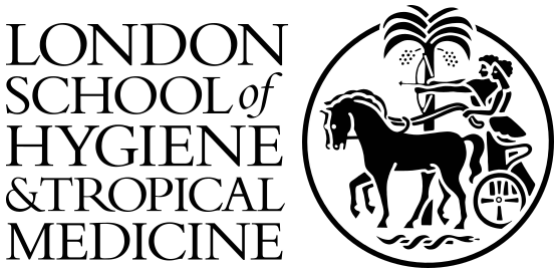

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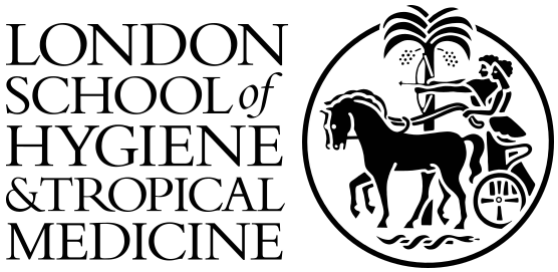

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An ethnographic study of the everyday lives of young women living with HIV in Zambia

CONSTANCE MACKWORTH-YOUNG

Thesis submitted in accordance with the requirements for the degree
of
Doctor of Philosophy
of the
University of London

DECEMBER 2019

Department of Global Health and Development
Faculty of Public Health Policy
LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

Funded by: Economic and Social Research Council
Research group affiliations: None

Declaration of originality

I, Constance Mackworth-Young, 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.

Signed: …….. Date: 13th December 2019

Abstract

Although young women in sub-Saharan Africa are disproportionately affected by HIV, limited research has documented their lives with HIV. This thesis aimed to understand the impact of HIV on young women's everyday lives in Lusaka, Zambia.

I conducted a 12-month ethnography with seven middle-income young women living with HIV in 2017-18. Participant observation with the young women, their friends and families was conducted in their homes, recreational spaces, churches, health facilities, colleges and workplaces. Additional data were generated through participatory workshops, diaries and visual collages. The young women had previously participated in a qualitative study in 2014-15. Data from the latter study were included for secondary analysis. Analyses were inductive, theory-driven and iterative.

Methodological critique assessed how collage methods effectively enabled self-reflection among participants in their representations of their lives with HIV. This thesis also prompted critical reflections on ethics-in-practice in conducting research with these participants, and identified areas of ethical tension, including the negotiated researcher-participant relationship and protecting participants' HIV status.

Theoretical findings showed how young women enacted agency through employing strategies to navigate their lives, including secrecy and limiting disclosure. This enabled them to cope with a stigmatising environment and the tight restrictions that were sometimes imposed around disclosure, sexual relationships and treatment adherence. Temporal analyses explored the impact of HIV on the participants' lives across time, showing how their everyday and biographical experiences were interlinked with the historical availability of ART.

My findings provide evidence of these young women's resilience, offsetting a historical focus on their vulnerability. I propose applying Reynolds Whytes' term "biogeneration" to capture how young people's lives are entwined lives to their biosocial-historical environment. I question overly-simplistic narratives urging routine HIV-status disclosure, and endorse support groups for young people living with HIV to provide critical safe spaces to share their experiences with their peers.

Acknowledgements

Principally, I would like to thank the young women and their families whose experiences form the basis of this PhD and who so generously shared their time, homes and lives with me. This thesis is dedicated to them.

I would like to give an enormous thank you to my supervisors, Ginny Bond and Ally Wringe, for their amazing enthusiasm and support for my work, for their guidance and encouragement, and for the wealth of input and knowledge they provided. Ginny, you are the reason why I did this PhD, and throughout you've provided me with wonderful inspiration, reassurance, kindness, tea, and fascinating discussions while walking your dogs. Ally, you gave me a huge amount of your time and energy, always being available, and providing consistently constructive and remarkably quick feedback.

Thank you to Sarah Bernays for wonderful mentorship throughout my PhD, for giving up your time and for your beautifully worded advice. Thanks to the others in my advisory committee, Kwame Shanaube and Gem Aellah, who assisted me in various aspects of my research, and gave helpful feedback on my PhD chapters. A huge thanks also to Janet Seeley for providing advice and guidance throughout my PhD, and for giving excellent feedback on the introduction to this thesis.

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I would also like to thank the clinic staff and volunteers who kindly assisted with the initial recruitment of the young women, and to the Zambian Ministry of Health for their support of the study.

Finally, I would like to thank my family. My parents, Iona and Charles, have been steadfastly supportive of my work and decision to move far away from home for it, and have always encouraged me to be curious, to explore, and to learn. My parents-in-law, Rachel and Peter have been inspirations and unbelievably encouraging over the last decade in my work, research and life. My partner, Tom, could not have been more supportive, moving with me to work in Zambia, endlessly encouraging me, and in enabling me to continue my PhD after the birth of our son by working part-time. And to Lewis, our son, for giving me some tight deadlines, and for the utter joy you've brought.

Photo: Lusaka, Zambia. Author's own

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Glossary

Acquired Immune Deficiency Syndrome	AIDS
Adolescents living with HIV	ALHIV
Anti-Retroviral Therapy	ART
Antiretrovirals	ARVs
Association for Social Sciences and Humanities in HIV	ASSHH
Economic and Social Research Council	ESRC
Human Immunodeficiency Virus	HIV
In-depth interview	IDI
International AIDS Society	IAS
London School of Hygiene and Tropical Medicine	LSHTM
Low and Middle-Income country	LMIC
Ministry of Health	MoH
Mother-to-child transmission	MTCT
Participant observation	PO
Research ethics committee	REC
Undetectable=Untransmittable	U=U
World Health Organisation	WHO

Prelude: Mavis, March 2018

When I arrived at Mavis' house, she led me through the kitchen to her bedroom, as she was just finishing putting on her make up. I sat on her bed, and we chatted while she did her make up in front of the mirror and I played with her two-year-old cousin. It was such a nice scene: we were very relaxed, intimate and chatting away. While she was doing her make-up, Mavis took out her pots of pills from her bedside table, and also a small plastic bag full of pills. I asked her if that was her medicine and if that was where she stored it. She said yes. "At least here I can be free, unlike there, where I was staying before, where I had to be hiding".

We spoke about Mavis' best friend, Monde, who was going to be celebrating her birthday in the evening the next day. Mavis had previously been living with Monde and they had a very close friendship, including sleeping in the same bed when they were living together. However, Mavis talked to me about how she couldn't tell Monde that she was living with HIV. She had tried 'testing the waters' with Monde, asking: "what would you do if a friend of yours, say someone like me, was HIV-positive?" Monde immediately reacted by saying "oh I wouldn't talk to you!" Then she said later that she was joking; of course, she would carry on talking to her, but that their friendship would definitely change.

Mavis said this made clear to her that she didn't want to disclose their HIV status to Monde at this point. They were still close friends, and Mavis spoke excitedly about their plans of going out the next day to celebrate Monde's birthday. However, Mavis continued to worry about Monde finding out, saying: "The bad part is that I can't tell. But I don't like it, because there's no lie that can stay hidden forever. One day she is going to find out, the way she always borrows my clothes and goes through my stuff. I'm sure she's going to find out."

Later that year, Monde did discover Mavis' HIV status, and their previously close friendship came to an abrupt end.

* * * * *

This is part of Mavis' story, a young woman living with HIV in Lusaka, Zambia. This extract is from one participant observation session that I conducted as part of the ethnographic study with seven young women living with HIV on which this thesis is based. This extract captures some of the aspects of Mavis' and the other young women's experiences, which I discuss and analyse as part of this thesis, including the impact of HIV on identity and social relationships, involving secrecy and silence around HIV and hiding of antiretroviral therapy, within the bounds of persistent stigma.

Chapter 1: Introduction

Background and rationale

Mavis is one young woman living with HIV in Lusaka, Zambia. There are an estimated 3.5 million young people aged 15-24 years living with HIV globally, the majority of whom live in sub-Saharan Africa, including an estimated 130,000 young people in Zambia (UNAIDS, 2018a). Young people and adolescents living with HIV have been identified in recent years as a focal population in the HIV response (World Health Organization, 2018). The burgeoning HIV epidemic among young people is largely driven by a perinatally-infected paediatric cohort whose survival probabilities have gradually improved with growing access to antiretroviral therapy (Eaton et al., 2013; Mofenson & Cotton, 2013). Additionally, uninfected young people aged 15-24 years are vulnerable to acquiring HIV, with this age group experiencing 32% of all new HIV infections globally in 2018 (UNAIDS, 2019b).

Young women are particularly affected by HIV, with young women having notably higher HIV incidence rates compared to young men (Birdthistle et al., 2019). For example, in Uganda, young women aged 15-19 years had four times the HIV incidence than boys the same age (Santelli et al., 2013). In Zambia, the HIV prevalence for young women aged 15-24 years is 5.0%, compared to 2.4% young men of the same age (UNAIDS, 2018a). Globally, this sex differential is greatest among those aged 15-19 years (Birdthistle et al., 2019). In Zambia, this sex disparity in HIV incidence led to more than double new HIV infections among young women aged 15-24 years (13,000 new HIV infections) compared to young men (5,600 new HIV infections) in 2018 (UNAIDS, 2018a).

Young women are at higher risk of HIV infection than young men due to a mix of behavioural, biological and social factors (UNAIDS, 2016). Behavioural

factors include age-disparate sex (Maughan-Brown, Kenyon, & Lurie, 2014), multiple partnerships (Lopman et al., 2008), sex work and sexual exploitation of young women (Kerrigan et al., 2012), transactional sex (Stoebenau, Heise, Wamoyi, & Bobrova, 2016), early sexual debut (World Health Organization, 2005), and limited knowledge or personal risk perception (Idele et al., 2014). Biological factors include biological susceptibility of young women (Porter et al., 2016), high HIV viral load among male partners (Jean et al., 2016), and presence of other STIs (Sexton, Garnett, & Rottingen, 2005). Lastly, structural factors include harmful social and gender norms (Shannon et al., 2012), low secondary school attendance (Hargreaves et al., 2008), barriers to accessing sexual and reproductive health and HIV services (Chandra-Mouli, McCarraher, Phillips, Williamson, & Hainsworth, 2014), orphanhood (Birdthistle et al., 2009), and gender-based violence (Li et al., 2014). Due to a combination of these factors, young women have persistently high HIV incidence in sub-Saharan Africa. For example, among young women in rural KwaZulu-Natal, HIV incidence was 4.54% per year among 15-19 year olds and 7.45% among 20-24 year olds between 2011 and 2015, with no significant decline in HIV incidence from the previous decade (Chimbindi, Mthiyane, et al., 2018).

This focus on young people and HIV is reflective of several recent global initiatives highlighting the importance of research focused on the health of youth. The Lancet Commission on Adolescent Health and Wellbeing demonstrates that adolescents and young people are a key group, due to the large and increasing demographic of adolescents, the significant health burden they face, and also the importance of their health for the future population of adults (Patton et al., 2016). Young people have been increasingly included in the women's and child health agenda, culminating in their inclusion in WHO's Global Strategy of Women's, Children's and Adolescents' health 2016-2030 (World Health Organization, 2016b). This acknowledged both the importance of understanding and conducting programs to improve adolescent health, and the previous under-emphasis on adolescents and young people. In its foreword, United Nations Secretary-

General Ban Ki-Moon states that adolescents are included "because they are central to everything we want to achieve, and to overall success of the 2030 Agenda" (World Health Organization, 2016b). As noted in a Lancet editorial, "this is a much needed and welcome extension of global attention to an age group that has long been neglected and now constitutes about 25% of the world's population" (Lancet, 2015).

This thesis focuses on the health and experiences of young women living with HIV, aged 15-20 years old. The UN defines adolescents as aged 10-19 and youth or young people as aged 15-24 (World Programme of Action for Youth, 2000; General Assembly resolution, 2008). Throughout most of this thesis I refer to this group, and the participants in the research, as young women, with the exception of the first paper that I wrote for this thesis (chapter 6), where I used the term adolescent girls, reflecting their younger age at the time.

HIV challenges and resilience among young people

Young people living with HIV face a range of complex challenges. Young people have poorer adherence and face a wider array of barriers to accessing antiretroviral therapy (ART), compared to other age groups (Fields et al., 2017). A systematic review of adherence rates showed that young people living with HIV (aged 13-24 years) take between 28% to 70% of prescribed doses (Reisner et al., 2009). Yet, between 75% and 95% adherence is needed to improve virological outcomes (Altice, Evuarherhe, Shina, Carter, & Beaubrun, 2019). In a context where good adherence is praised, and less than perfect adherence is scolded by healthcare professionals and others, young people are often afraid to talk about challenges they face around adherence, until it becomes visible through illness or viral load testing (Bernays, Paparini, Seeley, & Rhodes, 2017). In combination with other factors, challenges around adherence have led to persistently high AIDS-related deaths among young people. Indeed, AIDS is the second leading cause of death for young people aged 15-24 years in Africa (World Health Organization, 2016a). While AIDS-related deaths among all ages has decreased by 36%

from 2010 to 2018, AIDS-related deaths among young people aged 15-24 years decreased by only 15% in the same time period (UNAIDS, 2019b).

However, a significant number of the challenges that young women living with HIV face are non-medical, and occur outside of the health facility. In the context of persistent stigma, young people face issues around disclosure of their HIV status. One study in Uganda and Kenya found that 43.5% of adolescents living with HIV had never told anyone, except healthcare providers, about their HIV status (Nostlinger, Bakeera-Kitaka, Buyze, Loos, & Buve, 2015). There is a notable silence around young people and their management of HIV, with discussion around HIV being limited (Bernays, Seeley, Rhodes, & Mupambireyi, 2015). The exception to this is conversations using a language of sickness and medicalisation, leading young people's HIV experiences to often be framed around illness (Bernays et al., 2015). The focus of HIV on illness brought about by HIV occurs despite the fact that young people often have wider, and sometimes more pressing, concerns about their body image (Ezekiel, Talle, Juma, & Klepp, 2009); sexual relationships (Busza, Besana, Mapunda, & Oliveras, 2013; Fernet et al., 2011; Vujovic, Struthers, Meyersfeld, Dlamini, & Mabizela, 2014); self-regulation to appear like their peers (Philbin, 2014); and anticipated and experienced stigma (Winskell, Hill, & Obyerodhyambo, 2011). Young people living with HIV may face judgemental attitudes from others around their sexuality, and can subsequently feel forced to control their sexuality and postpone initiating sexual relationships (Busza et al., 2013). In some contexts, this judgement is especially heightened for young women. Indeed, in Zambia, HIV in young women can be linked to a label of "prostitution" (Stangl et al., 2015). Further, young women often fear transmitting HIV to their potential future children (Stangl et al., 2015).

Despite the fact that the challenges facing young women living with HIV are not all directly medical, most research studies with young people take place within clinical settings, with a focus on medical management of the disease. Yet, to better understand the impact of HIV more broadly on the lives of young

women living with HIV and to design optimum interventions that meet their real concerns and needs, research needs to be embedded outside the clinic in the settings where young people live, socialise, work and study.

Young people often display coping mechanisms and resilience in the face of their challenges, mediating the negative impact of HIV on their lives (Adegoke & Steyn, 2017, 2018). Viewing children and young people as "passive victims", associated with "innocence and vulnerability" is central to some policy, programming and research in sub-Saharan Africa (Skovdal & Daniel, 2012, p. 154). Skovdal and Daniel argue for the need to focus on coping as a "pathway to resilience" practiced by children and young people, and facilitated or constrained by their social and political environment, as a means to move beyond conceptualising children as passive beings (2012, p. 160). Through exploring such resilience and coping mechanisms, we can appreciate the culturally specific, gendered and locally contextual factors that young people galvanise to mediate the potential negative impact of HIV (Adegoke & Steyn, 2017; Skovdal & Daniel, 2012). Explicitly looking at the strategies that young people living with HIV practice to navigate the challenges they face can help highlight their resilience and advance appropriate interventions for supporting them (Skovdal & Daniel, 2012).

Middle-income young women living with HIV

Young women are far from a homogeneous group, and they have multiple heterogeneous identities and experiences, which are in part linked to their income-level (Crowley et al., 2018). This thesis focuses on middle-income young women living with HIV. There are three reasons that underlie the choice for the selection of this particular income group. Firstly, middle-income young people in Zambia are an under-researched population, despite having a high HIV prevalence. In several sub-Saharan African countries, such as Zambia (Central Statistical Office & Ministry of Health, 2014) and Tanzania (Long & Deane, 2015), middle-income populations have been documented to have high HIV prevalence. However, higher socioeconomic groups have been

notably under-researched (Long & Deane, 2015), with the HIV epidemic remaining firmly rooted in a poverty narrative (Fenton, 2004). In the most recent Demographic and Health Survey in 2014, the national HIV prevalence for young Zambian women aged 15-24 years (as well as for all ages 15-49 years) was highest amongst the two highest wealth quintiles: the HIV prevalence amongst women in the lowest quintile was 4.3%, 5.2% in the second, 8.6% in the middle, 9.4% in the fourth and 9.3% in the highest (Central Statistical Office & Ministry of Health, 2014). This is possibly linked to the higher prevalence in urban areas, although the relationship between HIV prevalence and income-level is complex and varied (Parkhurst, 2010). The focus of much research remains on lower-income populations, and a gap therefore exists in knowledge about the experiences of middle-income groups.

