what way (going through individuals)? Has this changed over the last couple of years (how and why)? Has it changed at all since you have left the trial?</p>	<p>prevention and having children.</p> <p>Post-trial experience- the early part of the interview is deliberately designed to give you an idea of how significant a shift the change in clinics has been. You should tailor your questions and the time you spend on this section dependent on what they describe at the beginning of the interview.</p> <p>In asking about the key messages we are developing on one of the key elements of this interview, which is asking for their advice and them having a say. Children may have varied answers on this- with some finding it difficult to understand and others having lots of ideas about the importance of funding etc. We will need to explore further where we can, but be aware that it might not be a useful question for all the participants.</p> <p>Support networks, ask about friends too.</p>

			<p>We'd like to try and explore each of these individually to give them the opportunity to provide different and distinct answers for each area.</p>	<p>We've spoken a lot about your feelings in these interviews. Can you tell me how you are feeling about your physical health right now? (using emotion cards as appropriate). How about how you are feeling about how you are getting on with people (<i>Personalise this in particular- for example those who have told you that they are feeling lonely/ no friends at school</i>)?</p> <p>Do you feel that you would like any other support than what you already have? What? Why? How do you feel about what you have now?</p>	<p>When using the emotion cards the point is to encourage them to reflect on the changes in their lives and to find out why they may feel certain ways about particular aspects of their lives. As always the tasks are only there to facilitate talk and if not needed this is fine.</p>
Key areas of investigation	Rationale	Themes	Tasks	Example questions	Explanatory notes
Timeline (current experiences and concerns as well as future expectations)	<p>This is a significant part of the interview and is designed to elicit children's thoughts on their life and their future. Critically we want to explore their present and future initially without any specific reference to HIV, before then asking explicitly about their life with HIV. This is because we are interested to understand the impact and influence HIV has on growing up, rather than assuming its dominance in their lives.</p>	<ul style="list-style-type: none"> -Future aspirations. -Expectations about growing up in the future, this includes key transitional events from childhood to greater autonomy. -Thoughts and feelings about present life and the role that HIV plays. -Thoughts and expectations about living with HIV in the future. -Perceptions about how these may be influenced by gender. 	<p>This section draws heavily on the timeline.</p> <p>In advance of the interview a timeline will need to be completed for each participant. What this will involve is plotting a few (2-4) past events on a gender appropriate timeline, drawing on what you have learnt from the first two interviews. Ensure that the events are not all sad.</p> <p>This timeline needs to be explained to the participant. They will then be asked what they would like to</p>	<p>Looking at this timeline which stretches out into the future this picture represents you growing up and the past marks events that have happened to you in your life. Can you tell me if there is anything that you can remember before you got sick? What as life like for you then?</p> <p>Can you tell me what you would like your future to be like? What would you like to do when you grow up? Other than work how else would you like your life to be?</p> <p>Do you think that there would be a time in this future timeline</p>	<p>It is important that you complete some of the timelines in advance of the interview because it will demonstrate to the participant that you have been listening closely to what they have told you in the past and they you have remembered. This should serve to consolidate their trust in the study and the researcher.</p> <p>In the cloud exercise whilst we do not want to skew them to only discussing negatives, we do want to make sure that we are</p>

	<p>This section will ask them to imagine certain scenarios and describe when they think these events may happen, if they think that they will.</p> <p>We will then ask them to describe the thoughts and feelings they have about their current lives (thought cloud exercise). This can be positive and/ or negative and so the question needs to be asked in a relatively neutral way to encourage both. This will be repeated with their expectations of future.</p>		<p>happen in their life in the future.</p> <p>This will particularly focus on their aspirations. You may know a good deal about this already so draw on this knowledge in generating appropriate prompts and probes. The order of questions will start with those which are focused on the long term future and move towards questions relating to their more immediate future (disclosure to others, increasing sole responsibility for adherence and household role). Each answer can be plotted on the timeline.</p> <p>The next part of the task is to then ask them to imagine that each cloud represents different thoughts, ideas or concerns that they have in their heads at the moment. Together fill in these clouds with words and prompt for explanations.</p> <p>The final part of the section is to repeat the exercise but discussing the thoughts, ideas and concerns that they have about the future and what it will be like growing up with HIV. Where appropriate this can draw on some of the issues that may have been touched upon-</p>	<p>when you will disclose to others? Say your best friend? Boyfriend? (Explore why then and what circumstances would allow it).</p> <p>Do you think that there might come a time when you will be the main person responsible for reminding yourself to take drugs? <i>Personalise this question to fit with their current circumstances.</i> When and why?</p> <p>In a few years' time (depending on when they have described the events above occurring) what do you think that your role will be in the household (exploring chores, responsibilities, position etc)? Would this be different do you think if you were not a boy/ girl (fitting with ongoing theme of exploring the perceived influence of gender)?</p> <p>Can you tell me about the thoughts, ideas and any concerns you have about your life, in the present, now? It can be about anything. If needed: what about in relation to living with HIV.</p> <p>Can you tell me about what your thoughts, ideas and concerns are when you think about growing up and the future? If needed: what about in relation to living with HIV.</p>	<p>capturing their concerns and worries too. So this will need to be carefully balanced.</p> <p>We are interested in ideas around any concerns that they may have about their appearance (HIV or ART related). This may not come up and we should not prompt for it without any reason. If it does come up this should be explored further.</p>
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			such as disclosing to future partners, the health of their carers and having a family.		
Close Reflections on talking and being part of the study	<p>Although they may not have too much to say on the topic, as has been the case for the majority in phase 2, we would like to ask them how they have found being part of this study and whether it was what they expected it to be.</p> <p>A few children have spoken about how it has changed how they talk with others. We would like to explore whether the study has had any effect at all on how they think and talk about being HIV positive.</p> <p>We want to emphasise that although this is the last time we will speak to them individually we would like, if they are interested, to tell them what we have found and for them to hear about other people's experiences. As well as informing them of this we would like to find out if they are interested in finding out.</p>	<p>-Reflections on talking and being part of the study</p> <p>-Whether talking with the researcher has made any difference to how they think about and/ or talk about living with HIV</p> <p>-Opportunities for further discussion</p> <p>-Whether and how they would like to find out about what the study is doing.</p>	No task	<p>Explain coming to the end of the interview.</p> <p>How have you found being in the study over these three interviews? Has there been any difference in how you have felt in each interview? Has the study been as you expected it to be? How have you found being asked about living with HIV?</p> <p>Has talking about your experiences with me made any difference to how you think about being HIV positive? As it made any difference to how you have or might talk about it with other people?</p> <p>We've spoken a lot and as I said at the start of today's interview this has been an opportunity for us to find out from you, the expert, what it is like and what adults might be able to do better. Is there anything that you think is important if I'm going to tell people what young people are going through, that we haven't talked about?</p> <p>Would you like to hear more about what we find?</p>	<p>Emphasise your appreciation.</p> <p>Make it clear that this will be the last time, so that this is not a surprise. This should be emphasised from the start of the arrangements for this interview.</p>