Secondly, certain circumstances and options are particular to middle-income young women in Zambia. These include going to boarding schools and higher education colleges, which involve sharing rooms with multiple other students; high levels of mobility, including traveling between relatives, travelling during holiday times; and having the financial resources to afford transport costs to access support groups and peer education. I hypothesised that this may lead to particular experiences, concerns and coping strategies.

Thirdly, most middle-income families in Lusaka speak English. Although I learnt to speak basic Nyanja (the most commonly spoken language in Lusaka) to greet and hold basic conversations with participants and their families, I was not competent enough to conduct fieldwork using this language. Selecting participants and their families who could speak English fluently enabled me to conduct the fieldwork without a research assistant, which aided relationship development with participants and their families. Thus, the research gap with middle-income populations, alongside practical and language considerations for data collection, underlies the purposeful selection of middle-income young women living with HIV for this thesis.

Interventions for young women living with HIV

Since 2015, there has been an increased drive to develop and deliver HIV interventions for young people, especially young women. In 2015, the United States President's Emergency Plan for AIDS Relief (PEPFAR), alongside private-sector partners, launched the Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) partnership, which included a package of interventions that aim to address the root causes of young women's vulnerability, with an ambitious aim of reducing HIV incidence by 40% between 2016-2018 in target areas in 10 sub-Saharan African countries (PEPFAR, Bill & Melinda Gates Foundation, Girl Effect, & Johnson & Johnson, 2015). Despite challenges involved in implementing such a multi-sectoral complex intervention, both the beneficiaries and the implementors viewed DREAMS as having empowered adolescent girls and young women to avoid HIV infection (Chimbindi, Birdthistle, et al., 2018). DREAMS was launched after UNICEF and global partners launched the 'All In to End Adolescent AIDS' campaign that seeks to reduce new HIV infections among adolescents by 75% between 2015 and 2020, and 'end' the AIDS epidemic among adolescents by 2030 (to fewer than 200 infections per year) (United Nations, 2012). This global investment and focus have led to a range of interventions being developed and evaluated to prevent new HIV infections amongst adolescents and young people (eg. LoVette, Kuo, & Harrison, 2019; Zuma et al., 2019), and increase uptake of HIV testing (eg. Zanoni, Elliott, Neilan, & Haberer, 2018). However, this large-scale focus and funding to reduce HIV incidence amongst adolescents and young people has not been matched by a focus on supporting young people already living with HIV, and there is limited evidence to show how best to support young people living with HIV, including how best to deliver care (Haghighat, Steinert, & Cluver, 2019).

Evidence regarding support for young people living with HIV emphasises the importance of focusing on the whole individual, rather than on medical conditions, or periods spent within the health facility. A systematic review of interventions to improve retention in HIV care and adherence to ART

suggests interventions need to go beyond health facilities to more broadly target the social barriers that young people face (Casale, Carlqvist, & Cluver, 2019). Calls to move the delivery of care and ART for young people living with HIV out of clinical settings and into communities have some support, however more evidence is required to confirm their efficacy (Haghighat et al., 2019). Interventions, including 'Yathu Yathu' in Zambia (Zambart, 2019) and 'Chiedza' in Zimbabwe (Zimbabwe LSHTM Research Partnership, 2019), are currently testing the efficacy of delivering services for adolescents and young people through community spaces. These interventions acknowledge that the lives of young people living with HIV, as well as other young people, are mostly led outside of health facilities.

Recent results from the Zandiri trial in Zimbabwe have shown a successful reduction in viral load amongst adolescents living with HIV through support groups (Mavhu et al., forthcoming). The intervention involved discussions and acknowledgment of the wider context in which young people are living and trying to adhere to ART, including high youth unemployment and persistent stigma, as well as a focus on personal concerns such as precarious social relationships, future aspirations, and concerns around having children (Bernays, Tshuma, et al., 2019). The success of this intervention may be due to how it managed to account for the structural and social context within which young people are managing HIV and trying to adhere to ART (Bernays, Tshuma, et al., 2019). Community-based support for caregivers of children and adolescents living with HIV has also been shown to be effective in reducing their viral load, demonstrating the importance of including wider social relationships in the provision of support and care for young people living with HIV (Ferrand et al., 2017). These findings demonstrate the importance of understanding and focusing on the wider social and structural environment for the health and wellbeing of young people living with HIV in order to provide optimum support.

Research methods and ethics of conducting research with young people

We lack critical assessment of novel methodologies as well as reflexivity of ethical issues researching young people. This thesis aims to contribute to these methodological gaps. Research with young people has historically positioned children as objects of research, rather than active participants in the research process (Bernays et al., 2015; Kirk, 2007). This is changing, as we move from move from the out-dated conceptualisation of children and young people as passive and incomplete beings to active contributors to communities (James & Prout, 2015; Prout, 2000). Traditional research methodologies, such as structured and semi-structured interviews may involve young people as participants, but are limited at facilitating meaningful participation and self-expression, as all other aspects of the research are orchestrated by the researcher (Leavy, 2015). Several new methodologies have been adapted, including participatory and arts-based methods that give young people a means to express themselves and contribute meaningfully to data generation and sometimes also to analysis (Campbell et al., 2015; MacDonald et al., 2011). However, detailing and critique of these methods is rarely documented, which is necessary in order to advance and improve ways of understanding young people's experiences, including those living with HIV.

Research with young people, and with young people living with HIV specifically, also requires particular ethical considerations and can throw up particular ethical issues (Nuffield, 2015). For instance, young people's autonomy and decision-making capacity is often questioned (Gibson, Stasiulis, Gutfreund, McDonald, & Dade, 2011). Ethical issues, which can be unexpected and unpredictable, can arise in research, and responsive ethical decisions are necessarily made during the course of the research studies (Iphofen & Tolich, 2018). These ethical decisions are practiced day-to-day by frontline researchers (Kingori, 2013), and not often enough made explicit in the literature. This engagement with "ethics in practice" (Guillemin & Gillam,

2004, p. 264) is important in enhancing understanding of the kinds of ethical challenges that researchers face when doing research with young people, and in developing ways of navigating these issues.

Study setting

The fieldwork for this PhD thesis was conducted in Lusaka, the capital city of Zambia. Zambia is a land-locked country in southern-central Africa, divided into 10 provinces (Central Statistical Office & Ministry of Health, 2014). There are 72 languages spoken in Zambia, with English being the official language and Nyanja being the most commonly spoken language in Lusaka. Zambia gained political independence from British colonial rule in 1964 and adopted a multiparty system of governance in 1991 (Central Statistical Office & Ministry of Health, 2014). The population is currently 16.5 million (The World Bank, 2019), and it is growing rapidly at 3% per year, with the highest growth rates in urban areas (Central Statistical Office & Ministry of Health, 2014). Between 2004 to 2014, there was rapid economic growth at an annual average of 7.6%, creating a significant urban middle-income population, although this economic growth has since slowed (The World Bank, 2019). In urban areas, 47.6% of the population are categorised in the highest wealth quintile, compared to 2.2% of rural populations (Central Statistical Office & Ministry of Health, 2014).

Figure 1.1 Map of Zambia (Source: Central Statistical Office & Ministry of Health, 2014)

HIV was first identified in Zambia in the early 1980s, and by the 1990s the epidemic had escalated, leaving the country grappling with affected families, HIV care, and education programming in the absence of effective treatment (Simpson & Bond, 2014). In 2004, antiretroviral therapy (ART) became available in public health facilities, enabling transformations for some people living with HIV from ill health to relative wellness (Simpson & Bond, 2014). Zambia now has an HIV prevalence of 11.3% among adults aged 15-49 years (UNAIDS, 2018b). Simpson and Bond describe the HIV epidemic as having "touched the lives of all Zambians", with all Zambians either infected with HIV of affected through friends, partners or family members (Simpson & Bond, 2014, p. 1067).

Disciplinary perspective

This thesis is situated at the disciplinary intersections of Anthropology and Public Health. I draw on social anthropological ethnographic methods, which involve embedded, in-depth participant observation, with the direction of enquiry shaped by the interaction of the researcher and the researched. Ethnographic research is people-centred, locally situated and can reveal the complexities and ambiguities of relationships, social structures and patterns of life (Biehl, 2016). While my methodological approach is rooted in anthropology, I draw from a wider net of theoretical approaches, including sociology and psychology.

Anthropology can provide a critical analysis of, or within, medicine and public health (Biehl, 2016). Rather than anthropology 'of' public health, this thesis sits 'within' the domain of public health, as it aims to provide evidence and recommendations that can be applied to the delivery of effective services to improve the health and lives of young women living with HIV. While the research that this thesis is based on was largely situated in the young women's homes and social spaces, and outside of institutional domains, it was conducted with support from health facilities (particularly during recruitment); in collaboration with health professionals (on study design, including design of, and contributions to, participatory workshops); and results were discussed with healthcare professionals as well as with the young women participating in the research. The anthropological methods and theories of this thesis are thereby grounded in public health application.

Aims and objectives

The overall aim of this thesis is to understand the impact of HIV on the everyday lives of young women living with HIV in Lusaka, Zambia.

The specific objectives are as follows:

1. To understand how HIV impacts young women's relationships and everyday activities
2. To understand the strategies that young women practice to cope with HIV
3. To understand how HIV impacts the lives of this particular generation of young women, and how this changed over time
4. To explore and critique the use of participatory methods with young women living with HIV
5. To reflexively review ethical issues involved in conducting ethnographic research with young women living with HIV
6. To generate policy and practice recommendations to improve support for, and research with, young women living with HIV

These objectives are outlined in Table 1.1, along with the chapters in the thesis where each objective is addressed.

Table 1.1 Research objectives and corresponding chapters

Objective	Paper which addresses the objective
1. To understand how HIV impacts young women's relationships, and everyday activities	Chapter 6: "My mother told me that I should not": a qualitative study exploring the restrictions placed on adolescent girls living with HIV in Zambia Chapter 7: Secrets and silence: agency of young women managing HIV disclosure Chapter 8: Coming of age with HIV: A temporal understanding of young women's experiences in Zambia
2. To understand the strategies that young women employ to cope with HIV	Chapter 7: Secrets and silence: agency of young women managing HIV disclosure
3. To understand how HIV impacts the lives of this particular generation of young women, and how this changed over time	Chapter 8: Coming of age with HIV: A temporal understanding of young women's experiences in Zambia
4. To explore and critique the use of participatory methods with young women living with HIV	Chapter 4: Critical Reflections on Individual Collages as a Research Method with Young Women Living with HIV in Zambia
5. To reflexively review ethical issues involved in conducting ethnographic research with young people living with HIV	Chapter 5: Navigating 'ethics in practice': An ethnographic case study with young women living with HIV in Zambia
6. To generate policy, practice and research recommendations to improve support for, and research with, young women living with HIV	Chapter 4, 5, 6, 7, 8, and chapter 9: Discussion

Overview of whole thesis

This thesis includes five academic papers, each of which constitutes a separate chapter (chapters 4 to 8). As detailed in the research paper cover sheets, the papers presented in chapters 5 and 6 have been published, and those presented in chapters 4, 7 and 8 have been resubmitted following review and revision. There is a short introductory overview before each of the papers, outlining the rationale for the paper and linking it to the other papers and to the rest of the thesis, to facilitate the coherence of the body of work. This thesis contains four additional chapters: introduction, literature review, methodology and discussion.

This first chapter provides an introduction to the topic, the rationale for the research, the disciplinary perspective of the research and an overview of the aims and structure of the thesis. Chapter 2 provides a review of the existing literature on the key topics, issues and theories explored in this thesis. Chapter 3 includes a description of the methods of data collection and the settings of the research. The chapter includes a description of the broad analytical methods and approaches used, but details of the specific analyses that were conducted are included in each of the papers. The settings where the research took place are described and illustrated.

Chapters 4 and 5 contain two papers relating to the methods of the thesis. Chapter 4 assesses collage methods as one of the participatory methods used in the study. In the paper, I assess the feasibility, value, and limitations of the collage method, used at two time points, to understand the experiences of young women living with HIV, and how this compares to other methods of data collection. Chapter 5 looks at the ethical issues that were encountered during the ethnographic research with young women living with HIV. In this chapter, I identify and explore practical ethical issues, and provide a reflexive account of how ethical issues were navigated in practice.

Chapters 6, 7 and 8 contain three papers detailing the results of the research. Chapter 6 details results on how HIV impacted young women's relationships and the restrictions that were placed on them. The paper describes three common messages that were told to young women living with HIV – don't disclose your HIV status, don't miss your antiretroviral treatment, and don't have sex – and how the young women responded to these restrictions.

Chapter 7 describes how young women's agency is limited or "bounded" (Evans, 2007) as demonstrated by their practice of secrecy to avoid the negative effects of unintentional disclosure of their HIV status. This was particularly in a social context of persistent stigma and limited private space. The findings question the typically pejorative view of secrecy, particularly in relation to HIV status, to argue that it is a strategy that enables the young women to enact agency in the management of their identities. However, the young women's agency to practice secrecy was not without anxiety over maintaining the secret, and continued fear of discovery of their HIV status.

Chapter 8 uses an analytical framework developed by Bonnington and colleagues (2017) to understand the impact of HIV on the lives of these young women living with HIV through the lens of three temporalities: everyday time, biographical time, and epochal time. Through this analysis, I suggest adopting Reynold Whyte's notion of a "biogeneration" (2014) and applying it to our conceptualisation of this generation of young women, as their HIV infection, survival and lives are intimately interlinked with the biosocial environment in which they were born and now live.

Chapter 9 concludes the thesis with a discussion of the overall findings from each of the research papers. In addition, it includes recommendations for policy, further research, and development of interventions to support young women living with HIV. It summarises the strengths and limitations of the PhD research, and finally ends with the conclusions of the thesis.

The appendices include ethical approvals, informed consent documents, data collection tools, and other disseminated work, including posters and slides presented at international conferences.

Role of candidate

I designed the overall concept, research questions and study design of this thesis' main ethnographic study in collaboration with my supervisors, Virginia Bond and Alison Wringe. I wrote the study tools, sought ethical approval, recruited the participants and led all data generation processes. This ethnographic study contributes the substantial majority of data to this thesis.

The thesis additionally includes secondary data analysis of qualitative research conducted prior to my PhD in 2014-15. Prior to my PhD I worked as a Social Science Researcher at Zambart, a Zambian research organisation based within the School of Public Health, University of Zambia, Lusaka. In this role, I was involved in the study design of that qualitative study, including writing the study tools, recruiting participants, and collecting the data, alongside colleagues at Zambart, the International Centre of Research on Women, and 3Cs Regional Consultants. I subsequently conceptualised and led the secondary analysis of this data as part of my PhD.

I conceptualised and conducted all the analysis, with input from my supervisors and co-authors. I have written the whole thesis, including all papers and linking material. I am first author on all papers.

Funding

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My fieldwork costs in Zambia were covered by ESRC Research Training Support Grants. I was awarded additional funding from ESRC for language training, which covered three terms of Nyanja lessons that I undertook in Lusaka, Zambia. The qualitative research, conducted prior to my PhD and secondary analysis of which is included within this thesis, was funded by MAC AIDS Foundation.

Chapter 2: Literature Review

This chapter outlines the conceptual and theoretical underpinnings that inform this thesis. It begins with a discussion around youth, characterised as a period of transition and sociability, providing a backdrop to this thesis's objective of understanding the impact HIV has on young women's social relationships. I then detail the literature on HIV-related stigma, and its impact on relationships and social identities. I draw on this literature to understand the social environment within which young women living with HIV navigate their lives, and the impact of HIV on social relationships, stigma, identity and disclosure. This leads into an exploration of the literature on resilience that is often shown by young people, and the coping strategies that they may adopt to deal with a restrictive social context. I discuss literature on the individual and environmental factors that can be enabling or restrictive to resilience. This is linked to debates around agency and the degree to which individuals' choices can determine their actions, while considering how this it may be limited by social and structural contexts. I draw from these debates, in this thesis, through investigating young women's coping strategies of limiting disclosure in the context of a stigmatising environment. Lastly, I consider literature on participatory methods and ethics in research with young people, which both form critical components of this thesis.

Youth and social transitions

In this thesis I focus on young women, aged 15-24 years, and I trace their social relationships and how HIV impacts these. I draw on literature that explores the sociability of youth, understanding it as a period of social transition and relationship-formation. While age is a convenient way to define youth, with those aged 15-24 years defined as young people (United Nations, 2008), more characteristic are the social transitions that occur throughout this period (Barrett, 2004). In his ethnographic study with young

people in Western Zambia, Barrett demonstrates how "categories like 'youth' and 'adulthood' are not only corollaries of biological or chronological age, but rather social and cultural interpretations that have developed their own logic and coherence" (2004, p. 23). He describes how age classifications reflect variable access to authority and knowledge within social environments (Barrett, 2004). Young people's process of becoming is interlinked with growth, social belonging and agency (Barrett, 2004). Youth is often marked by social events. For instance, in Southern Zambia, social events, such as marriage, are seen to mark the end of adolescence, and entry into adulthood, regardless of age (Reynolds, 1991). The physical changes connected to adolescence and youth take on social meaning too, which influences how adolescents view themselves, as well as how society views them (Wamoyi, Fenwick, Urassa, Zaba, & Stones, 2011).