Focus group discussion topic guide

<p>Preamble to set scene of focus group discussion</p>	<p>Explain that this is the last time you will be meeting them. Thank them for agreeing to participate in the study and valuable information that they shared in all the three interviews.</p> <p>Obtain consent and assent</p> <p>Explain that the purpose of focus group discussion that it is to give them what has been coming of the study and to explore more issue on the formal and informal support available to them especially support groups and other people who have been supporting them.</p> <p>The interviews will include questions on disclosure, adherence HIV knowledge and formal and informal support</p> <p>Explain how the focus group works as some maybe participating in FGDs for the first time</p> <p>Set the ground rules and allocate numbers or initials to them for easy identification when transcribing the interview</p> <p>Explain to them that you will be assigning them to smaller group to work on different tasks and you expect them to report back to the group</p>
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Key area of investigation	Rational	Theme	Example questions
<p>Open discussion to make everyone feel comfortable and relax</p>	<p>Catch up</p>		<p>Start by a game they can choose a game of their choice</p> <p>How has been the last school term and exams</p> <p>What do children normally do on Christmas holidays</p> <p>Tell them that you are now going to talk about the study they have been participating in</p>
<p>Disclosure</p>	<p>Discussion of what they thought came out from the interview</p> <p>Tell them what that trend has been and explore how they take the preliminary findings on disclosure</p>	<p>Disclosure process at home/clinic</p> <p>Disclosure as a process</p>	<p>Whom do you think the child cited as the rightful people to disclose and why</p> <p>What challenges do you think HIV positive people face when it comes to disclosing their status</p> <p>After the discussion sum up all the challenges and make them rank them according to the what they perceives to be the most difficult challenge to deal with or address and who can help them or</p> <p>What can be done to address the challenge and by who</p>

			<p>would that help to know the status of other children say in the same house or in the same class with you (have three card yes it helps, no it doesn't help and I don't know ask children to stand in the three corners)</p> <p>What do you think adults think of children who are HIV positive</p> <p>What do parents think children got HIV from Children are afraid of HIV being spread to other member why would other household members spread LNG you were afraid the your big sister would tell other why is that Some children have said it's difficult for children to tell adults what to do why is it hard</p> <p>Do you think that stigma and discrimination towards children is different from adults</p> <p>If a child discovers that he got HIV from his mother and he is angry with his mother would you agree with him for being angry Or would you disagree Or disagree with him</p>
<p>Adherence</p>	<p>On adherence we asked children about adherence experiences We used the adherence hypothetical scenarios to explore more of reasons for non-adherence Explored their own adherence experiences</p>		<p>Playing, forgetting and not being reminded were the main reasons children talked about for failing to adhere Does anybody think it's not true</p> <p>Whose responsibility is it for children to adhere well to drugs</p> <p>When do you think it becomes a child's responsibility to take drugs on their own When does it stop to be a parent's responsibility Some children said that orphans might have to look after themselves if carers are not concerned –</p> <p>Do you think they might learn to look after themselves quicker than children with parents</p> <p>Do you think being reminded of previous illness works</p> <p>Why is that some don't adhere well even when they are reminded of their previous illness</p>

			<p>Some children were reported to be having adherence problems once they were disclosed what could be the reasons for that</p> <p>What do you think you would do if you are have deep thoughts about taking drugs</p>
Key area of investigation	Rationale	Themes	Example
HIV knowledge and talk	<p>We explored what HIV information children have</p> <p>The sources of information and how HIV is talked about in different care environments</p>	<p>HIV knowledge- transmission route</p> <p>Incurable</p> <p>HIV talk</p>	<p>What do they think about the poor or lack of HIV knowledge in most children</p> <p>What can be done to address this gap</p> <p>Do you think that children who have little HIV knowledge don't want to know about HIV</p> <p>They don't care or they are not curious</p> <p>Do you want to know anything else besides perinatal infection and taking pills</p> <p>To know how long one would live for</p> <p>To know what the CD4 count means</p> <p>To know how to look after themselves and the food to eat</p> <p>Ask them to write one question they would like to know about HIV</p> <p>Whom do you think is responsible for providing this information</p> <p>In what form would they like the information to be in (put them in groups and let them write 4-5 ways in which they would want the HIV information to be delivered unto them and let them feed back to the whole group and discuss)</p> <p>When we have the actual results from this study whom do you think need to know about them and why</p> <p>What would be the best ways of disseminating the results</p>
Key area of investigation	Rationale	Themes	Example questions
Support (formal and informal support)	<p>Focuses on the forms of support available to children and what's missing and what children would require</p>	<p>Support at home/ families</p>	<p>What form of support do they need from family members and other relatives</p> <p>Do you think that children are getting the support they require if not where is the gap</p> <p>List all the forms of support children require and let them stand in what they feel is the most important form of support that HIV positive children require</p>