Youth is not only characterised by social events, but young people are also a particularly social group. Barrett asserts that young people are "inextricably embedded in the social landscapes of kin, neighbours and peers, and understands their social persons as being the sum of the relationships that have brought them into the world" (Barrett, 2004, p. 37). Wamoyi and colleagues showed how interlinked young people's behaviours are to their relationships and communication with their parents (Wamoyi et al., 2011). They described how parents in Tanzania try to control their children's behaviour in part to ensure good social reputation of their families (Wamoyi et al., 2011). This control was particularly strong for girls, in part because of "the economic burden of an unintended pregnancy", and in part because of "traditional social norms surrounding male power and sexual behaviour" (Wamoyi et al., 2011, p. 5).

Beyond familial relationships, youth is a period characterised by the formation and development of romantic and peer relationships. In his ethnographic work of boys' transition from childhood to adulthood in Zambia, Simpson demonstrates how having a girlfriend was a key part in the transition from boyhood, and the socially recognised acceptance as a man

(Simpson, 2009). Relationships with peers can be fundamental during youth, and have been shown to impact young people's behaviour, including sexual behaviour (Fearon, Wiggins, Pettifor, & Hargreaves, 2015), and substance use (Mason et al., 2015). The formation, navigation and maintenance of social relationships are key aspects of youth, and, thus, represent a main theme in this thesis.

HIV-related Stigma

This sociality and the social transitions during youth leads to issues around social stigma being particularly pertinent among this age group. Goffman's work on stigma has been seminal since its conception in 1963 and has framed much theorising on stigma (Goffman, 1963). Goffman defined stigma as "the situation of the individual who is disqualified from full social acceptance" (1963, p. 9). Goffman theorised that central to stigma is "an attribute that is deeply discrediting", but that, beyond this, it is the social and relational dimension of stigma which is fundamental to the social consequences of such an attribute (1963, p. 13). Since Goffman, other authors have given a multitude of definitions of stigma, with the concept of stigma having been applied to a wide range of contexts, and used by a wide range of disciplines (Deacon, 2006). Deacon cautions use of stigma too loosely, suggesting that coherence between theoretical perspective on stigma is needed in order to understand how to manage and mitigate stigma, which continues to be a major barrier to quality of life, management of illness and access to health care (Deacon, 2006). I here outline how different theoretical perspectives interlink and touch on similar social and structural stigma processes and how particular attributes can assign negative meaning, highlighting the theories that I draw on in this thesis.

Link and Phelan provide an encompassing definition of stigma "as the co-occurrence of its components: labelling, stereotyping, separation, status loss, and discrimination", within a wider context of power and relations (2001, p.

363). They proposed a model of stigma that explores how structural factors lead to institutionalised disadvantages placed on stigmatised groups (Link & Phelan, 2006). They show how human difference is a necessary component to stigma, and the first step in the process of generating stigma (Link & Phelan, 2006). However, it is not difference per se that creates stigma, with many human differences being socially irrelevant, while only particular differences are socially charged (Link & Phelan, 2006). One can see evidence for this through comparing the notable variation in social significance of medical conditions, such as hypertension and bone fractures, compared to HIV and schizophrenia (Link & Phelan, 2006). Link and Phelan build other layers of stigma processes (2006). Stereotyping labels individuals to undesirable characteristics, and then separates of "them" from "us", with a constructed rationale for this separation (Link & Phelan, 2006). Finally, exercising of power is an essential part of the stigma process (Link & Phelan, 2006). This model has been key to the literature on stigma, and contributes to understandings on how institutionalised disadvantages are placed on stigmatised groups (e.g. Kleinman & Hall-Clifford, 2009).

Kleinman and Hall-Clifford build on Link and Phelan, and add a moral dimension to the experience of stigma, emphasising the moral processes that underlie stigma, which they acknowledge are surprisingly poorly understood (Kleinman & Hall-Clifford, 2009). They view stigma at an individual-level, but embedded in social and cultural processes, since these enable structural discrimination that leads to individual stigma (Kleinman & Hall-Clifford, 2009). In this, they also build on Crocker and colleagues, who detail how the social context must define an attribute to be devaluing (1998). Kleinman and colleagues have critiqued some studies on stigma as being uninformed by the lived experiences of those who belong to stigmatised groups (1995). This highlights the importance of giving priority to the stories and experiences of the people within stigmatised groups, who are often the subjects of study (Kleinman et al., 1995). Kleinman and Hall-Clifford have criticised Goffman's work for centring on the stigmatised, without a focus on those who impose stigma, thus situating stigmatised individuals as victims who lack agency and

overlooking how social life and relationships are altered by stigma (Kleinman & Hall-Clifford, 2009). Kleinman and Hall-Clifford suggest ethnographic methods can be particularly suited to understanding what stigma does to individuals and groups, and, through this, understanding how it can be addressed (Kleinman & Hall-Clifford, 2009). In this thesis, I draw particularly on Goffman (1963), Link and Phelan (2001), and Kleinman's and Hall-Clifford's (2009) theoretical definitions of stigma, to understand the social and moral dimensions of stigma for young women living with HIV. I draw on these theories to explore a social context that is prone to stigma for young women living with HIV and how these young women adapt their social life to navigate the stigmatising environment.

Stigma has been central to HIV experience and research throughout the epidemic. Horter details how HIV stigma is intimately interlinked with judgements of immorality (2019). Simbayi and colleagues claim that HIV may be "the most stigmatised medical condition in the world", with common stigmatising beliefs and negative views of people living with HIV, including connotations with being "contaminated" and "tainted" (Simbayi et al., 2007, p. 1823). Goffman argues that stigma extends to those related to the stigmatised individual. He describes that there is a "tendency for a stigma to spread from the stigmatized individual to his close connections provid(ing) a reason why such relations tend either to be avoided or to be terminated, where existing" (Goffman, 1963, p. 43). This can be particularly the case for infectious, including sexually transmitted, diseases, which hold connotations with being "contaminated" and risk of contagion (Simbayi et al., 2007).

Along with others (e.g. Mbonu, van den Borne, & De Vries, 2009), Simbayi and colleagues describe how HIV-related stigma is often inextricably interlinked with other stigmas related to risk behaviours, such as sexual "promiscuity", homosexuality, sex work and drug use (Simbayi et al., 2007, p. 1824). These risk factors lead to responsibilisation of HIV infection, instilling a culture of blame around the infection (Simbayi et al., 2007). Further the associations with danger, including contagion, incurability, sickness and death contributes

to stigmatising responses of avoidance and isolation (Mbonu et al., 2009). These associations with risk behaviours and dangers of sickness lead to a complex web of stigmas associated with the disease.

Fielden and colleagues build on the work of others to show how HIV-related stigma can be layered with other intersectional identities, such as race, gender, class, age and sexuality (2011). They detail how these inequalities produce a "layering of stigma", and note that this has the effect of leading to notable variation in how individuals experience HIV-related stigma (Fielden et al., 2011, p. 269). This risk of disease contamination and contagion discussed above is one layer within this intersectional layering of stigma (Fielden et al., 2011). Another layer is age. Fielden and colleagues suggest that age is one layer that is relatively under-explored in HIV-related stigma research (Fielden et al., 2011). Abadia-Barrero and Castro demonstrate this layering of stigma in their work with young orphans in Brazil, living with, or affected by HIV (2006). They demonstrate that their HIV-related stigma experiences are intimately interlinked with other intersectional inequalities related to income, race, social status, gender and age, and argue that HIV-related stigma is interwoven with layers of unequal identities (Abadia-Barrero & Castro, 2006). Fielden and colleagues argue that young people are one population that is most affected by HIV stigma (Fielden et al., 2011). HIV is a sexually transmitted disease and is associated with the taboo of sex. HIV among young people can constitute a double taboo, since sex among young people is not viewed as acceptable (Fielden et al., 2011).

The consequences of stigma, including discrimination, can also be heightened for young people. I follow Deacon's approach (2006), and that of others after her, of analytically separating HIV-related stigma from discrimination, which builds understandings of how discrimination can emerge as an outcome from stigma. Stigma can have damaging effects on a wide range of young people's lives, for example, leading to young people living with HIV delaying educational and vocational aspirations (Hosek, Harper, & Robinson, 2002). Wiener and colleagues have documented clear discriminatory acts towards

young people living with HIV, such as schools refusing their entry (Wiener, Battles, & Heilman, 2000). HIV-related stigma can therefore have tangible effects on young people living with HIV, including discrimination, avoiding certain spaces, and limited disclosure. In this thesis, I build on this literature around the social, structural and moral dimensions of stigma, and the social and cultural processes that generate it. I focus on the particularities of HIV-related stigma toward young women living with HIV, and their experiences of stigma, the impact it has on their lives, and how they navigate it.

Identity and disclosure

Goffman considered stigma as a process that is grounded in the social construction of identity (1963). He discussed how individuals who are unable to conform to society's standards of normality are seen to have "spoiled identities" (1963, p. 31). Goffman introduces the idea of discrepancy between "virtual and actual social identity", where "normative expectations" of an individual's identity are challenged (1963, p. 12). An illness or health condition, such as HIV, can challenge these normative expectations, and as Bury states, can be a "disruption" to identity (1982, p. 167). Bury contends that illness is an experience where "the structures of everyday life and the forms of knowledge which underpin them" constituting one's identity, are disrupted (1982, p. 169). He goes further to say that such disruptions in biography are simultaneously disruptions in social relationships, including altering normal social rules, such as reciprocity and mutual support (Bury, 1982). Corbin and Strauss build on this to explore how such disruptions to identity require review, maintenance and repair (Corbin & Strauss, 1987). Individuals affected by chronic illness, including the young women at the heart of this thesis, therefore must navigate through such disruptions to develop methods of reviewing, repairing and maintaining their wider identity.

One route of maintaining a wider identity that has been explored in the literature is through non-disclosure. Research with people living with HIV has documented how most are very selective about to whom they choose to tell their HIV status (e.g. Bond, 2010; Mburu et al., 2014; Westad, 2017). This is the case for young people, with over half of adolescents living with HIV in a study in Uganda and Kenya having never told anyone their HIV status (Nostlinger et al., 2015). Even to close friends and family, young people attempt to keep their HIV status secret (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Mburu and colleagues have discussed barriers to young people's disclosure of the HIV status, including stigma, fear of abandonment by romantic partners, and family members making decisions over who should or shouldn't know about their HIV status (Mburu et al., 2014). In particular, disclosure to sexual partners can be particularly challenging for young people (Toska, Cluver, Hodes, & Kidia, 2015). Even amongst those who know their HIV status, young people's HIV experiences are usually managed in relative silence, with HIV rarely spoken about (Bernays et al., 2015). Bernays and colleagues found that the exception to this was "medicalised talk", which was the only socially sanctioned conversation around HIV, both within and outside health facilities (Bernays et al., 2015, p. 276). This included conversations about past illness, HIV medicines and clinic appointments; communication outside of this framework were rare and often inadvertently shut down (Bernays et al., 2015).

Choosing not to disclose their HIV status to friends and family can lead to young people living with HIV feeling isolated, anxious, depressed, and withdrawn, and reduce the potential sources of support which they can draw on (Mburu et al., 2014). Where young people do disclose their HIV status, Mburu and colleagues showed that this can create a social space for valuable support, both psychosocially and around adherence (Mburu et al., 2014). Choices around disclosure are intimately interwoven with the social environment, which is often laden with HIV-related stigma, and concerns around maintaining wider identities. In this thesis, I build on this literature, and apply understandings of identity and disclosure to the experience of

young women living with HIV, to explore HIV's disruption to their identity, and their entwined decisions and restrictions around disclosure.

Resilience and coping strategies

In this thesis, I explore the degree to which young people are able to navigate the thorny social environment described above. Skovdal and Daniel outline two academic perspectives on children's abilities at polar ends of a continuum (2012). At one end of this continuum, children are viewed as active social contributors to society and households, while at the opposing end, orphans and HIV-affected children can be represented as passive victims (Skovdal & Daniel, 2012). They describe how focusing on children as victims is central to much policy, research and advocacy in Africa, and reflects associations of children with innocence and vulnerability (Skovdal & Daniel, 2012). This characterisation of children can promote a culture of urgent relief aid at the expense of interventions that could rather develop coping strategies and enhance resilience (Skovdal & Daniel, 2012).

Resilience is "both a process and an outcome characterised by positive adaptation to adversity" and is understood to be both dynamic and flexible (Theron & Theron, 2010, p. 1). Through a literature review on South African studies on resilience, Theron and Theron identified a mix of individual traits, as well as familial, community and cultural resources that were associated with resilience (2010). Individual traits included empathy, optimism, autonomy, assertiveness, and being goal-oriented, while external factors included supportive family relationships, school support, peers, as well as religion and cultural values (Theron & Theron, 2010). This idea that resilience emerges from the interaction of the individual with their environment is taken up elsewhere (Ungar & Liebenberg, 2011), leading to understandings that resilience is susceptible to both individual and contextual variation. The concept of resilience has been applied to understand children and young people's responses to adverse circumstances

(e.g. Adegoke & Steyn, 2017, 2018; Ungar & Liebenberg, 2011). Such understandings of resilience inform a focus on health instead of illness (Ungar, 2008).

A special issue about resilience and coping strategies explored the interaction of the social environments and the differing abilities of HIV-affected children and young people that can lead to resilience (Skovdal & Daniel, 2012). In this special issue, Evans demonstrate the interaction of material (such as land and property) and social resources (such as social networks) in leading to resilience among orphaned young people in Tanzania and Uganda (2012). The value of social capital in enhancing resilience is reinforced by Skovdal and Ogutu, who show how the formation of friendships led to support through sharing school materials, food and domestic duties, particularly in times of hardship (Skovdal & Ogutu, 2012). However, in some settings, extended family members and neighbours could not be relied upon to provide support by young people (Van Dijk & Van Driel, 2012). For young people living with HIV, in particular, such social capital is only fully available from those to whom they have disclosed (Midtbo, Shirima, Skovdal, & Daniel, 2012). Midtbø and colleagues demonstrate how HIV-status disclosure, enabled young people to access support (Midtbø, Shirima, Skovdal, & Daniel, 2012). Such disclosure was particularly valuable in spaces where they felt safe, including safe to disclose their HIV status, such as support groups (Midtbø et al., 2012).

The concept of resilience in relation to HIV was explored by Wiegers who defines two types of resilience (2008). Firstly she describes resilience as the ability to accept one's HIV status, to retain a level of optimism about the future and to see beyond the illness (Wiegers, 2008). Secondly, she sees resilience as individuals or households adopting strategies to avoid the worst impacts of HIV on their lives and livelihoods (Wiegers, 2008). Wieger's first form of resilience links back to discussions above on the disruption of illness to identity leading to the need to review and maintain wider identities. In her ethnography in East Africa across the HIV epidemic, Seeley details how, for

families affected by HIV in high prevalence areas, HIV is interwoven throughout their experiences, families and lives (Seeley, 2015). Despite the impact of HIV on loss, grief, orphanhood and poverty, many of the individuals whose lives she describes were able to see beyond HIV, including through memories before HIV, and also through focus on other, sometimes more pressing, aspects of their lives (Seeley, 2015). Adegoke and colleagues demonstrate through photovoice how young people living with HIV portray their lives through their education, their motivation to succeed, and their desire to secure employment, which inspire self-esteem and purpose (Adegoke & Steyn, 2017). Further, through a focus on positive relationships, young people living with HIV can demonstrate and reinforce their resilience within their social landscape and strengthen access community resources (Adegoke & Steyn, 2017). This focus on their lives beyond HIV not only demonstrates, but also reinforces resilience to HIV.

The second of Wiegers' two forms of resilience involves adopting coping strategies (2008). Coping strategies can be defined as "responses that individuals, households and communities adopt in order to avert a negative effect" (Wiegers, 2008, p. 261). As referred to earlier, Skovdal and Ogutu explored how young people affected by HIV in Kenya cope with hardship, for instance by developing supportive friendship groups (2012). Rael and colleagues explored the coping strategies developed by women living with HIV in the Dominican Republic that included educating oneself and others about HIV, considering HIV as a manageable condition, and finding support from family and friends (2017). Rael and colleagues detail the women's preferences for being able to choose when and to whom to disclose their own HIV status, but also the challenges they faced retaining control over this (2017). One method of coping with potential gossip about their HIV status was to pre-emptively disclose to ensure that individual friends or family did not find out in another way (Rael et al., 2017).

Individuals' ability to adopt coping strategies to HIV can vary by several factors, including economic status, social capital, gender, and individual

capacity for learning and adaptation (Wiegers, 2008). One example of individual factors predicting resilience is internalised stigma (Garrido-Hernansaiz, Murphy, & Alonso-Tapia, 2017). Dulin and colleagues conducted a systematic review of the literature on resilience and HIV, and detailed that the majority of research on HIV resilience focuses on resilience at the individual level (2018). Individual-level resilience, and understanding the factors that contribute to it is key, and have been highlighted by a number of studies (e.g. Du, Li, Chi, Zhao, & Zhao, 2017). However, without interrogating the social and environmental factors that also contribute to resilience, we place too much responsibility on the individual to cope themselves, rather than addressing structural factors that lead to challenging situations or that can facilitate resilience. Dulin and colleagues highlight that resilience is also built upon interpersonal or social support, and they advocate for more research based on socioecological models of health that can more wholly represent resilience as a construct (2018). A more limited set of research has examined resilience at multiple levels, from individual, to interpersonal, to environmental (Dulin et al., 2018). For example, Harrison and Li highlight the compounding effects of environmental factors, such as poverty, and individual factors, such as gender, on HIV-affected youth (2018). They describe how such layered factors, not only produce HIV-related challenges, but that individuals and interventions can draw on individual, social and structural factors to shape resilience against these challenges (Harrison & Li, 2018). I build on such understandings of how resilience and coping strategies can emerge from the interaction of the personal traits of young people and their environment (Theron & Theron, 2010).

Highlighting young people's resilience is important because the language of resilience can be empowering to young people. I align with Skovdal and Daniel's view of using a lens of resilience and eliciting young people's coping strategies, to shift the narrative away from victimisation and hopelessness and towards children and young people's ability to respond to, and navigate, challenging situations (2012). I build on understandings of resilience as generated from individual traits and environmental factors, both of which can

and should be enhanced through intervention (Dulin et al., 2018; Theron & Theron, 2010). In this thesis, I draw on the concept of resilience, particularly Wiegers' two forms of resilience (Wiegers, 2008), through examining how young women living with HIV present optimistic representations of themselves, and practice coping strategies within their particular social and structural context.

Agency

The practices of resilience and coping strategies discussed above arguably require individual agency. In parallel to debates around the individual and contextual determinants of resilience, theorists have debated the relationship between structural determinants and agency, with differing perspectives along a continuum of individual free will at one end, and structural determinants at the other. At one end, Bandura, with his theories of self-efficacy, places the locus of control internally within the individual, arguing that individuals can achieve what they set out to do (Bandura, 1997). However, others place greater emphasis on the limitations of personal control to construct ones' life course through the constraints of their world (Elder, 1994). Bourdieu theorises agency as the interactions between agents and their environment, thereby positioning choices within, and responsive to, social processes (1977). He offers a view of agency where the social, structural and personal-historical influences on individuals are understood as the "habitus", which shape and determine individual's choices and actions (Bourdieu, 1977). Bourdieu's work has been criticised by some theorists who suggest that structural constraints and individuals' choices are not as separable as he suggests. For example, King contends that Bourdieu's theories of the structural processes do not account for the complexity of negotiated and fluid social relationships and exchanges, and how the effects of 'structure' are woven into individual's choices (2000). Like Bourdieu, Giddens assesses agency within the constraints of social and structural context on individual action, but acknowledges the ability of individuals to

resist or alter the social context within which they are acting (Giddens, 1979). These debates around agency have been summarised by Pincock who concludes that there is a need to determine space between narratives that are overly deterministic, emphasising how social structures rigidly constrain choice, and those that are overly optimistic emphasising the scope of individual's free will (2017).

In relation to young people, narratives often tend towards constraints of choice and a lack of agency. As Pincock discusses, work with young people is often based on "assumption(s) of passivity" (2017, p. 42). In public spheres, treatment of children and young people can be characterised by control and surveillance (Prout, 2000). This is despite the acknowledgement that children are capable contributors to social life (Prout, 2000). Campbell and colleagues argue that research with young people often overlooks the participants' own objectives, including by foregrounding the researchers' views in the interpretation of data generated through participatory methods with children (Campbell et al., 2015). Beyond acknowledging young people's agency, researchers need to focus on the factors that mediate this agency within social and structural constraints, and understand the optimum end-goal that young people would like to move towards (Campbell et al., 2015).

In the context of young people's agency, Evans introduced the term "bounded agency" (2007). She defines "bounded agency (as) socially situated agency, influenced but not determined by environments and emphasising internalised frames of reference as well as external actions" (Evans, 2007, p. 17). This moves from Bandura's models of individual control (1997), accounting for Bourdieu's theories of structure (1977), and includes King's suggested interplay with fluid social interactions (2000). This concept opens up space for individual action within social landscapes "which are not wholly reducible to the effects of social reproduction or underlying structural factors" (Evans, 2007, p. 17). Evans acknowledges that there are some social and structural factors that are challenging to change or erase, but others can be reduced or navigated by individuals or policy. Others have subsequently

drawn on this concept of "bounded agency" to examine the structural constraints on individual's agency, shaped by the environment, time and space (e.g. Bernays, 2011). In this thesis, the concept of "bounded agency" resounds with how young women living with HIV navigate the social and structural landscape in Lusaka, Zambia to make choices around their everyday lives, social relationships, and management of HIV.

HIV across time in Zambia

This thesis is situated in the specific context of the HIV epidemic in Lusaka, Zambia. Simpson and Bond detail the HIV epidemic in Zambia across historical time over three decades from the 1980s (2014). The epidemic has been so widespread and protracted that it has "touched the lives of all Zambians in one form or another" (Simpson & Bond, 2014, p. 1066). They describe the changing HIV response over time (2014). The initial bio-medical observations of HIV-related illnesses in the University Teaching Hospital in Lusaka in the mid 1980s led to early bio-medical research on HIV and TB (Simpson & Bond, 2014). By the early 1990s, without effective and accessible treatment, social behaviour change was emphasised, but often failed to recognise that knowledge does not necessarily mean learning, and that learning may not be able to be applied (Simpson & Bond, 2014). In the mid 1990s, the response was heavily social, with a focus on supporting affected families, HIV care, education, and expanding NGO involvement (Simpson & Bond, 2014).

A major change came in 2004, when ART was made available in public health facilities, enabling transformations for some people living with HIV from ill-health to relative wellness (Simpson & Bond, 2014). The focus of research returned to the bio-medical, with clinical trials of HIV treatment and technical HIV prevention strategies (Simpson & Bond, 2014). This has led to a number of policy changes. In 2004, the Zambian national policy expanded to include using ART to prevent mother-to-child transmission (World Health

Organization, 2004). In 2013, treatment was expanded to individuals with CD4 counts below 500 after WHO recommendations (World Health Organization, 2013a), and in 2016, universal test and treat was introduced (National HIV/AIDS/STI/TB Council, 2016). Individuals' and communities' experiences of HIV have been interwoven with this ever-changing political and historical landscape. Young people currently aged 15-24 years were born into this shifting HIV landscape and grew up through changing HIV policies and treatment availability. Young people's lived experiences of growing up with HIV are intertwined with this shifting context as it changes over time.

This changing biosocial context has shaped the bodily and social experience of people living in Zambia and other heavily affected countries. Reynolds Whyte describes an HIV-infected generation who were expected to die from AIDS but have survived due to medical intervention as a "biogeneration", due to their shared relationship to ART when this biotechnology became widely accessible (Reynolds Whyte, 2014). Reynolds Whyte links the notion of generation back to PEPFAR policy stating their intention in 2011 to work towards an "AIDS-free generation" in reference to biomedical prevention of mother-to-child transmission of HIV and then following the life course under a comprehensive biotechnological program. Reynolds Whyte therefore sees a "biogeneration" as defined within the "frame of the epidemic… in relation to biological maturation, and determined by its relation to medical policies, procedures and pharmaceuticals" (Reynolds Whyte, 2014, p. 11). Understandings through the lens of a "biogeneration" can shed light not only on the epidemiology of groups, but also on members' cultural and historical experiences, and their reflections on their situation and the world.

Time and temporalities

So far, I have discussed the social context of HIV in Zambia in terms of historical time. Anthropological understandings of time are often not linear, rather understood through "temporal diversity and heterogeneity" (Munn, 1992, p. 94). Munn discusses the social nature of time, which can "reflect the

groupings and varied rhythms of social life" (1992, p. 95). This draws on Evans-Pritchard's conceptualisation of time being "perceived" through a cultural lens, with social and cultural patterns often linked to natural cycles, for instance of days or seasons (1940, p. 103). Seeley builds on this, detailing how we simultaneously manage calendar time, clock time, while responding to the cyclical and temporal nature of natural events (2015).

The notion of "temporalisation" extends beyond linear and even social and cultural perceptions of time to view time as "a symbolic process continually being produced in everyday practices" (Munn, 1992, p. 116). A growing body of research has looked at the experience of health and disease through a temporal lens (e.g. Beynon-Jones, 2017; Golander, 1995; Reddy, Dourish, & Pratt, 2006; Seeley, 2015). Bonnington and colleagues have drawn on this concept of overlapping temporalities to identify three temporalities – everyday, biographical and epochal time – to examine the manifestation of stigma for people living with HIV at stages of the HIV care continuum (2017). They detail these temporalities as being "not philosophically discrete, detached ways… but imbricated ones that flow into and influence each other" (Bonnington et al., 2017, p. 2). Through this temporal lens, one can understand how these "overlapping modalities of time effect the contexts and concerns of people living with HIV" (Bonnington et al., 2017, p. 2)

Time is an important theme in this thesis. Including a historical perspective to individual's experiences of HIV is crucial to contextualise experiences within a particular temporal and local setting. The methods used to research this thesis were intentionally longitudinal, and enabled and encouraged the concept of time to be as a backdrop to analysis, with a focus on changes over time, and the influence of spatial and temporal context. This is particularly important for young people, whose lives are often more fluctuating than adults, and major life changes often occur within short periods of time, for instance leaving school or starting new relationships.

Participatory methods and ethics in research with young people

Given this backdrop of temporal investigation, and given the aim of the thesis to understand the lives of young women living with HIV broadly, rather than a particular aspect, I took at longitudinal approach in the methods of this thesis. I draw on the "slow research" movement, which calls for a shift in values from a new normal of global health focused on pace, the next big thing, multitasking, and scale, to values that are more focused on conducting local research, patience, striving toward knowledge rather than information acquisition, and valuing what is already working (Adams, Burke, & Whitmarsh, 2014). Adams and colleagues propose these methods of "slow research", borrowed from the "slow food" movement, and draw parallels between the importance of local, the understanding that quality takes time, and the value of community involvement (2014). They argue that "slow research, like slow food, is good for health" (Adams et al., 2014, p. 179). As Adams and colleagues recognise, ethnographic research is well suited to this concept of slow research (2014). In the methods of this thesis, I intentionally seek slow, longitudinal, and local understanding with a small number of young women living with HIV in Lusaka, Zambia.

Participatory methods

The discussions about agency of young people that I outlined earlier in this chapter can also be drawn on to discuss young people's involvement in research. There is increasing encouragement of engagement of young people in research, reflecting the increasingly common perception of young people as active agents rather in than objects of research (Kirk, 2007; MacDonald et al., 2011). This aligns with the transition from the out-dated perception of children and young people as incomplete persons, to active contributors to social life, with agency of their own (James & Prout, 2015; Prout, 2000). MacDonald and colleagues argue that meaningful involvement of young

people in research is critical on multiple grounds (MacDonald et al., 2011). From a human-rights perspective, young people have a right to participate in research and decision-making processes around issues that will affect them (MacDonald et al., 2011). From a programmatic approach, it is recognised that without young people's engagement in developing programs that are acceptable and relevant, programs can be irrelevant, ineffective and disengaging for young people (MacDonald et al., 2011). And from an expertise approach, Hodes and colleagues argue for the benefits of "positioning adolescents as the primary experts on their own health behaviours" (2018, p. 73). Discussions remain however about how to best engage young people in research, and the extent to which it is feasible and effective.

As Ansell and colleagues state, "participatory research is concerned with producing knowledge *with,* rather than *about*, those who are the subjects of the research" (Ansell, Robson, Hajdu, & van Blerk, 2012). They reflect that this involves the co-production of knowledge by young people as participants, alongside researchers (Ansell et al., 2012). Yet, a range of levels of participation is used in participatory research. Larsson and colleagues divide participatory studies with children and young people into five levels of participation in a scoping review (Larsson, Staland-Nyman, Svedberg, Nygren, & Carlsson, 2018). They demonstrate that participation can range from young people taking part and encouraged to express views as informants through involving young people in decision-making processes, to young people becoming co-researchers with high levels of mutuality and shaping of the research (Larsson et al., 2018). Ansell and colleagues argue that it is the co-production through the social relations involved in the generation and analysis of data that constitute participatory research, especially where the control and power in the research lies, rather than necessarily the methods themselves (Ansell et al., 2012). Yet, particular methods can aid with shifting the position of control and power in research, and in enabling the co-production of knowledge. For example, within HIV research, Hodes and colleagues demonstrated how young people could be

included as partners in the design and implementation of research or programs, through participatory and arts-based methods (Hodes et al., 2018).

A range of participatory methods has been explored in order to include young people in research and to actively engage them in the co-production of knowledge. MacDonald and colleagues describe how participatory research is commonly informed by visual- and arts-based methodologies (MacDonald et al., 2011), which have been assembled in Leavy's book, '*Arts-Based Research Practice*' (Leavy, 2015). Visual arts-based methods include drawings (Tay-Lim and Lim, 2013), body mapping (Lys et al., 2018), photo voice (Velez-Grau, 2018), and collages (Khanare and De Lange, 2017). These methods can facilitate young people to express their experiences not only verbally but also through different means.

However, some participatory methods have been critiqued, and found to be challenging to practice with young people. In using drawings and collages with children, Mayaba and Wood found that even when given space to express their views, young people can feel that they lack the skill or knowledge to contribute to research (2015). With some methods, researchers may need to provide significant instructions, support and direction to enable young people to participate (Mayaba & Wood, 2015). There is also need for sensitivity to young people's emotional reactions to participation, and having support mechanisms in place (Mayaba & Wood, 2015). Further, visual methods raise questions around interpretation, validity, reliability and integration with other data (Hodes et al., 2018). Engagement with participants can sometimes be a box-ticking exercise, and as such, participatory approaches fail in their aims of empowering participants to become agents in the research process, and may misrepresent their experiences and needs as a result. Renedo and Marston found that participant engagement in decisions around healthcare involves dynamic social interplay between 'professionals' and participants, and that more or less involved participation can be shaped by participants, 'professionals' and organisations (Renedo & Marston, 2015). Despite these challenges and critique,

participatory methods have much to offer in their potential for engaging young people in research (Hodes et al., 2018).

The ethnographic method of participant observation is by definition participatory, with the direction of research controlled and shaped to a large degree by participants. For decades, ethnographic research has explored the experiences of children and young people in Southern Africa (e.g. Gelfand, 1979; Reynolds, 1991; Simpson, 2009). Reynolds conducted early ethnographic research with children in Zimbabwe, and experimented with a range of participatory methods to involve children in understanding their lives and their work (1991). In the Zambezi valley, children's work was not viewed as 'work', and Reynolds documented that their contribution to society was easily hidden (1991). Her research actively included children through participatory methods and, through this, was able to unveil this area of their lives that was usually invisible (Reynolds, 1991). For example, through using participant observation and diary methods, adolescents' everyday experiences around work, school, chores, as well as sexual experiences and fantasies were documented, and which illuminated gender differences in experiences and social expectations of adolescents (Reynolds, 1991). In such a context where young people's perspectives are often obscured, participant observation focused on young people can place their experiences at the centre of investigation and provide a platform for them to co-create their own stories.

Ethics of research with young people

Research with young people, and especially participatory research, where young people can be heavily involved in the research process, raises questions around ethics. As discussed at the beginning of this chapter, young people are in the process of growing up, in a period of social transition, with increasing autonomy and agency, while not yet socially or legally recognised as adults. This leads to ethical questions and concerns, and the development

of specific ethical guidelines to provide direction around research with young people (Nuffield, 2015).

Various scholars have debated questions around young people's ability and agency to give informed consent or assent (Cheah & Parker, 2014; Gibson et al., 2011; Higgerson et al., 2014). Different ethical guidelines suggest different ages at which young people can provide informed consent without a parent or guardian, as well as having different requirements for informed consent procedures (Vreeman et al., 2012). Vreeman and colleagues suggests that decisions around consent should be sensitive to cultural differences around the appropriateness of children to make decisions, beyond calendar age (2012). Beyond sensitivity to cultural differences, and within age-limits based on empirical evidence, Hein and colleagues suggest the importance of accounting for individual differences in child development and specific characteristics of child and parent or caregiver relationships (Hein et al., 2015). This variation, and the need to account for cultural and individual differences, mean that research with young people presents researchers conducting studies with young people with particular ethical challenges to navigate.