		Peer networks and other forms of informal support	<p>what will be the sessions like for example the first three sessions</p> <p>after they have given the choices rank get them to rank them</p> <p>What support do you think children who have not disclosed their status are missing out on from:</p> <ul style="list-style-type: none"> Friends Relatives Neighbours Teachers Church leaders
Key investigation area	Rationale	Theme	Example questions
Concluding questions	Exploring how they really feel about each care environment		<p>Ask them choose the care environments they feel they have been getting the most of support from (put all the care environments in different corners and ask children to stand where they feel)</p> <p>Ask them to revisit the forms of support they expect to find from the clinic/hospitals, school, home and ask them to rank in order of preference i.e. what are their immediate needs or those things they need fixed urgently</p>

Audio diary guidelines

After having spoken about it with the researcher you have chosen to keep an audio diary. You do not have to keep an audio diary and can change your mind at anytime.

There is one tape that you can use which will give you an hour and a half of recording over a two week period. Please remember to bring this tape with you to your next clinic visit and give it to the nurse. This will be kept safely before being collected by the researcher. Only the research team will listen to your tape. They will have listened to it before your next interview.

If you like recording your audio diary for the study and would like to record another in a few months time, this can be arranged. The researcher will give you a call to talk about whether you would like to do this.

We would like you to use the audio diary to record **your thoughts, experiences and feelings that you have about living with HIV**. As in the interviews we are interested in many different parts of your life, not just the times when you visit the clinic. Anything that you say will be interesting to us. There are no right or wrong answers or 'right' things to talk about in your diary.

Please use the audio diary as often as you like. Speak for one minute or up to an hour and a half!

Please make sure, as was discussed with the researcher, that you feel comfortable in the place and the time you are using the audio diary.

So **we are interested in anything you have to say**. Here are some ideas in case you are having problems thinking about what to say.

- What did you do today?
- Who were you with?
- Were there times when you were thinking about HIV? Were there times and places when you do not think about it at all? Tell us about the differences.
- What do you like doing? Where do you like being?
- Where are you recording your diary? Are you on your own or with other people?
- Visits to clinic
- Visits to other forms of care i.e. traditional healers, faith healers, healing crusades (if applicable)
- Adherence (feeling on taking pills, the adherence routine)

- Disclosure (your feelings towards disclosure and how it should be done)
- Support groups/ adolescent meetings
- HIV knowledge
- Future expectations

These are just ideas. You can talk about anything you would like to on the audio diary.

The recorders will be submitted to the interviewer once you feel that you have recorded all that you want to record or when the memory of the recorder is full. This should be done before the last interview so that the interviewer will have time to listen and process the data from the recorders before the next interview. Any issue that maybe interesting issue from the audio diaries will be followed up in the interviews. As with all the material collected in the study it will be confidential and anonymous.

Appendix B: Participant List

Phase 1 only				FGDs	
	Pseudonyms	Sex	Age		
1	Tinotenda	Girl	12		
2	Allleta	Girl	11		
3	Brighton	Boy	12		
4	Talent	Boy	12		
5	Lydia	Girl	11	✓	
6	Rose	Girl	11	✓	
7	Paidamoyo	Girl	13		
8	Shamiso	Girl	13		
9	Shelton	Boy	13		
10	Bernard	Boy	11		
11	Patrick	Boy	13		
All phases					Kept Audio diary
12	Charity	Girl	13		✓
13	Rudo	Girl	12	✓	✓
14	Garikai	Boy	13	✓	✓
15	Betty	Girl	12	✓	✓
16	Memory	Girl	13	✓	✓
17	Elias	Boy	11	✓	✓
18	Faith	Girl	11	✓	✓
19	Lucia	Girl	11		
20	Simbarashe	Boy	12		
21	Moses	Boy	11		
22	Kumbirayi	Boy	13	✓	✓
23	Kennedy	Boy	12	✓	✓
24	Farai	Boy	12	✓	✓
25	Sekai	Girl	12		✓
26	Grace	Girl	13	✓	✓

Appendix C: Healthcare worker topic guide

Key area of investigation	Rationale	Themes	Example questions
<p>ROLE WITHIN THE CLINIC</p>	<p>This is a warm up to encourage them to feel comfortable talking and to help situate them in the clinic and the interaction they have with children.</p> <p><i>Relatively short section.</i></p>	<p>Understanding of individual's role</p> <p>Background to function within clinic</p> <p>Interaction with children</p>	<p>Can you tell me about what you do within the clinic?</p> <p>So can you talk me through what happens when you see a child in the clinic?</p> <p>How well does this mean you are able to get to know some of the children?</p>
<p>OPPORTUNITIES AND CHALLENGES IN CARING FOR CHILDREN AT CLINIC FOR CARE</p>	<p>We are interested in exploring how everyday life influences children's capacity to live well with HIV – i.e. difficulties in taking treatment, fears and anxiety around disclosure- and therefore want to learn about how this is perceived by those delivering care in the clinic.</p> <p>We will explore specific aspects of the answer that they give to this general question in the following section of the topic guide.</p> <p>Opportunity to move from talking about their specific role into the opportunities and challenges they perceive there to be in providing satisfactory care to the children at the clinic. This will also give us information about what they prioritise.</p>	<p>Role and remit of the care that is provided at the clinic to children.</p> <p>Challenges in providing care for children living with HIV at the clinic.</p>	<p>What are some of the key things that you think children need from you when they come to the clinic to help them live well with HIV?</p> <p>What are some of the challenges for you in being able to provide this?</p> <p>We are interested in understanding how everyday life- including what happens outside of the clinic- influences children's capacity to live with HIV. What are some of the challenges that you think encounter in living well with HIV?</p> <p>How can you tell if someone is living and coping well with HIV?</p>