When viewed as too difficult, or too cumbersome to overcome, these challenges around child consent often lead to paternalistic decision-making, such as children and young people being excluded from research, and thereby excluded from the benefits that participation in research may give rise to (Farrell, 2010; Vreeman et al., 2012). Frequently, the voices of others, including parents, teachers, or healthcare providers, are used as proxies for children and young people's experience, eclipsing the active involvement of young people (Bernays et al., 2015). The importance of involving vulnerable populations in research is now emphasised in international guidelines (Council for International Organizations of Medical Sciences, 2016), but there remain regulatory hurdles of doing research with such populations. For example, consent processes requiring parent or guardian consent can hinder children's participation, particularly in research on sensitive or secretive

topics such as sexual and reproductive health (Farrell, 2010). Given these ethical challenges, the importance of responsiveness and reflexivity when conducting research with young people is heightened. This led to specific engagement with ethical issues within this thesis.

Chapter 3: Methodology

This chapter outlines the study design of this thesis, describes the selection and recruitment of participants, and details the methods of data collection. It gives an overview of general analytical methods used in this thesis, although further details of specific analyses are detailed in each chapter. I then outline ethical procedures, including the informed consent process. Lastly, this chapter details of the settings in which data collection occurred.

Study design

The literature discussed on participatory methods with young people in chapter 2 informs the choice and development of methods within this thesis. This PhD research is based on a longitudinal qualitative research with young women living with HIV. It draws on primarily on primary data collection and analysis of data from an ethnographic study in 2017-18, as well as secondary analysis of data from a qualitative study in 2014-15. The ethnographic study contributed the most substantial part of the dataset drawn on in this thesis.

Qualitative dataset for secondary analysis

Qualitative data were generated around the experiences of young women living with HIV in Lusaka, Zambia during an exploratory study in 2014-15. This study was conducted by Zambart and the International Centre for Research on Women. The aim of this study was to identify the key challenges and stigma-related concerns of adolescent girls living with HIV in Zambia as they transition to adulthood, and identify areas for intervention development to support them. I was recruited as a researcher at Zambart on this study, prior to conducting my PhD. Together with a colleague at Zambart, I recruited twenty-four young women living with HIV between the ages of 15 and 19 years to participate in the study from two urban, government health facilities

in Lusaka. We collected data between January and April 2015 through a total of four participatory workshops and 34 in-depth interviews (IDI). These explored participants' experiences living with HIV, including around disclosure, treatment, support, gender and future aspirations.

Four 6-hour participatory workshops were held with two groups of 10 and 14 participants each. Participatory tools, including creating collages, were used in the workshops. Two rounds of IDIs were then conducted with 17 participants purposefully selected from the workshops. The IDIs included using 'network tools' (Wallman, 1984) to describe the participants' 'affective networks' of who knew their HIV status, and their 'effective networks' of who provided them with support. Data were captured through audio recording, transcription and translation of interviews, note taking in the workshops, and photos of workshop materials. The main study results were published in a dissemination report, which was disseminated in Zambia and the US in 2014 (Stangl et al., 2015). Later, during my PhD research, I conducted secondary data analysis on the same dataset, namely: notes from workshops (n=4), transcriptions of IDIs (n=34), network diagrams (n=34), and photos of collages created in workshops (n=24).

The study ended in 2015, but at their request, and utilising some left-over funding, all participants were invited to participate in monthly support groups meetings spread over one year, from 2015-16, during which I sustained contact with them.

Ethnographic primary data collection

The ethnographic fieldwork, which generated the most substantial part of my dataset for this thesis, was conducted with seven of the young women living with HIV in Lusaka who had participated in the earlier qualitative research and support group intervention, described above. I purposefully sampled a sub-group of these young women to participate in the ethnographic study in 2017. The aim of the fieldwork was to understand the impact of HIV on the

everyday lives of young women living with HIV in Lusaka. The primary focus was on the individuals, their behaviours, emotions and relationships, the spaces they occupied, and the interactions they had with others. My intention was to immerse myself in participants' everyday lives to gain an understanding of all domains of their lives.

Data generation with the seven young women occurred over 12 months from September 2017 to September 2018. The main method of data generation was participant observation, which I conducted with the young women in their homes, colleges, workplaces, recreational spaces, churches and clinics, during their interactions with family, friends and boyfriends. Additional data were generated through participatory workshops, collages methods, and diaries. Details on the participants and data generation are described below.

During the course of both the qualitative and ethnographic study, from 2014 to 2018, I lived in a flat in Lusaka. I undertook Nyanja classes before and during data collection, which enabled me to have basic conversations in Nyanja, although the majority of data collection took place in English.

Participants

Recruitment for participants in ethnography

When I first contacted participants they were aged 15-16 years. I met with them and their parents or guardians to discuss their participation in the earlier qualitative study in 2015. In 2017, for the ethnographic study, I purposefully selected participants from the original sample of 24 participants based on their middle-income household status, when they were aged 17-19 years old. Middle-income was defined as their parent or guardian having a formal job, and living in a relatively affluent area of Lusaka, where there is a lower population density and houses generally have a wall around them and their own supply of electricity and water. Participants from middle-income

families were selected for three reasons, which are detailed in chapter 1. In summary, these reasons were:

- Middle-income young people are an under-researched population, despite having a high HIV prevalence in Zambia.
- The particular circumstances of middle-income young women, including going to college and high levels of mobility, were hypothesised to lead to particular experiences living with HIV.
- Most middle-income families in Lusaka speak English, enabling ease of fieldwork without a translator, which was important in enabling me to build on relationship with participants.

Table 3.1 outlines the characteristics of these seven ethnographic young women participants who were living with HIV.

Table 3.1. Characteristics of participants at the start of the ethnography (2017)

Participant*	Age	Key family member who they stay with	Orphan status	Mode of HIV acquisition	Education
Rose	19	Father and step-mother	Single orphan (father alive)	MTCT	Completed grade 12; studying to re-sit Maths and Science in 2018
Thandi	18	Mother	Single orphan (mother alive)	MTCT	Studying Clinical Officer at College, started 2017
Natasha	18	Aunt	Double orphan	MTCT	Complete Grade 12, applying for College
Rhoda	19	Grandmother	Single orphan (mother alive)	MTCT	Completed Grade 12, applying for College
Mavis	19	Grandparents	Single orphan (mother alive)	Sexual abuse	Completed Grade 12, applying for College
Mary	17	Mother and Aunt	Single orphan (mother alive)	MTCT	Studying Clinical Officer at College, started 2017
Sophie	19	Uncle and Aunt	Double orphan	MTCT	Completed Grade 12, studying to re-sit Maths and Science in 2018

*All names used are pseudonyms

The Demographic and Health Survey 2013-14 provides information on young women across Zambia (Central Statistical Office & Ministry of Health, 2014). The national HIV prevalence is 4.8% for 15-19-year-old females and 11.2% of

20-24-year-old females, and this is highest in urban areas. Across Zambia, 16.7% of 20-24-year-old females have completed secondary school (Grade 12), and 5.1% are in further education. 19.4% of 15-19-year-old females and 39.6% of 20-24-year-old females are in formal employment. 23.7% of children aged 15-17 years old are either single or double orphans, and 69.7% stay with a biological parent. 16.5% of 15-19-year-old females and 55.4% of 20-24-year-old females have been married, and 30.7% of females by the age of 18 years, and 58.9% of females by the age of 20 years old have given birth. (Central Statistical Office & Ministry of Health, 2014).

The seven participants in the ethnographic study are reflective of a minority of young women in relation to being an orphan, living with HIV, completing secondary school, not being married and not having a child. Those either formally employed (2) or in further education (2) or hoping to start further education soon (3) were also part of a minority. They are therefore not a representative sample of the population. All the participants' homes had drinking water piped into their house, a flush toilet, electricity, a TV and a fridge. This compares to urban household characteristics where 40.8% of households have drinking water piped into their house, 17.3% have a flush toilet, 61.5% have electricity, 66.0% have a TV and 43.9% have a fridge (Central Statistical Office & Ministry of Health, 2014). The young women in the ethnographic study therefore lived in households that were higher income, with greater access to amenities, than the majority of the Zambian population.

Participants for workshop with young women with negative or unknown HIV status

Additional to this ethnographic data generation, I conducted a one-day participatory workshop with a group of 14 middle-income young women who had unknown or negative HIV status. Participants for this workshop were recruited through both convenience and snowball sampling. I asked eight colleagues if they knew of any middle-income young women who had

unknown or negative HIV status, and if they did, I requested they each send the information sheet, which had the recruitment criteria and my contact number on it, to up to four young women (Appendix 1.2). If the young women themselves considered that they fulfilled the recruitment criteria and were interested, they were asked to contact me. If the young women contacted me, I first checked that they fulfilled the recruitment criteria, that they knew what the workshop would involve and were happy to participate. All of these young women were over the age of 18 years, and were asked to provide informed consent at the beginning of the workshop (see Appendix 1.2 for information sheet and informed consent forms).

Five colleagues recruited nine young women through convenience sampling. Some of these young women recruited an additional five young women through snowball sampling, totalling 14 participants (Table 3.2).

Table 3.2. Recruitment of young women with negative or unknown HIV status

Initial contact	Convenience sampling	Snowball sampling
Colleague 1	Young woman 1	Young woman 10
	Young woman 2	Young woman 11
	Young woman 3	
Colleague 2	Young woman 4	Young woman 12
	Young woman 5	
	Invited but couldn't attend	Young woman 13
Colleague 3	Young woman 6	Young woman 14
Colleague 4	Young woman 7	
	Young woman 8	
Colleague 5	Young woman 9	

Data generation methods

Participant observation

Over 12 months, I conducted participant observation with each of the seven young women recruited for the ethnographic study. Where, when, how, and with whom these observations occurred was led as much as possible by the participants themselves, as I encouraged them to choose where and when to meet with me. In the introductory workshop, I discussed with participants that I wanted to understand their lives to as great an extent as possible, and to understand their different activities and their relationships to different people they interacted with. We also discussed how the study was quite flexible. Slightly different approaches were taken with each participant, depending on their specific circumstances and how comfortable they felt with me entering into different spaces and interacting with different people in their lives.

The participant observation occurred in a range of spaces where participants spent time, including in their homes, at their colleges and workplaces, recreational spaces and churches. These were predominantly in Lusaka, but for one participant who was studying at college out of Lusaka, participant observation also occurred in Southern Province of Zambia. I describe the spaces where participant observation took place in more detail in the section on settings below. The participant observation generally occurred during weekdays. However, I made an effort to ensure participant observation was conducted in the evenings and on the weekends, to gather the most complete understanding of their lives, activities and interactions throughout the day. Evenings and weekends were often the times when the primary caregiver was in the house, and the activities in the home varied at these times. These observations were primarily with the participant themselves, but due to their interactions with others, it also included participants' families, friends, boyfriends, pastors, workmates and health professionals (Table 3.3).

Table 3.3. Family, friends, partners and professionals of participants with whom I had substantial interaction

Participants	Mother	Father	Aunts	Uncles	Grandparents	Sisters	Brothers	Cousins	Friends	Boyfriends	Maids	Workmates	Pastors	Medical professionals	Neighbours
Mary	1	d.	1					1	6					1	
Mavis		d.		1		1	1	5	3		1				1
Natasha	d.	d.	3			1	1	6	2				2		
Rhoda	1	d.	1	1	1			4	4		1	1	1	4	4
Rose	d.	1						4	3		1				
Sophie	d.	d.		1				1	1					2	
Thandi	1	d.	1					1	2	1					

d. – parent is dead

Participant observation was organised between the young women and myself, with the young women suggesting the time and place to meet up. Some of the participant observation involved conversations with the young women, some also involved conversations with people with whom they interacted, and some involved participating in the activities that the young women were doing, including cooking, shopping, and watching TV at home. After each participant observation, I wrote up detailed notes to record the space in which the participant observation took place, the conversations had, topics discussed, points of interest and areas to follow up with next time. These notes were guided by a field-note template to ensure certain details were consistently recorded at each participant observation session (Appendix 2.1).

Workshops

In addition to participant observation, I held two participatory workshops with the seven young women. The first participatory workshop was held at the beginning of ethnographic data collection. The aim of this workshop was to introduce the research to the participants as a group, and ask for their input on the research questions and the data collection tools. The workshop included a session creating collages, discussed below and in detail in chapter 4. Additionally, in the workshop, the participants and I discussed as a group how best to present the research to others in order to prevent unintentional disclosure of their HIV status. This is discussed in more detail in chapter 5.

A second participatory workshop with the seven ethnographic participants was conducted at the end of the study to present and discuss the preliminary findings of the study to participants. In this closing workshop, the participants were asked for their input around whether they felt the preliminary findings captured their experiences adequately. In particular, the findings on secrecy and silence around HIV were collectively analysed, discussed and built on in this closing workshop. This included a card storm activity, where participants brainstormed words they used to talk about HIV and ARVs, and wrote these on cards, before discussing them as a group. This workshop was also used as a way to bring closure to the study, and to be clear about what the closing of the study means in terms of contact with each other, with me as the researcher, and in terms of dissemination of results. The closure of the study is discussed more detail in chapter 5. Appendix 2.3 includes the workshop agendas for these two workshops.

Collages

During the first participatory workshop in the ethnographic study, participants were asked to make collages that represented themselves. This collage method was also used in the first workshop of the qualitative study in

2015, and the use of the collage method at these two time points is critiqued and discussed in chapter 4.

Figure 3.1. Collage making, participatory workshop, 2017

Diaries

I asked participants to write diaries for one month during the study. This tool has previously been used with children and adolescents in Zambia and elsewhere (Mupambireyi, 2017; Reynolds, 1991). In the ethnography introductory workshop, I discussed different options for keeping a diary with the young women, including written diaries, audio diaries with a voice recorder, and keeping a diary via a private social media platform. After a discussion in small groups, all participants chose to use written diaries. Participants were provided with a diary with a combination lock, which required a code in order to open the diary. This was to provide some security for the diary when the participants kept it at home. They were also provided with a pen to use for writing in the diary. Each participant was given the diary during a participant observation session.

I gave open-ended instructions about writing in the diary verbally, saying that they could write whatever they want in the diary, including, but not limited to, what they did that day, how they were feeling, how their health was, and whether anything unusual or different happened. I explained that the purpose of using the diaries in the study was for me to understand what they do on a day-to-day basis and to allow them space to talk about other aspects or things in their lives that they may not have talked to me about face-to-face. An outline of these instructions can be found in Appendix 2.2.

I called each participant two weeks after I gave each participant their diary to ask them how they were getting on with writing the diary. This was to check in on how the process was going, and to offer any support where needed. After one month, I contacted the participants to arrange to meet up to collect the diaries from them.

Figure 3.2. Diaries given to participants

Table 3.4. Data collected for each of the seven participants in the ethnography

Participants	Qualitative study 2014-16			Ethnographic study 2017-18: spaces of participant observation, and participation in workshops								Physical & visual data	
	Participatory workshops (2 groups)	In-depth interviews	Support group sessions (2 groups)	Home	College	Workplace	Recreational spaces	Church	Clinic	Zambart	Workshops (opening and closing)	Collages	Diaries
Mary	2	2	10	1	2	1	3		1		2	2	1
Mavis	2	2	10	9			5				2	2	1
Natasha	2	2	10	9			1	1			2	2	1
Rhoda	2	2	10	3		3	6	1	1	3	2	2	1
Rose	2	2	10	1			2		2	2	2	2	1
Sophie	2	2	10				6		1	2	2	2	1
Thandi	2	2	10	5	6					2	2	2	1
Total	**4**	**14**	**20**	**28**	**8**	**4**	**23**	**2**	**5**	**9**	**2**	**14**	**7**

Participatory workshops with young women with negative or unknown HIV status

Additional to participant observation, workshops, collages and diaries, I also conducted one participatory workshop with a group of 14 middle-income young women who had unknown or negative HIV status. This workshop aimed to compare the experiences of the young women living with HIV (understood through the ethnography) to their peers of similar age and experience whose HIV status is negative or unknown. The workshop was participatory and also included the participants creating collages to represent themselves. The workshop was facilitated by two experienced facilitators, which enabled me to focus on note-taking and observing interactions between participants. The topics explored in these participatory workshops were developed based on the initial findings from the ethnographic data collection and included:

1. My life so far, what is important to me, and hopes for the future (through creating collages)
2. Secrets that I keep or I share
3. Challenges I face
4. Thoughts about HIV
5. Networks and relationships

This workshop was held at Zambart, in a private room, after the 12-month period of ethnographic data collection had finished. Appendix 2.3 contains the agenda for this workshop.

Data Management

Participant observation notes were typed up in Microsoft Word after each period of participant observation. A field-notes template was used to guide note taking (Appendix 2.1). Notes were recorded as soon as possible after data collection. Workshop notes were taken at each workshop by two note-takers (myself and an additional researcher). Collages were scanned once

completed. If the scanned copies contained personal identification components (e.g. occasionally the participants wrote their names on them), I removed these from the soft copies. Once the diaries were returned, they were typed up and scanned. Where appropriate (i.e. it was considered the participant hadn't written anything that would harm her if her diary was read by someone else), and where the participant wanted to keep the diary, the diaries were returned to the participant. With one participant, both myself and the young woman considered it unsafe for her to keep the diary which she had written in, as she had written private things that she didn't want her family to read. Further, during the month during which she was writing in it, she thought that someone in her family might have tried to break into the diary. I therefore kept the diary that she had written in, and gave her a blank identical diary to keep. Photographs were taken of the spaces in which data collection took place (including participants homes, recreational spaces, health facilities etc.). I didn't take photographs of participants faces, or their family or friends, to preserve confidentiality.