Key area of investigation	Rationale	Themes	Example questions
ADHERENCE	<p>To understand what healthcare workers consider the extent of adherence problems amongst children aged 11-13 years old within this trial to be. We also want to explore, from their perspective, what are the causes of the problems in being adherent.</p>	<p>Common reasons for adherence problems</p>	<p>Within the age group that we are working with, 11-13 year olds, how adherent do they tend to be?</p> <p>What are some of the most common reasons in why children struggle to take their drugs as they are prescribed to everyday?</p> <p>How do you identify whether a child is having a problem with adherence? (<i>Our interest is whether they use social as well clinical diagnostics.</i>)</p> <ul style="list-style-type: none"> • What do you do? <i>We will return to ideas around discipline, monitoring and action (as we know that such action may be interpreted as being reprimanded by children).</i> <p><i>Prompts for exploring challenges with this particular age group:</i></p> <ul style="list-style-type: none"> • Who tends to be responsible for reminding the child to take their drugs? • Is it common for there to be a shift in responsibility for adherence (from carer to child)? • What do you think can be the influence of this transition towards increasing autonomy on a child's adherence?
	<p>Interest in ways in which adherence problems are approached, discussed and addressed within the clinic.</p>	<p>Issues of discipline- poor adherence perceived as a weakness to be addressed?</p> <p>Whether and to what extent is adherence constructed as a failing of the child, the carer, the household and others.</p>	<p>There are a few cases we have heard about where children have in the past thrown out their treatment, can you tell me a bit more about some of those cases?</p> <p><i>Example prompts:</i></p> <ul style="list-style-type: none"> • What do you think prompts/ causes it? • How did you find out about it? • Can you give me an example of how you would address this with the child? • How would the conversation go? (<i>explore what they tell the children- children commonly report that they are told they will die if they do not take their treatment exactly as prescribed.</i>) <p>What would you do if a child tells you that they were late with their treatment? <i>Use a scenario or a case that they have already mentioned:</i></p> <p>If they had:</p> <ul style="list-style-type: none"> • Skipped a day or two? • Appears to have been throwing out their drugs?

		Some children have described being introduced to someone who is suffering with complications due to adherence problems to encourage them to take their own drugs. Is it used in the clinic and what do you think of this approach?
	How 'naturalised' are adherence problems considered to be amongst this age group.	<p>Would you expect this age group to encounter problems? Why?</p> <p>What do you think is good enough adherence? (<i>i.e. how often is it acceptable that they miss?</i>)</p> <p>What are the effects of missing treatment? (<i>Children report that even if they miss it once or twice they cannot sleep, skin itches and they feel the heat acutely.</i>)</p>
Phase 1 interviews with children imply that this is dealt with in a disciplining way and also suggest that participants may stick to a script of good adherence, even if their own adherence is erratic or poor. To what extent do healthcare workers engage with these issues?	Adherence talk- open talk, scripted talk, negotiated talk (one slippage= many slippages) and silence.	<p>When you ask about them taking their drugs do you feel that most of the time children are telling you the truth? (<i>incorporate information that they have already told you about their role or how they approach discussions about adherence into your phrasing of this question</i>)</p> <p><i>Example prompts:</i></p> <ul style="list-style-type: none"> • Why do you think that? • Are there any times when you feel like a child might be holding back from telling you about problems they are having taking their drugs? • Do you think that carers may know of adherence problems but not tell you? Why might that be? <i>Explore the examples given by a few participants where carers have discouraged children from telling the counsellor about them throwing drugs away or examples that they have themselves given.</i> <p>If you find out about adherence problems who do you tell about this? <i>This is because we are interested to understand what gets done with this information. Some children have told us that this can be referred to doctors and to carers- this may prompt concerns around confidentiality and possibly their reticence to talk openly with healthcare workers.</i></p>