All hard copies of data were stored in a box in a locked cabinet in Zambart. These included informed consent forms, diaries, and collages. All soft copies of data were stored on my personal laptop, which is password protected. In all notes, including participant observation notes, workshop notes, and typed up transcripts from the participants' diaries, I used pseudonyms for participants as well as their friends and family. I kept a list linking real names to pseudonyms, and saved this on a password-protected document, accessible only to me. This was to ensure participants' anonymity is protected as much as possible. Soft copies of visual data, for instance scanned copies of the collages and the diaries were stored on my personal laptop, in password-protected folders. I stored participants' contact details on my phone, saved under the participants' pseudonyms. The phone was password protected. After completion of this thesis, and once results have been published, the data will be transferred the LSHTM Secure Server. Data will be stored there for 10 years after study completion. The data will not be shared beyond my supervisors and myself as it contains very sensitive information, and since

the sample size is small, the risk of the data potentially identifying participants is too great. However, results have been, and will be published, with anonymised quotes.

Data analysis

Approaches to data analysis are described below. This includes analysis of the qualitative dataset generated prior to my PhD, and analysis of the ethnographic dataset generated as part of my PhD, and how analyses of both datasets were combined. I outline details of general approaches I took towards data analysis, as well as specific analyses undertaken. Further details of the specific analyses undertaken for each paper can be found within the methods sections of each paper.

Secondary data analysis of qualitative dataset

The earlier qualitative dataset, generated in the qualitative study in 2014-15, included notes from participatory workshops, transcripts from IDIs (which had been translated into English where relevant), and visual data created in the participatory workshops and IDIs, including individual collages. A coding framework was developed based on the themes explored during data generation, and the areas discussed by participants. Key codes included: learning of HIV status, disclosure to others, experiences living with HIV, relationships (with family and non-family, and intimate partners), messaging received, changes with age, experiences with ART, experiences at the clinic, support systems, and experiences related to gender. All the written data were coded using ATLAS.ti Version 7. The main study results were published in a dissemination report, which was disseminated in Zambia and the US in 2014 (Stangl et al., 2015).

For my PhD research, I conducted further, secondary analysis of these data, which contributed to the following chapters in this thesis: chapter 4, chapter

6, and chapter 8. Chapter 6 was the only chapter that drew on analysis of the qualitative dataset alone, and was the first analysis that I conducted as part of this thesis. For the analysis in chapter 6, I explore restrictive messaging, as a key theme that had emerged from the data during discussions with the research team. I focused on the written data that had been coded under 'messaging received', 'relationships', 'disclosure to others' and 'experiences with ART'. Through reading the data within these codes, and during discussions with the research team, we identified key themes of restrictive messages around disclosure, sex and adherence to treatment. From the coded data, I wrote up an analysis report that collated data and key quotes around these themes. This formed the basis of the analysis undertaken in chapter 6. It was this analysis that highlighted to me the restrictive social environment for young women living with HIV, and that contributed to my later focus in the ethnographic study on investigating the ways in which they navigate and cope with this restrictive environment. This then formed a central component in the analysis undertaken in chapter 7.

Analysis of primary ethnographic data

The secondary analysis of the qualitative dataset described above influenced the focus of the ethnographic data collection and analysis, as described above. Further, conducting the ethnography over twelve months allowed time for findings to initiate both further enquiry and deeper analysis. This was partly through the consistent inclusion of personal reflections in participant observation notes (see participant observation field-notes template in Appendix 2.1). In the notes written after each participant observation, I included details on whether there was anything striking or notable about the session, areas to look into more deeply in future data collection, key ideas that emerged or were developed from this session, and personal thoughts and reflections (Appendix 2.1). The process of ethnographic fieldwork was therefore iterative with cross-influencing between cycles of data collection, analysis and literature review. Thematic ideas (for example, on secrecy and silence, discussed in chapter 8, and on ethical issues discussed in chapter 5)

emerged inductively during data collection. These ideas built on previous analyses. For example, the theme on secrecy and silence built on the analysis regarding the restrictions placed on the young women, as secrecy was partly a response to the restrictions. Preliminary rapid analysis, and discussions with my supervisors, allowed subsequent data generation to include specific observations and active reflection on the identified themes.

The ethnographic study generated the following data: notes from participatory workshops, notes from participant observations (which were the most substantial part of the dataset), transcripts and photos of written diaries, and visual data, notably collages. All data relating to each participant were stored together, under the participants' pseudonyms, in order to preserve the narrative thread for each participant over the time in which the data were generated. During analysis I was also cognisant to group and analyse all the data on each participant to ensure understanding of their particular experiences over time. For all analyses using data generated in the ethnographic study, written data were coded manually.

Data generated in the ethnographic study was used for analyses in chapters 4, 5, 7 and 8 of this thesis. Chapter 4 includes methodological analysis and critique of visual collage methodologies. The analysis includes collages created in the qualitative study in 2015 and also in the ethnographic study in 2017. The analysis aimed to critically reflect on the collage method, including its feasibility, value for data collection, comparison to other methods and limitations to understand the experiences of young women living with HIV. For comparison purposes, data from the IDIs and workshops from both studies were also included. Since this paper is an analysis specifically of methods, the analytical methods are described in detail in the chapter (see chapter 4 for further detail).

Analyses for chapters 5 and 7 draw only on data generated in the ethnographic study. For both these analyses, the topics of enquiry arose through the iterative data collection and analytical process described above.

Through identifying the topics of 'ethical issues' (discussed in chapter 5) and 'secrecy' (discussed in chapter 7) early in fieldwork, subsequent data collection included a particular focus on these topics. For both these analyses, after the completion of data collection, data relating to the thematic areas were manually extracted from the complete dataset, and collated in a separate document, or analysis report. Data were grouped into inductive themes, and within these themes, data were inductively grouped into sub-themes. The analysis in chapter 7 also drew on the data generated in the participatory workshop with young women with unknown or negative HIV status. Workshop notes around the theme of secrecy were manually coded and comparatively analysed to the data generated through the ethnography with young women living with HIV. Particular themes that emerged through the ethnography with young women living with HIV were interrogated through comparison with the data from the workshop with young women with unknown or negative HIV status.

The analysis conducted in chapter 8 draws on a theoretical temporal framework, developed by Bonnington and colleagues (2017). This framework was identified prior to data collection, as being of particular interest because of its layered approach to viewing experiences across time, which I considered might help understand the multiple experiences of the young women that might emerge across the longitudinal enquiry. This interest in temporalities influenced the lens that I applied during data generation, including discussing with the young women how HIV impacted them both every day and across their biography. For this analysis, data were thematically coded, using the three temporalities outlined by Bonnington and colleagues: everyday time, biographical time and epochal time (2017). For this analysis, I included all written data from the seven young women who participated in the ethnographic study, including data generated in the earlier qualitative study and in the ethnographic study. I grouped the data generated by each individual together for analysis. I conducted coding manually, by reading through all the written data, and extracting data relevant to each of the three temporal themes. I collated data on each of the three temporal

themes in an analysis report, which formed the basis of the content in chapter 8. This temporal analysis was the last analysis that I conducted in this thesis.

Ethical considerations

For the qualitative study, ethical clearance was obtained from the review boards of the International Center for Research on Women in Washington, DC, USA (Approval number: 14-0009), the University of Zambia Humanities Research Ethics Committee in Lusaka, Zambia (Approval number: 00006464), and, for the analysis of the data, from the London School of Hygiene and Tropical Medicine (Approval number: 12101).

For the ethnographic study, ethical clearance was obtained from the review boards of the University of Zambia Humanities Research Ethics Committee in Lusaka, Zambia (Approval number: 006-08-17), and the London School of Hygiene and Tropical Medicine (Approval number: 13875). See appendix 1.1 for ethical approval certificates.

For the ethnographic study, participants as well as their parents or guardians were asked for their written consent to participate. Due to the home-based, intensive and intimate nature of this ethnographic study, and the cultural context of close and inter-dependent familial relationships, it was decided that it would be appropriate to involve both participants and their parents/guardians in the informed consent process. The study protocol thus stated that both participant and parental/guardian consent would be necessary for participation, despite six out of seven of the participants being over the age of 18.

Appendix 1.3 includes the standard operating procedure for the process of contacting participants and asking for their consent to participate in the ethnographic study. I outline the procedure here. Ten participants from the qualitative study cohort fulfilled the recruitment criteria of being middle-income. One of these had a mental impairment, and on ethical grounds, I

decided not to ask her to participate in the ethnographic study. Her participation in the qualitative study was facilitated through her always being together with her cousin, who was also living with HIV and a participant in the research, and who greatly supported her. However, participation in the ethnographic study, in which individual conversations, interactions and observations were central, was felt to neither be appropriate nor ethical. I contacted the remaining nine middle-income participants to ask if they were interested in participating in the ethnographic study. When I first contacted these nine young women, I initially spoke to them on the telephone to briefly discuss the study. All nine young women were interested in participating, and agreed to meet with me to discuss the research further. When we met, I explained the research in more detail. If they were interested in participating, I conducted the informed consent process. Appendix 1.2 includes the information sheets and informed consent forms. Participant's parents/ guardians were first asked for their written informed consent, and if that was given, then the participant was asked for her written informed consent. When asking for parental or guardian consent, two of the participants reported that their guardians did not want them to participate. In the case of one potential participant, this was because her sister (her guardian) was currently going through a challenging divorce, and needed the potential participant at home to support her and look after her children. In the case of the other potential participant, her grandmother refused for her to participate, possibly because of the fear that it might impact the potential participant's mental health, as she had reported having been very depressed following a stillbirth a year earlier, although this reason was not explicit. Seven participants therefore participated in the ethnographic study, and there were no dropouts during the duration of the study.

The primary risk for participants in the research was considered unintentional disclosure of the young women's HIV status. This was openly discussed with participants during the consent process as well as regularly during the research. In the introductory workshop, participants were asked to collectively decide how to describe the research to others who did not

know their HIV status in a way that protected their HIV status and that of other participants. A consensus was reached to describe the research to others who did not know their HIV status as anthropological research looking at the everyday lives of young women in Lusaka, thereby maintaining confidentiality about HIV status unless participants explicitly gave permission. I also agreed to adapt this to the specific circumstances for each participant, if the participant felt that a different story would be more appropriate in a particular context to hide their HIV status.

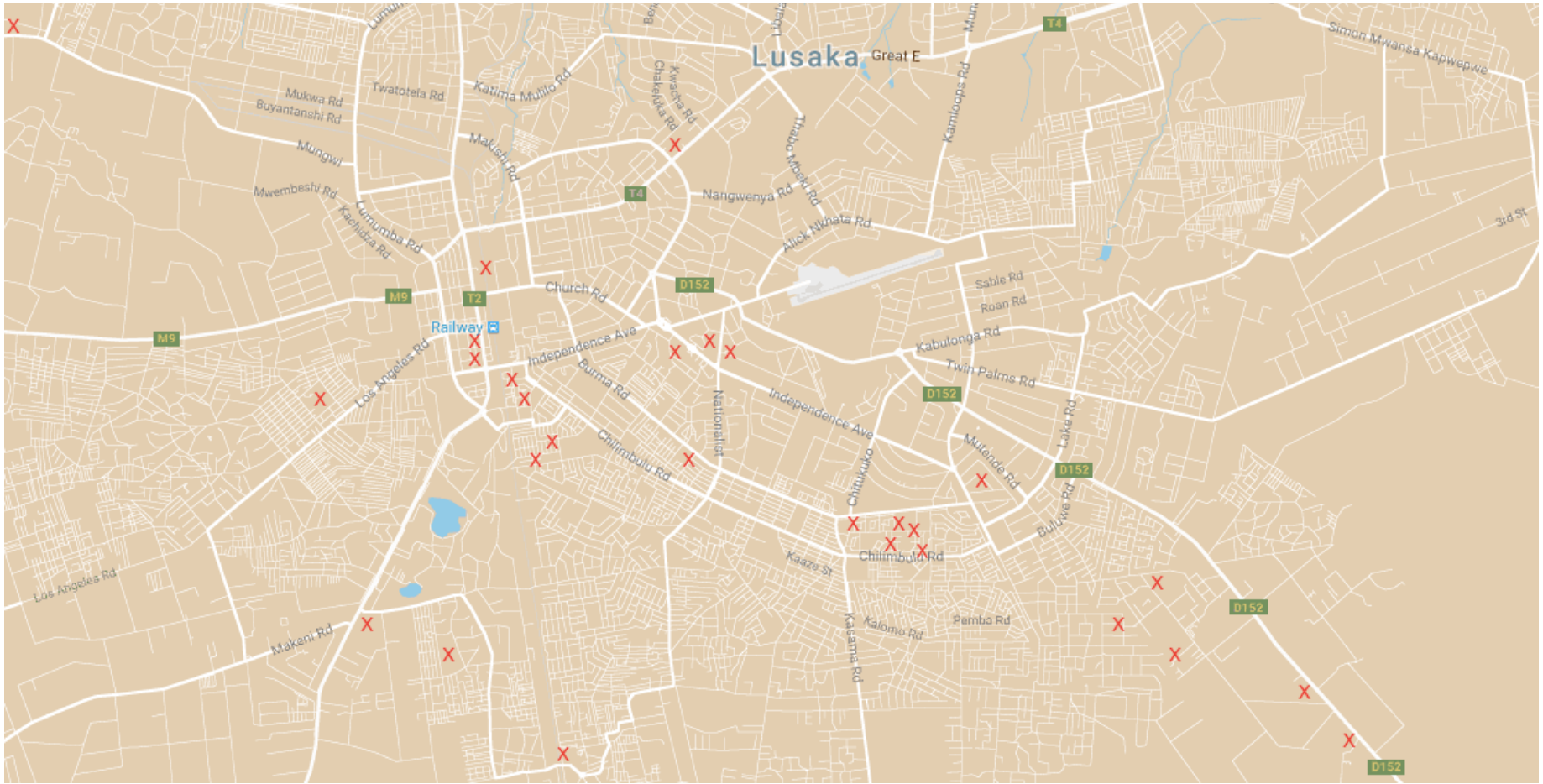
A number of ethical challenges were faced throughout the research, and this was a key area of reflection. These are discussed in detail in chapter 5.

Settings of ethnography

Lusaka

Zambia is divided into 10 provinces, with Lusaka being the largest urban province and the capital of Zambia, in the south-central part of the country (Central Statistical Office & Ministry of Health, 2014). Lusaka is separated into many geographical zones, which often reflect different socio-economic status and levels of population density. High, medium and low-density areas are situated next to each other and in close proximity. Lower income and high-density areas are referred to locally as "compounds" and often mainly consist of one to three room housing usually built of concrete blocks, with no fence around them, and limited space between houses. Within these high-density areas, there is usually one tarred road demarcating the boundary of the area, and a network of small dirt roads, which frequently get flooded in rainy season. Middle income and medium-density areas are connected with several tarred roads, with dirt roads connecting the tarred roads to residential areas. The houses are spaced apart, leading to a lower-density of housing in these areas. This PhD study was predominantly conducted in these middle income, medium-density areas, as the focus was on middle-income young women.

Figure 3.3. Map of Lusaka with area locations where participant observation occurred



Map data ©2018 Google

Homes

Much of the participant observation took place in the young women's homes, including observing interactions with their families. I observed and participated in activities such as preparing and eating food, chores such as sweeping or cleaning, Bible reading at home, meeting with other family members and guests, relaxing and watching television.

All participants lived in middle-income areas of Lusaka, with several of their families owning the plot of land and the house, while some rented. In these middle-income areas, the typical house was surrounded by a boundary, either a wall or a fence, with a gate at the entrance, and a yard around the house, where there usually were washing lines, and sometimes a tap for water. In three of the participants' yards, their families were in the process of building an extra building, either as an extension of the house, or to rent for extra income.

Figure 3.4. Photos of roads, houses and walls, near participants' homes

Inside most participants' houses, there was a kitchen, living room, usually two bedrooms, a toilet, and usually a separate washing room. The kitchen was usually a relatively small room, with a sink with running water, a fridge, shelves with pots and pans, and usually a gas cooker. The living room was the formal room of the house, with the nicest furniture, always including a sofa and armchair set, a large flat screen television on a television stand, with speakers, and a low table in the centre of the room. In most of the houses, in

the living room, family photos were hung up on the walls. The head of the household (which were mostly female) always had their own bedroom, which was a private room, with the door usually shut. I had more access to the other bedroom(s), which usually had a few beds in there, sometimes with two or more people sharing a bed. In the bedrooms, there was usually a bedside table with a mirror, a tall cupboard and a chest of drawers with clothes. Many bedrooms had suitcases and bags full of clothes and other items stored there. The toilet was usually in a small room, with a flush, and most of the houses had a separate small washing or shower room, with an enamel floor.

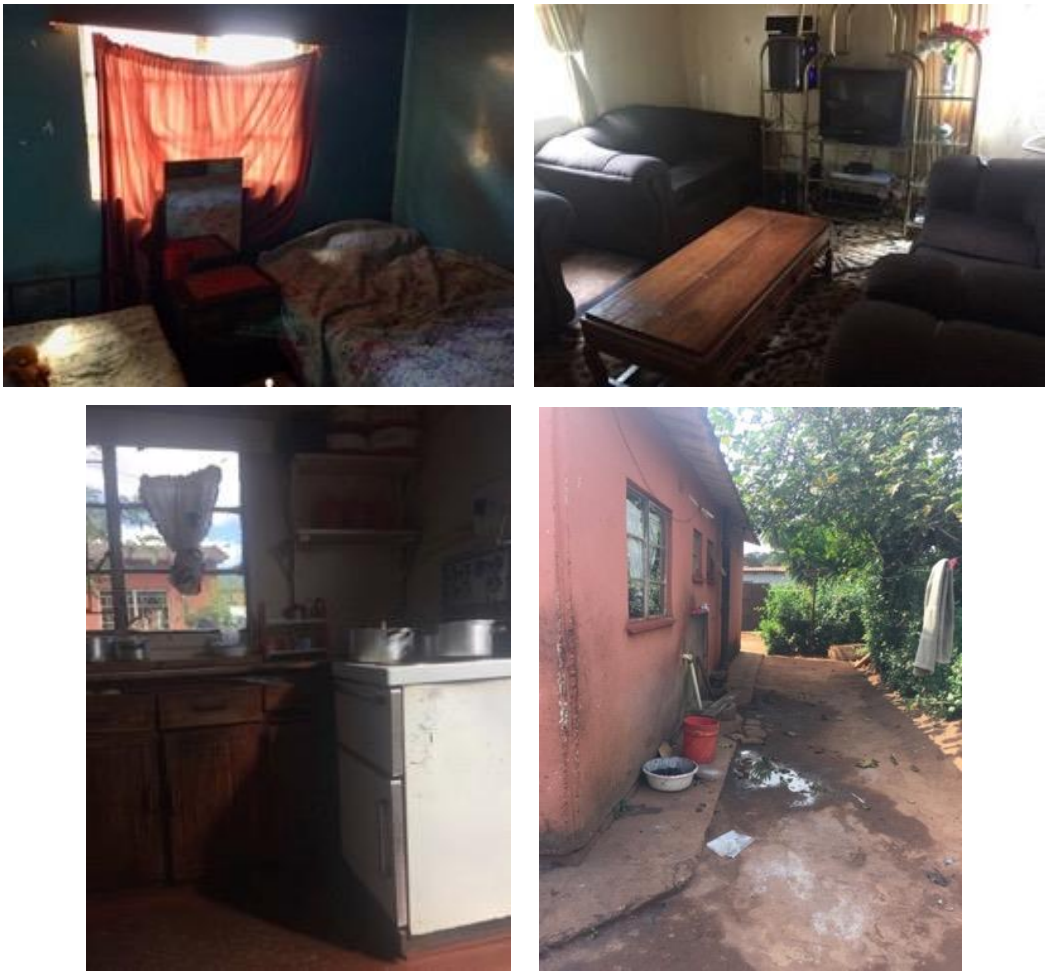
Participant observation notes with Rhoda, 2018

> *The house was behind a big, well-kept gate. Immediately when you came into the yard, there were lots of building cement blocks, and the first few layers of building cement blocks have been laid for an extension of the house. The house took up most of their plot, with a small yard at the back for hanging laundry. I later learned that Rhoda's grandmother owned the house. She had bought it back in 1969. She said that she was trying to build the extension because the house got so full especially during holidays with all her grandchildren coming to stay. She said that sometimes they have 18 people coming to stay during the holidays! I found that quite astonishing in a relatively small, albeit well-kept, house.*
>
> *The house consisted of four main rooms, firstly the kitchen when you walked in, which was tidy with big table and a big fridge, as well as shelves for pots and pans. In the living room there were three comfortable brown velour sofas, with cushions covered in chitenge, and a big flat-screen TV on TV stand. There were two rooms leading off the living area living room: firstly, the grandmother's bedroom, and secondly, Auntie Beatrice's bedroom. The grandmother said that Auntie Beatrice's bedroom could not really be described as her bedroom because there were so many people living there. There was also a toilet and a washing room round the back of the house. The extension that they*

were building was supposed to extend the living room so that it could be much bigger, and then also build another bedroom.

I said to the grandmother that I thought it was a very convenient location for the house, so close to town. She said that it was, but that when it rains, the roads can be terrible. She said that the roads can get really flooded, which is a problem. I asked if it was better now that the tarmac road had been built within the last year, leading to their road. She said, yes it was much better but the floods were still really bad on their road, and she thought it was important that they should tarmac the road that they lived on.

Figure 3.5. Photos of participants' homes: a) bedroom b) living room; c) kitchen; and d) yard



College

Two of the participants were studying at college at the time of the study, and I met with both of them at their colleges. With one, Thandi, I frequently met with her outside the college, as she wanted to avoid being asked too many questions by her classmates. The other participant at college, Mary, invited me to walk around her collage, giving me a full tour of the buildings, the lecture rooms, the boarding houses, and her dormitory. Both young women at college stayed in college-owned and college-run boarding houses. Thandi stayed in a four-person dormitory, Mary in an eight-person dormitory, both of them choosing to sleep on the top bunks, where they felt there was more privacy to store their ARVS.

Participant observation notes, Mary, 2018

> *After we had met in town, Mary offered to show me around her college. I was thrilled to get this opportunity. Mary first took me to her dormitory. This was in one of eight boarding colleges (four for boys and four for girls). She had chosen one of the boarding colleges that was more expensive, as she explained that in the two cheaper ones, you had to share with 25 other girls. We entered the boarding house. It was spacious and very clean. The entrance hall led to three corridors, with doors to the rooms all the way along each. We walked straight ahead, through a 'common room', where students were sitting watching TV. We walked to the end of the corridor, and then Mary showed me into her dormitory. The room was quite spacious, with 4 bunk beds to sleep 8 young women. Only four of the roommates were back from the holidays: by their beds, they had their suitcases on the floor, and clothes on chairs. By each bed there was a metal truck, which I later confirmed with Mary was where she keeps her medicine. Mary's bed was the top bunk, but her friend was sleeping in it. There were a few wooden chairs, a clothes hanger holding knickers out the window, hangers with coats and clothes handing off the bed, but the centre of the room was empty.*

Four of Mary's roommates were in the room, all lying on their beds, chatting or sleeping or watching films. I greeted them all and we had a nice conversation. They found it hilarious when I spoke Nyanja to them, and Mary said "you see, I told you my roommates are crazy!" Mary told them that she was going to give me a tour of the college. Two of her roommates said that they wanted to join to the main building, as they had to hand in some forms to the admin office. One of the roommates asked Mary to bring her back some chicken, and gave Mary money for it. Mary changed from her black jeans to a black stretchy knee-length pencil skirt, as she said that they are not allowed to walk around campus in jeans. The other girls who walked with us were wearing similar pencil skirts.

We walked out of the dormitories to the main University building. It was an impressive big building, three stories, built mostly in red brick. To reach there, we passed through an open area, which Mary said was where graduations happened. There were several students sitting on the steps and old desks there. On the left as we walked towards the main building, there was a single-story building, which is where Mary said that they have their exams and sometimes church readings. We walked into the main building. There were lots of students gathered there, some with papers to hand into the admin block, others meeting and chatting. Mary and her friends bumped into quite a few people who they knew, and we greeted them, and I introduced myself, although never needing to give many details as to who I was. We walked up to the top floor of the main building, and Mary showed me around some of the classrooms. Some were large lecture-style rooms, others small rooms with few chairs and tables. Mary said that some of her classes there were 300 students, but in others only 15 or so. We walked past computer labs that any student can use. Mary said that most students have their own laptop, but some don't and anyone can use the computer labs.

From the main building, Mary walked with me through the rest of the campus. We passed the buildings where students can do photocopying and printing. The whole campus was beautifully laid out, with lovely glades of trees between buildings and boarding houses. We bumped into a few of Mary's friends as we walked and had conversations with some of them. We also saw Mary's cousin outside his boarding house. Each boarding house was contained in its own area, and Mary said it's forbidden for boys and girls to go into each other's boarding houses, except one day a year, when everyone is free to go into the other boarding houses. We walked through much of the campus, passing a modern-designed library building and the church. We reached a tuck-shop attached to one of the boarding houses, and went inside to buy chicken for Mary's roommate. While we were there, Mary talked to the staff about ordering a cake for her friend's birthday.

We walked back through the campus, and Mary said that the last part of the campus that she wanted to show me was the dam. We walked out of the campus, and felt very quickly like we were in the bush. Mary said "see what I mean when I say the school is in the middle of the bush". We turned the corner and could see the dam, which was a beautiful lake, surrounded by bush. When we were there, a couple arrived, and Mary pointed out another couple the other side of the lake. She said, "this is where couples like to come to play!" I asked her if she came here with her boyfriend, and she said she did sometimes. But she also came alone when everything was a bit stressful, or she was annoyed at a roommate, as it was a beautiful place to unwind.

Figure 3.6. Photos of college dormitory

Workplace

During the period of the ethnography, two of the young women had regular formal jobs, and a couple of others had informal jobs. For one young woman who had a formal job, Rhoda, I met her several times at her workplace (an internet and printing shop), including with her colleague and clients who came into the shop.

Participant observation notes with Rhoda, 2017

> *I met with Rhoda at her workplace. She is working as an IT/printing company and has been working there for about the last month. There were two other people in her company both men. She says that it's been good to work, it's been good to do things, but it is quite tiresome and tiring. She said it's been good because she's been able to learn a lot of things about IT and she's become quite an expert now, in terms of printing or photocopying or doing things around IT. She got the job through her cousin, who used to work there, but he stopped working there, so she got the job.*

Rhoda invited me to come inside and to sit on the small sofa by the entrance. The office was small, with one large desk in it, where Rhoda sat. On this desk, there were two printers (one black and white, one colour), a binding machine, a laminating machine, and a desktop computer. Rhoda's desk was clearly was the main desk, and when her colleague is in the office, Rhoda said that he sat at "the number two desk". There were also two big scanners/ photocopiers, plus about five booths with desktops for clients to use. The office was small, but clearly offered a good range of printing and copying services.

It was nice to see Rhoda in her professional environment. She seemed knowledgeable and efficient at her work. One client came in while I was there, asking to photocopy a card of hers. Without any hassle, Rhoda photocopied it, and organised the payment very efficiently.

Recreational spaces

With all the seven young women, data collection occurred in recreational spaces, including shopping malls, cafes, markets, and sometimes on the street. I met many of the young women in cafés near their homes. These were usually in small shopping malls. The cafes were usually relatively small, with a couple of people working there, selling cold soft drinks and some fast food, for instance kebabs, pizza or sausage and chips. These meetings were usually alone with the young women, but occasionally their friends or family joined. We mostly sat outside the café for relative privacy to talk openly, although people walked past frequently, and occasionally participants' friends would come and greet them and talk to us.

A handful of times I went shopping with participants in a market, for instance when Sophie was buying groceries with her young cousin, or when another Mavis was buying clothes. We would walk together through the market, looking at various stalls, and talking together. Sometimes I would accompany the young women when they had to run errands. When we walked on the

streets near participants' houses, they frequently greeted friends and acquaintances of theirs. Usually this was a passing greeting, but occasionally it turned into longer conversations, and I met a number of the participants' friends and neighbours this way. The young women usually introduced me as a friend of theirs, and they were usually open and friendly.

Participant observation notes with Mavis, 2018

> *Mavis said that she had reserved some clothes yesterday, but hadn't had the money to buy them then. If she didn't come back with the money today, they might be sold to someone else. So, we went to the market together. It was nice wandering around the market with Mavis. We walked past the place where she gets her hair plaited, we walked past lots of shops with people tailoring, some with people selling food, others old TVs, and others corner shops. The market was full of little windy paths through the shops. Mavis explained the structure of the market to me – which parts were new, which parts were pulled down and rebuilt, where the large food market was, and where her Grandmother usually sold fritters. She greeted a couple of people as we walked, including a young woman who she said plaits her hair.*
>
> *We reached the shop where Mavis had reserved her skirt and crop top. It was a 'salaula' (second hand clothes) market, with second hand clothes hanging up, and a young woman looking after the shop, who was the cousin to the owner. Mavis asked for her clothes, and it took quite a while for the woman to find them. In the meantime, Mavis was anxious that they had been sold, saying that she would be so upset if they had been sold, as she loved them, and they made such a nice outfit together. While we waited, we looked through the clothes hanging, and showed each other ones we liked, and laughed at some of the clothes. Mavis particularly liked the crop tops. The young woman manning the stall talked to us a bit, asking how Mavis knew me, to which Mavis replied that I was just a friend. Finally, someone came with the skirt and crop*

top for Mavis and she beamed that they weren't yet sold. She paid 40 kwacha (£4) and we left with them, back through the market, with Mavis saying how thrilled she was that she had them.

Figure 3.7. Photos of recreational spaces where I met with participants: markets, cafes and shopping malls

Church

All seven of the young women were Christian, and I attended church services with two of them. The setting of each church was relatively similar, with wooden benches for the congregation, a stage decorated with fake flowers,

banners, and a microphone for the pastor, and with areas at the front for the choir and band.

Participant observation notes with Natasha, 2017

> *As we were walking to church, we passed several other churches. It was clear that there were quite a large number of church groups in this area. There were several Sunday groups who were meeting there in the school where Natasha and her cousin used to go. The church that Natasha and her family go to was under a big white tent. There were lots of chairs laid out in rows. As a rough estimate, I would say that there were about 150 people there. At the back there were a few tables: one with information, one with visitors' information and sign-up. At the front there was a stage, with two pots of fake flowers, and one real flower arrangement at the front. There was one pulpit in the middle. To the left, the choir and the band sat: there were six singers in the choir, a guitarist, drummer, and the pianist. Two of the singers were part of Natasha's family: one was her cousin; the other was her sister's husband.*
>
> *We arrived late, when the singing had started. The entire congregation joined in the singing: when the singing was taking place, everyone was standing up, swaying from side to side, and dancing, and clapping along to the music. It was very interactive and lively. I joined in the singing and dancing enthusiastically where I could. I was glad I did, as quite early on in the service, the pastor pointed to a few people at the back, and said that they should feel the spirit more, and then pointed to me, saying that even our new friends here have been dancing very enthusiastically.*

Health facilities

The young women attended one of two health facilities in Lusaka. I attended both health facilities with participants when they went for their 'review' to be

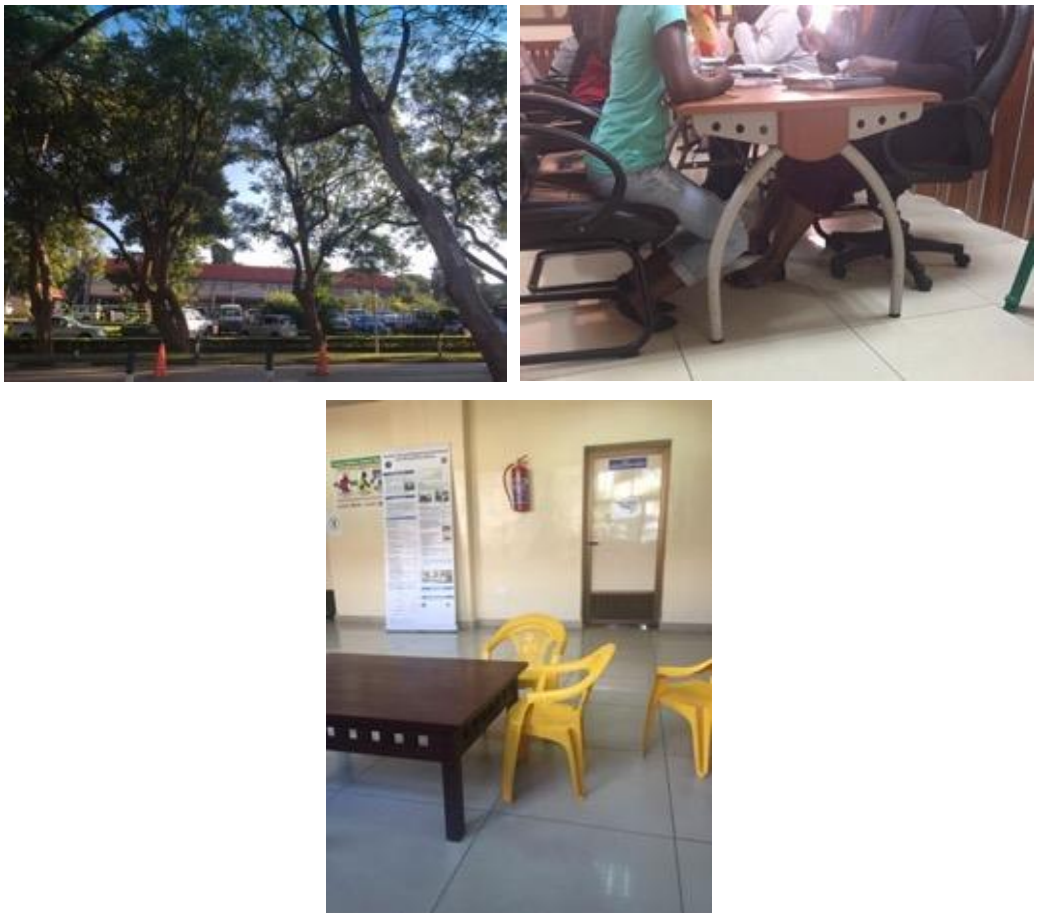
seen by the doctor and collect their ART. The two health facilities were strikingly different.