	<p>When I spoke to the pharmacist at the MRC Entebbe site I was told that none of the children were on drug combinations which needed to be taken with food. Yet it is a commonly reported problem from children. We would like to know why, whether service providers are aware and recognise this problem, inform how children associate drugs with nausea if this is not meant to be a side effect of the drugs.</p>	<p>Side effects of taking drugs- nausea etc.</p>	<p>A number of children that we have spoken with report feeling nauseous once they have taken their treatment, why would they be feeling this do you think?</p> <p>Are any of them likely to be on treatment that needs to be consumed with food/ not on an empty stomach?</p> <p>Do the children discuss this with you? What strategies do you advise to deal with this? Eg. Warm water?</p> <p>How does the clinic manage the issue of food insecurity?</p> <ul style="list-style-type: none"> • <i>(If an intervention is available)</i> Do you know whether this will continue after the trial?
	<p>A few children have told us that they have improved adherence since having been disclosed to.</p> <p>Linking question from adherence to disclosure.</p>	<p>Influence of disclosure on adherence.</p>	<p>What influence do you think knowing their status has on a child's adherence? <i>Ask for examples.</i></p> <p>Do you think it makes any difference to a child's adherence if parent/s are taking ART on the child's management of their drugs? Adapting to HIV?</p>
Key area of investigation	Rationale	Themes	Example questions
DISCLOSURE	<p>The YPLHIV data so far suggests that there is a great variety in how they are disclosed to between and within the clinic sites. The existing literature and our data suggests that how disclosure is done appears to influence how YP approach the management of their HIV.</p> <p>Some children appear to consider that because no one has directly told them that they are HIV positive that they have not been disclosed to and do not know why they are taking the drugs, despite deductive disclosure having taken place.</p>	<p>Disclosure as a one-off or a process.</p> <p>Use of language and words in describing and explaining HIV.</p> <p>Ambiguity around what 'disclosure' is.</p> <p>Extent of individual discussion.</p>	<p>Can you tell me about how a child is disclosed to here? <i>Prompt for specific examples in talking through disclosure practices and strategies, including use of specific language and phrasing.</i></p> <p>Do you have a preference for whether disclosure is done by healthcare worker, by carer but assisted or by carer alone? Why? <i>Specific examples.</i></p> <p>There have been a few cases when children have been reported to have been disclosed to but in interviews the child implies or says directly that they do not know why they take the drugs and/ or that they have not been disclosed to. Can you think of why this might be the case?</p>

	<p>Despite disclosure being constructed as a process, children's accounts suggest that this is done through a one off discussion, which is commonly not brought up again. We would like to understand how healthcare workers consider this process is done and how HIV is talked about when disclosure is being done and afterwards.</p>	<p>How is HIV 'talked' about?</p> <p>HIV talk or HIV talked about only through drugs.</p> <p>Opportunities for talking explicitly about HIV- available, considered necessary (?) and with whom?</p>	<p>Once disclosure has occurred how is HIV talked about with the child in the clinic after this? In what circumstances?</p> <p>What aspects of HIV do you talk about with the child within the clinic? Aspects you rarely do- why not?</p> <p>Do you think that the talk done about HIV with the children within the clinic is adequate for children?</p> <p>Where else do you think they can talk about HIV?</p> <p>Do you think that young people talk with their carers about HIV? With anyone?</p> <p>Do they talk about it with other YLPHIV? How do/ have support groups engaged with talking about HIV?</p>
	<p>To investigate how HIV is constructed through the disclosure process and how disclosing to others is discussed.</p>	<p>Learning to fear HIV.</p> <p>HIV= secret. Disclosure= risk.</p>	<p>Many of the children that we have spoken with are frightened in case anyone finds out their secret that they are HIV positive, how do you think that they come to learn this? <i>If this has not already been addressed prompt for further information about how disclosure to others is approached and discussed by healthcare workers in the clinic.</i></p> <p>What advice are children given to explain absences at school etc for clinic appointments? <i>Explore how children come to learn to substitute HIV for fever and whether this comes from the clinic.</i></p>
	<p>Cases of disclosure to others.</p>	<p>Concerns around children disclosing to others- but little experience of it coming out of children's accounts.</p> <p>Deductive disclosure</p>	<p>Have you come across children telling other people?</p> <p><i>Example prompts:</i></p> <ul style="list-style-type: none"> • Can you give me an example? • What were the consequences? • How have you managed this? <p>(For home care visitors) When you visit people's homes on behalf of the clinic how do you manage disclosure?</p>

	Rationale	Themes	Example questions
HIV KNOWLEDGE	In the phase 1 and early phase 2 interviews we have found that the majority of YPLHIV have low knowledge about HIV. This section is to investigate whether this is what healthcare workers think and their opinions as to whether HIV knowledge is appropriate for children of this age and why.	<p>Extent of HIV talk</p> <p>Knowledge about drugs and transmission.</p> <p>Appropriateness of HIV knowledge amongst this age group.</p> <p>Talk and knowledge about sex and relationships.</p>	<p>How much do you think most children of this age know about HIV?</p> <ul style="list-style-type: none"> • What are the exceptions and why? <p>Where do you think that they get their knowledge about HIV from?</p> <p>Do they have questions about HIV?</p> <ul style="list-style-type: none"> • What are they? • Would you expect more questions? • In cases where counsellors have been asked questions, after the interview, what has been their reaction to this? <p>Some children report having changed drugs. When a child has their drugs told what do they get told? <i>Ask for specific examples.</i></p> <p>What do you think most children aged 11-13 years old know about HIV?</p> <ul style="list-style-type: none"> • Do you discuss perinatal transmission with them? • How is this dealt with? • How do they come to know? • Do you think that it is significant that they understand this? <p>When do you (or other healthcare workers) start talking about relationships and sex with children in the clinic?</p> <ul style="list-style-type: none"> • Can you tell me more about this? • Do you think that this is appropriate (timing, approach, attitude)? • Do you think that there is anything that needs to be improved in approaching this issue?
EXPECTATIONS ABOUT THEIR GENERAL HEALTH AND FUTURE	To understand how they consider the health and strength of these children compared to others. Eg. do they consider children to be weaker and need to be exempt from chores? What are the effects on the children?	<p>Extent of YPLHIV's health.</p> <p>Limits on care in supporting YPLHIV growing up well with HIV that the clinic can provide.</p>	<p>In your opinion what are the things that a child living with ART are not as able to do as other young people their age who are HIV negative?</p> <p>From your experience do you think that there are any challenges that children might have to face in growing up with HIV and adhering to treatment, which are not addressed or considered in the HIV clinic?</p> <p>A few children have been described by clinic staff as retarded. What do you think that means? Do you think cognitive impairment is a significant issue affecting this group?</p>

<p>EXIT FROM ARROW TRIAL</p>	<p>Perception of effects of leaving trial. Particularity of being in the trial rather than in general clinics.</p>		<p>Do you think that there will be any noticeable changes in young people's health and management of HIV once they have left the ARROW trial? <i>For example, exploring any concerns around access to government clinics (adherence etc) if not receiving transport assistance- and what effects this will have.</i></p> <p>Make any difference to child being in the trial rather than in a public clinic? Effects on them? How do you think this will influence the children- <i>talk through particular cases?</i></p> <p>If you had a child who was HIV positive would you have wanted them to have participated in this trial?</p>
<p>EXPERIENCE OF WORKING IN TRIAL</p>	<p>Healthcare workers' perspectives on working in a trial- emphasis on research and/ or care?</p> <p>This is to connect up with other research on trial experience.</p>		<p>What do you think the contribution of the trial has been? <i>(This is a deliberately broad question, as we are interested in whether they talk about this being for the children, HIV science etc).</i></p> <p>What do you think that the future of paediatric HIV care is in this country?</p>

Appendix D: Carer topic guide

Key area of investigation	Rationale	Themes	Example questions	Explanatory notes
<p>Household dynamics</p> <p>Care needs-household circumstances/challenges</p>	<p>Introductory questions to encourage them to discuss and contextualise the household in which they live with X and what their everyday life is like in terms of 'caring' for X and meeting the needs of the household.</p> <p>This will give an indication in how the context which you are familiar with from the YP interview is described by the carer. Also give an idea of their priorities.</p> <p>Also start to explore X's needs, as well as the household's, and the challenges they may encounter in meeting these.</p>	<ul style="list-style-type: none"> Household structure Biological relationship to young person Household stability, if possible to gauge. Status of others within the household. Other adults or older children within the house and their role and contribution. 	<p>Can you tell me a bit about your family and the household that you live in with the child you care for?</p> <p>How long have you lived here? Have any of these people moved in recently?</p> <p>Is X the only one taking ART in the household?</p>	<p><i>Deliberately not start with HIV or the clinic. We want to understand HIV, and their treatment needs, within the context of everyday life. This beginning is to encourage them to talk in a more informal way to and to emphasise that the interview is not for monitoring purposes like previous home visits may have been.</i></p> <p><i>We're looking for information about other adults, and older children, within the household and encouraging them to reflect on their role so that we are able to bring this up later in the interview in relation to whether they are aware of the child's HIV status, their role in adherence support and any discrimination or mistreatment.</i></p> <p><i>When asking about whether anyone else is HIV positive within the household, it may be worthwhile emphasising the confidentiality of the interview.</i></p>
<p>Non-biological carer (if applicable)</p>	<p>To explore the relationship between the carer and the child, if they are not a biological parent and to explore how they came to be their carer. This should lead to discussions around how the carer perceives this responsibility, for example whether it is considered a burden, and why they are in this situation.</p>	<ul style="list-style-type: none"> Relationship to child Attitude towards this responsibility of caring for the child, particularly in comparison with other children in the household 	<p>Please can you tell the story of how they came to live with you?</p> <p>Can you tell me about their biological mother/ father and the circumstances of their illness and death?</p> <p>What have you told them (the child) about their parents?</p>	<p><i>We'd like such conversations around the 'burden' of care to come up 'naturally' without prompting.</i></p>

		<ul style="list-style-type: none"> Explanation given to child, if any, about their role, what happened to the child's parents 	<p>What is it like caring for X? Is it in anyway different from the way that you feel or treat the other children in your household (such as their own children)?</p>	<p><i>For some carers this may be a complicated situation and as far as possible you will need to not reveal what you have learnt from either the clinic or the child, but instead be led (and move the conversation where possible) by the carer themselves.</i></p>
Disclosure	<p>We have heard from both young people and healthcare workers how they think disclosure has been done. We'd like to understand how carers report the disclosure experience.</p>	<ul style="list-style-type: none"> Disclosure experience Is it considered a process by the carer? Extent of disclosure- what is 'full' disclosure? Attitudes towards and their role in explaining perinatal transmission Other's knowledge of child's HIV status and effect Child's knowledge of other's HIV status within the household and effect 	<p>Can you tell me about how X came to know about their HIV status? What prompted this (i.e. them telling the child)?</p> <p>Can you explain to me how you went about this? Did you discuss it with anyone beforehand (i.e. counsellor)? How did you feel about it beforehand? Afterwards? What was their reaction at the time? How do you think that they feel about living with HIV now?</p> <p>What did you tell them (including what information about HIV)? Do you feel that that is all they need to know? Whose responsibility would it be to tell X anymore?</p> <p>What are your thoughts about whether how they contracted HIV should be explained? By whom, how and why?</p> <p>How long do they think that they will be taking their drugs for?</p> <p>Have you spoken about HIV since? In what way? Can you give me an example (way of exploring disclosure as a process)?</p> <p>How do you think HIV should be talked about with children (<i>could revisit in HIV talk section</i>)?</p>	<p><i>It's important that as far as possible the experience of disclosure is reported in the carer's own words, with as little guiding as possible around the concept of disclosure being a process. This will enable to us to better evaluate how it is considered by the carer without them being encouraged to use the correct language or ideas (which may shape or 'police' what they are saying to be what they think we want to hear).</i></p> <p><i>This is a particularly rich section and so many prompts will be needed to unpack their rationale for certain actions.</i></p> <p><i>We also want to get data on how much the child's reactions, wishes are taken into account and how much attention is paid to this.</i></p>

			<p>Having gone through this do you have any advice for carers disclosing to children? Is there anything that you would like to have known or better appreciated?</p> <p>Who else knows about X's HIV status? Has that made any difference? How did they find out? (Why did you tell them?) Do you know what X's (the child's) feelings about this were?</p> <p>What is your attitude about X telling people? Have you given him any guidance on whether he should disclose to others?</p>	
Adherence	<p>Similarly to the experience of disclosure we have heard how young people and healthcare workers characterise adherence, the circumstances which support it and the challenges to maintaining good adherence. We now want to hear about this from the perspective of the carer and what they think their role and responsibility is and about their specific experience in supporting, monitoring and communicating about adherence.</p>	<ul style="list-style-type: none"> • Treatment taking routines • Characterisation of child's adherence • Circumstances which support good adherence • Perceived challenges to child's adherence • Examples of adherence problems- how find out about them, how manage them and whether the clinic was involved. • Explore circumstances of how autonomously the child takes their treatment • The role of others in the household in supporting or hindering adherence • Opinion about why this age group may encounter adherence problems 	<p>Can you tell me about how X has found taking drugs?</p> <p>Has it changed over time? Why? What have been the circumstances which affected this do you think?</p> <p>Can you tell me about what role you play in X taking his drugs? Has this changed in any way since X began? Do you imagine it will change over the next couple of years, for example when X is 15 years old?</p> <p>You mentioned that Y knows, do they play any role in X taking his drugs? / You mentioned that W & Z don't know about his status, how does it work with X taking his drugs if they are in the same household?</p> <p>When there have been adherence problems, how have you found about these? What happened (i.e. what did they do)? Was the clinic involved in any</p>	<p><i>One of the areas we are particularly interested in is communication about adherence, both between the child and the carer but also between the carer and the clinic. A number of the healthcare worker interviews have indicated that it is the carers who are dishonest about adherence at the clinic.</i></p> <p><i>Pick up on any opportunity to explore how play may disrupt adherence.</i></p> <p><i>Remember those carers who told you prior to the phase 1 or 2 interviews about their children previous adherence behaviour- rather than disclosing what the child has told you.</i></p>

			<p>way (why not?)? What was the reaction of the clinic? What did you think about that?</p> <p>Do you have any advice for other carers supporting children living with HIV to adhere well/ to overcome adherence problems?</p>	
Adherence- those carers also taking ART	<p>For those carers who tell us they are also taking ART we want to explore how treatment taking is done, the extent of awareness the children are perceived to have as to why the carers (and others in the household) are taking ART and their opinions on what effects this may have in supporting adherence.</p>	<ul style="list-style-type: none"> • Treatment routine taking – examples of shared routines? • Extent to which the child knows about them also taking ART, as well as the reasons for them to be taking treatment. • Treatment support through shared ART • Talking about ART and adherence • Circumstances which support adherence 	<p>You mentioned that you are taking ART as well, can you tell me about X's treatment taking routine (i.e. does it coincide with yours)?</p> <p>Is X aware that you also take treatment? How did that come about?</p> <p>If you take treatment together, do you think it makes any difference to their adherence? And to yours?</p> <p>Do you talk about ART with X? In what way/ what do you talk about? Do you talk about adherence problems – in what way?</p> <p>How do you find taking drugs every day? Do you ever discuss this experience with X?</p>	<p><i>To be combined with above themes and questions, should the carer also be taking ART.</i></p>
HIV talk- household	<p>We know that in general there is very little discussion of HIV within the home. What is discussed appears to be limited to talk/ reminders about drug taking. We want to explore whether and in what circumstances HIV is discussed within the home with the child and why carers tend to not discuss HIV.</p>	<ul style="list-style-type: none"> • Extent and focus of HIV talk within the household • Circumstances which influence whether HIV is spoken about (household composition, fear of inadvertent wider disclosure, discomfort with questions, protection of carer's status). 	<p>Apart from the moment of disclosure how have you spoken about HIV with X?</p> <p>Apart from talk about ART (reminders) do you speak with X about HIV in any other way? How when? Why?</p> <p>How do you think that HIV should be talked about?</p> <p>How do you feel about HIV being spoken about in the household?</p>	<p><i>This is to explore whether and how HIV is talked about. Although our focus is primarily on talk within the household, we are also interested in learning whether and in what ways carers may be aware of HIV talk and its effects on the child in other care environments- and how this is supported or whether the child needs to</i></p>

	<p>This links with the HIV disclosure section and may work best to follow that section, but it may also be an opportunity to probe further the answers given to the HIV disclosure questions when a carer might state that they have spoken about HIV more than once (HIV is a process) but also say that HIV is not discussed with the child. We would also want, where possible, to encourage them to reflect upon what the impact may be on the child of not talking about HIV.</p> <p>For the exceptional cases where HIV is talked about relatively openly within the household, we want to take this opportunity to explore what enables this to happen (relational and contextual circumstances) and to capture their opinions on what the effects of this more open talk is. We are particularly interested in understanding more about how space and time is managed within the household to find and to manage opportunities to talk about HIV.</p>	<ul style="list-style-type: none"> • Perceptions of the effects of talking or not talking about HIV on the child and their understanding of what it means to live with HIV (link back to disclosure section). • Support groups- attendance (reasons for attending or not) and perceived effects. • General sources of support 	<p>Do you know if X talks about HIV with anyone/ anywhere else? How do you feel about that?</p> <p>What about at school/ community/ Church (whichever relevant for participant) do you think that HIV is talked about there where X can hear?</p> <p>Do you think that X should talk about his HIV?</p> <p>Do you think it matters whether X speaks about HIV with you? Has X ever attended any support groups? Why/ not? Have you noticed any difference through their attendance- what?</p> <p>What do you think supports X? What helps you?</p>	<p><i>manage the situation silently on their own.</i></p>
<p>Expectations of child's current/ future capacity</p>	<p>Opinions and expectations about current capacity of child living with HIV and their future. We are interested to explore how the carer accounts for any restrictions on their capacity. Are they based in what the child has said/ feels,</p>	<ul style="list-style-type: none"> • Perceptions about current physical and intellectual capacity of the child currently? • Expectations of the effects of HIV in future? 	<p>What do you think it means to grow up with HIV? Do you think this is anyway different to living with HIV (and contracting it) as an adult? Why?</p>	<p><i>In cases where the child has reported being verbally abused by their carer, especially about not having long to live etc, this needs to be handled delicately so as not to risk disclosure but also to try to explore whether</i></p>

	<p>advice given by the clinic or the perceived needs of the carer. How much are these ideas coming from the carer?</p> <p>Some literature suggests that carers looking after children living with HVI will be more reluctant to pay their school fees etc prioritising other HIV negative children. This topic is an opportunity to explore how the child is perceived by the carer and the influence of the child's HIV status on their perceptions.</p>	<ul style="list-style-type: none"> • Comparison with other children in the household, for example those who are growing up in similar social conditions but are HIV negative. • Carer's awareness and engagement with X's perceptions of the future? • Carer's needs in supporting children living with HIV. 	<p>Do you notice if X is affected by HIV in anyway? <i>This may require probes to move beyond just physical scars etc.</i></p> <p>Do you expect that X will be affected by HIV in anyway?</p> <p>What do you think that X's expectations of the future are, <i>i.e. does the carer know if the child thinks that they will have a family etc?</i></p> <p>Do you think that there are any restrictions of what X can do? <i>Current- and future-Eg Household chore, schooling, long terms futures?</i></p> <p>Is this in anyway different from the other children in the household?</p> <p>What support do you think children living with HIV need- outside of the clinic?</p> <p>What helps carers support children living with HIV? What would you need?</p>	<p><i>and how this is accounted for by the carer.</i></p> <p><i>We are also interested to explore how much the carer engages with the child's perceptions of the future.</i></p>
<p>Arrow-experience and post-trial</p>	<p>Again this is an opportunity to understand how the trial is perceived by carers and how they are experiencing the exit from ARROW.</p> <p>This may be particularly important given that travel expenses now are more likely to fall to the carer, not the clinic. We want to know whether this is likely to have any effect on the child's access to care and how this is accounted for and perceived by the carer, for example it may be that certain</p>	<ul style="list-style-type: none"> • Decision making process (if applicable) in the child participating in the trial • Reflections on the experience of participating in ARROW as a clinical trial. • Effects on X, if noticed any, on participating in qualitative component of the study. 	<p>Now that the trial has finished, can you tell me how the child came to participate in the trial?</p> <p>Were you involved in this decision? Can you explain why you chose for them to participate?</p> <p>How has the experience been for you as their carer? And for X, do you think?</p> <p>Would you allow them to participate again? Why? Any advice to healthcare workers or those designing similar trials?</p>	<p><i>It may be that carers misinterpret the role of the social science study or that they consider that these questions are an opportunity to get some concrete help. These questions, and the interview in general, therefore need to be handled carefully to minimise and preempt any confusion or heightened expectations about what this study may be able to provide for these individuals.</i></p>

	<p>opportunities are now lost, such as nutritional support, which benefitted the whole household of that within this context they discuss the increased burden the child now poses.</p>	<ul style="list-style-type: none"> • Post-trial experience, including implications on X's health and the experience of caring for him now that they have joined the mainstream care system 	<p><i>I.e. around how to meet the needs of children and carers.</i></p> <p>How has it been since X was exited from the trial? Effects for you? <i>Eg shifts in access to healthcare which is not HIV specific, but was dealt with at the ARROW clinic.</i></p> <p>Do you have any concerns about the future?</p>	
<p>Finish by a) if not already covered, asking for advice that they would give to other carers – from what they have learnt from their own experience and b) what they would like healthcare workers to know about how best to engage with i) carers and ii) children.</p>				

Appendix E: Publications and conference presentations related to case study

<p>Mupambireyi, Z., Bernays, S., Bwakura-Dangarembizi, M., Cowan, F. M. (2014), "I don't feel shy because I will be among others who are just like me..." The role of support groups for children perinatally infected with HIV in Zimbabwe. <i>Child Youth Services Review</i>. 45: 106-113</p>
<p>Mupambireyi, Z., Bernays, S., Cowan, F. Complexities around friendship and HIV status disclosure among HIV perinatally infected children in Zimbabwe: Results from a longitudinal qualitative study. The 3rd Structural Drivers of HIV conference. Cape Town South Africa, 5-6 December 2013</p>
<p><u>Mupambireyi Z.</u>, Bernays S., Mutsa Bwakura-Dangarembizi., Frances M Cowan. An exploration of the structural barriers to support group attendance among HIV infected young children participating in the ARROW clinical trial, ICASA, Poster presentation, ICASA, Harare, Zimbabwe, 29 November to 4th of December 2015</p>
<p>Bernays, S., Seeley, J., Rhodes, T., Mupambireyi, Z. (2015) What am I 'living' with? Growing up with HIV in Uganda and Zimbabwe. <i>Sociology of Health and Illness</i>. 37(2): 270-283.</p>