Participant observation notes, with Rhoda, 2018 (in health facility 1)

> *The whole space was exceptionally clean, with enough chairs to sit in. The entrance opens out into a big room. In the middle is the reception, where visitors sign in. Behind there is a room, with glass walls, which is where patient's height and weight is taken. There are two nurses in that room, with a desk and equipment such as weighing scales, and blood pressure machines. To the left of that room is a waiting area, as well as the registry. The registry is one room, manned by one woman, who organizes the next appointments, and registers any new files. On the right is another waiting area with wooden benches, as well as small plastic tables and chairs for children. The space is made to be quite child-friendly, with the small plastic chairs, and with a television on in the waiting area. On the right by the entrance is the pharmacy, where all the medicines are dispensed. On the far right of the entrance room are the toilets, and also the 'blood test room' where blood samples are taken from patients for viral load tests.*
>
> *If you follow the corridor round to the right, there are a few doors off the side, where nurses sit. This is where 'adherence' is done, where the nurses ask a set of questions to assess the patient's current health and their adherence to medication. Those waiting for 'adherence' sit on benches in the corner of the corridor. At the end of the corridor, in the corner, is a table with two nurses seated on it, where 'nutrition counselling' is conducted. Patients sit opposite each nurse to discuss with him or her. Behind the 'nutrition table', is a large 'conference room'. This appears to act partly as a storage room, but also has lots of chairs and is where the peer education discussions occur.*

Further along the corridor, around the corner is another waiting area with benches and plastic tables and chairs for children. There are four doctors' offices that lead from this waiting area, each for an individual doctor. The whole space was clean, and the floors were even mopped while we were waiting for the doctor.

Figure 3.8. Photos of health facility 1



Participant observation notes with Sophie, 2018 (in health facility 2)

Whilst I was waiting for Sophie, I had plenty of time to observe the clinic space, and to begin to understand the process and the interactions between health workers and clients there. The ART clinic was located right at the back of the main clinic. You had to walk past all the other clinic buildings to reach it. But then once you were inside the ART area, it was relatively private, and one assumed everyone who was there was there for ART. There was a very friendly atmosphere between the clients

waiting, with lots of chatting and laughing together. The main building was along one side of the area. Inside this building was a long corridor all the way through with offices off the corridor. This was where all the doctors' and nurses' rooms were. On the outside wall of this main building, there was a small window, which opened onto the pharmacy room. There was a large crowd outside the pharmacy, waiting to collect their medicines.

Outside, there was a covered shelter, with no walls, where I sat waiting for Sophie, and where others sat waiting to be called by the nurses. The nurses sat in the entrance to the main building and shouted out names of clients. Next to this were two red containers, where all the files were kept. Two men in white coats were responsible for finding the files. These file rooms were where everyone went when they first arrived, to collect their files, and start the process. There was a small crowd of people outside the file container waiting to collect their files.

Figure 3.9. Photos of health facility 2

Zambart

The participatory workshops with the young women were held at Zambart. The workshops were held in the conference room, which is a large room with windows looking out onto the garden at the back of the building. The building

and room were familiar to all participants who had all attended previous participatory workshops there in a prior qualitative study. The room provided privacy for the workshop, and a neutral space where the young women felt comfortable, even taking selfies of themselves around the room while waiting for the workshop to begin.

Since the young women knew Zambart and knew that I worked there, a couple of participants visited me there when they were passing by. Rhoda, visited me there with her friend, as she had wanted to talk to me and introduce her friend. We sat outside in the garden, talking and catching up on her life.

Figure 3.10. Photo of space for participatory workshops

Participation observation notes with Rhoda, 2017

> *The space in the Zambart conference room was a nice place to meet. We mostly had privacy, except for a couple of Zambart staff walking through. Rhoda towards the end said: "I really miss this place. It is filled with so many good memories. I always think of it as a safe place." She then took a few selfies of the two of us; almost as a way of showing how much she liked the place and how she'd enjoyed spending time there with me.*

Chapter 4: Critical Reflections on Individual Collages as a Research Method with Young Women Living with HIV in Zambia

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Student ID Number	1511419	**Title**	Ms
First Name(s)	Constance		
Surname/Family Name	Mackworth-Young		
Thesis Title	An ethnographic study of the everyday lives of young women living with HIV in Zambia		
Primary Supervisor	Dr Virginia Bond		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

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Where was the work published?			
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Stage of publication	**Undergoing revision**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	This paper draws on data from two studies. The first study was led and designed by VB and AS, with data collection conducted by SC, MC, CC, KK and myself. The second study was led and designed by me, and I conducted all data collection, with some assistance in the participatory workshops from MM and MM. I led on analysis and writing for the paper, including writing the first draft. All authors commented on the paper and gave final approval.

SECTION E

Student Signature	[redacted]
Date	02/12/2019

Supervisor Signature	[redacted]
Date	10/12/2019

Overview

> *"The collages are all me; they have helped me express myself. I'm not afraid to talk about my status on a collage. It's very expressive, and we can all say lots of different things on the same picture."*
>
> Sophie, participatory workshop, 2018

In Chapter 2, I engaged with existing literature around using participatory methods with young people, which emphasised the importance of methods which actively engage young people in the generation of data that represent their lives. And in chapter 3, I outline how I used participatory methods in this thesis.

In this paper, I critically reflect on individual collages as one of these participatory methods that I used. I describe the method, and critique its feasibility, value and limitations, to understand the experiences of young women living with HIV, and how the method compares to other methods of data collection. I draw on the experience of creating collages with the young women in workshops at two time points: firstly in 2015 during the qualitative research that preceded my PhD research, and secondly in 2017, in the introductory workshop of the ethnographic study that I conducted during my PhD. Analysis of the collages from these two time points enabled me not only to have a deeper understanding of the utility of the method, having conducted it twice with different groups, but also provided me with the opportunity to compare the collages created by the same individuals almost three years apart.

The findings presented in the paper demonstrate that the collage method was feasible, enjoyable for the participants and that it facilitated the active self-representation of the young women. The findings further show that in this context, the collage method not only gathered valuable data, but also went beyond traditional research methods by providing a space for the young

women's positive self-reflection, processing of emotions, and self-expression of their diverse and complex identities.

This paper contributes to research objective 4:

4. To explore and critique the use of participatory methods with young women living with HIV

Critical Reflections on Individual Collages as a Research Method with Young Women Living with HIV in Zambia

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Abstract

Art-based research methods can enable young people to generate data that provide insights into their lives. We assessed the feasibility, value and limitations of collages as a participatory research method to understand the experiences of young women living with HIV. Individual collages were created in participatory workshops, firstly in 2015 and secondly in 2017, by a cohort of young women living with HIV in Lusaka, Zambia. Collages were analysed visually and thematically and compared to other qualitative methods. Participants engaged readily with making collages, and expressed how the collages represented themselves. The collages conveyed aspirations, resilience, optimism and identities beyond HIV. Other data collection methods focused more on challenges associated with HIV. The second collages demonstrated more complex portrayals of participants' life and developmental transitions. Collages provided a feasible, effective and therapeutic method of empowering young women living with HIV to tell their own stories and express their full selves.

Introduction

Over the past decade, heightened global attention on the health and wellbeing of adolescents and young people (Patton et al., 2016; World Health Organization, 2017a) has yielded a burgeoning number of research studies employing a range of methods. Young people (aged 10-24 years) are increasingly being viewed as participants in the research process, rather than merely research subjects (Bernays et al., 2015; Kirk, 2007; MacDonald et al., 2011). This reflects the move from the out-dated conceptualisation of children and young people as passive and unfinished persons to active contributors to social life (James & Prout, 2015; Prout, 2000). However, authentic involvement of young people in the data production process is often challenging. This can be due to young people feeling inadequately skilled or knowledgeable to contribute, the researchers' need to scaffold the research process (i.e. providing instructions, support and direction), and a lack of sensitivity to young people's emotional reactions (Mayaba & Wood, 2015). Traditional research methodologies (e.g. structured and semi-structured interviews) may not adequately facilitate meaningful participation and self-expression in young people, due to the researchers holding more control over the direction of investigation (Leavy, 2015). Participatory and arts-based research can offer alternative methods, which address some of these limitations, either alone or in conjunction with traditional research methodologies. This study presents the use of collage methods, alongside in-depth interviews (IDIs) and participatory workshops, and demonstrates their added value.

Innovative, participatory, and arts-based research methods give young people a means to express themselves, and their concerns, aspirations and needs (Campbell et al., 2015; MacDonald et al., 2011). As Ansell and colleagues describe, "participatory research is concerned with producing knowledge *with*, rather than *about*, those who are the subjects of the research" (2012, p. 169). Visual arts-based methods, including drawings (Tay-Lim & Lim, 2013), body mapping (Lys, Gesink, Strike, & Larkin, 2018),

photo voice (Velez-Grau, 2018), and collages (Khanare & De Lange, 2017), have been shown to be appropriate, empowering and therapeutic data generation tools for conducting research *with* children, adolescents and young people across a range of disciplines and topic areas (Chiiya, Chonta, Clay, Kidd, & Rohr-Rouendaal, 2010; Mayaba & Wood, 2015; Rodriguez Vega, 2018; Tay-Lim & Lim, 2013; Theron, Mitchell, Smith, & Stuart, 2011; Thomson, 2008). Campbell et al. describe using 'draw-and-write' exercises with school children to understand their representations of HIV-affected peers in Zimbabwe (2015). They demonstrate how these arts-based methods encouraged independent reflection and self-representation by children, despite limited agency due to the constraints and lack of power in their lives (Campbell et al., 2015). Taking a social constructionist viewpoint, the meaning from such arts-based data is understood, not as authentic representations of experience, but rather as acknowledging the co-production and socially-embedded nature of the data in the context of research (Blumer, 1969; Kitzinger, 1994; Seale, Charteris-Black, Dumelow, Locock, & Ziebland, 2008).

Collages are one art-based method that can be used effectively with young people, who can be marginalised by more traditional research methods. Marginalised populations, such as young women, can be disempowered in interview settings or group workshops due to power dynamics between researcher and participant (Leavy, 2015). Collages can achieve the balance of being fun for young people and, simultaneously, being accessible for those who may be daunted by drawing. Khanare and De Lange (2017) have shown how, in the production of group collages in South Africa, school children can show an intense sense of engagement in the process of selecting how to represent their experiences. They show how, through group collages, school children could present their ideas of what they need in terms of care and support at school in the context of HIV (Khanare & De Lange, 2017). As such, children could be included as knowledge producers to contribute to school decision-making processes (Khanare & De Lange, 2017). Despite a few studies detailing the findings from the use of collages with young people and

other marginalised populations, there has been relatively little critical reflection on the method, including the potential challenges and the lessons learnt.

As they grow up, and transition to adulthood, young people living with HIV face a host of complex challenges. These include challenges relating to adherence to antiretroviral therapy (ART) (Bernays et al., 2017; Denison et al., 2015; Fields et al., 2017); disclosure of their HIV status (Kidia et al., 2014; Mburu et al., 2014); mental health (Menon, Glazebrook, Campain, & Ngoma, 2007); anxiety around body image (Ezekiel et al., 2009); concerns around sexual relationships (Busza et al., 2013; Fernet et al., 2011; FHI360, 2013; Vujovic et al., 2014); anticipated or experienced stigma (Winskell, Hill, et al., 2011); and restrictions on their behaviours (Mackworth-Young. et al., 2017). Although less prominently discussed, young people living with HIV often display resilience in the face of these and other challenges (Adegoke & Steyn, 2017, 2018; Skovdal & Daniel, 2012). However, in part because of limited disclosure, and in part because of limited effective support options, young people living with HIV are rarely given the space to express these concerns and their resilience (Mackworth-Young. et al., 2017). Applying arts-based research methods with young women living with HIV has the potential to support expression of feelings that may be difficult to put into words, including around experiences living with HIV, such as stigma, loss and trauma, as well as resilience.

In this article, we critically reflect on the collage method, including its feasibility, value for data collection, comparison to other methods, and limitations to understand the experiences of young women living with HIV. We draw on research with young women living with HIV (aged 15-19 years) in Lusaka, Zambia who participated in creating individual collages at two time-points.

Methods

Study overview

In the context of two linked and consecutive qualitative studies investigating the experiences of young women living with HIV, individual collages were created by young women living with HIV at two time points. The first time point was in January 2015, with 24 young women living with HIV (then aged 15-18 years), recruited from two health facilities in Lusaka, who each created an individual collage. The second time point was in September 2017, with seven of the same participants (then aged 17-19 years), who were asked to participate in a follow-up study, and who each created a second individual collage. In the two linked studies, the collage was one research activity embedded in other qualitative methods, namely participatory workshops and in-depth interviews (IDIs), to investigate young women's experiences of living with HIV. The rationale for including a variety of methods follows Langevang's suggestion that combining data generation approaches enables researchers to capture "the diversity and complexity of youth experiences in the present as well as longitudinal processes of transition" (2007, p. 267).

These studies spanned a key period of the young women's lives, as they transitioned into adulthood, including leaving school. All the young women were black Zambian, from mixed Zambian ethnic groups. The seven young women who created collages in September 2017 were all middle-income. The young women in this study were marginalised in some ways (e.g. age, gender and health status), but not in others (e.g. for some, economically).

Participatory Workshops and Collages

The individual collages were created in two introductory participatory workshops, which were held at the beginning of each of the two studies, with the first study introductory workshop in January 2015 and the second study introductory workshop in September 2017. These workshops were held in a

private space that was accessible for participants, run by facilitators trained in adolescent counselling and participatory methods. The workshop in January 2015 was co-facilitated by a young woman living with HIV. Collages were introduced by the facilitators primarily as an icebreaker tool at the beginning of the first workshop. The facilitators chose to use the collage method as they felt that producing collages would encourage participants to start telling stories about their broad lives and to interact in a safe way with the other participants and the facilitators who they were meeting for the first time. This method was selected again for the second workshop during the follow-up study with a sub-set of participants (n=7), as it had worked well previously both as an icebreaker and as a data collection activity. Additionally, the researchers felt that comparisons with the earlier collages might help understand participants' transitions over time. The workshops were recorded through note-taking by two researchers. Notes included researchers' reflections on the use of individual collages as a method for understanding the experiences of the participants, and how collage making compared to the other forms of data collection used.

Individual Collage Activity

Prior to creating the first collage, facilitators explained to the participants that a collage is a piece of artwork that is made up of images, drawings and words used to represent oneself. To illustrate this, the young woman living with HIV co-facilitator prepared a collage and showed it to participants as an example. Participants were then given relatively open-ended instructions to each create a collage that they felt represented themselves, what they liked, what they had experienced in the past, and what they wanted in the future. They were provided with scissors, glue, colourful pens, an array of different magazines and newspapers and a sheet of A3 card each, and given around one and a half hours to create an individual collage (Figure 4.1). Magazines provided included those on fashion, travel, food and home, with most magazines purposively chosen and produced in South Africa, to represent appropriate ethnicities. For the second collage, the researcher verbally

reminded participants about the collage that they had previously made. They were given the same materials as before and given similar instructions to create a collage. Participants were not shown their first collages before creating their second collages, but were asked to reflect on the period between their two collages when making their second collage.

Figure 4.1. Participants making collages (Participatory Workshop, September 2017)

After each of the collages were made, the participants were asked to explain them to the wider workshop group, and were probed to describe why they had included certain words, pictures and visuals. Participants were encouraged to use the collages as an aid to tell their experiences as young women living with HIV. The workshop facilitators probed participants to describe their stories in more detail and to discuss why they had included parts of their collage that they did not mention when presenting their collage. They were also asked if the time and materials at hand had limited them in any way. After creation and discussion about the individual collages in each study, the collages were scanned.

In-depth Interviews and Collages

After the workshops in which the collages were created, participants took part in individual IDIs. The IDIs covered a range of topics, including disclosure, support they received, their relationships, and experiences at the clinic and with treatment. The interview guide included open-ended questions, with the focus on understanding participants' experiences of HIV. One component of the IDIs offered participants the opportunity to give extra detail about their collages. Participants were shown their collages again and were asked in more detail to describe what the collages represented about themselves, their experiences and their aspirations for the future. The IDIs after the first set of collages were semi-structured, took place in a private room in the clinic or Zambart's head office in Lusaka, and were recorded, transcribed and translated. The IDIs after the second set of collages were unstructured, took place in participants' homes, and were recorded through note-taking.

The participants were offered the option of keeping their individual collages after the IDIs. It was emphasised that participants should only take collages home after data collection if they felt comfortable doing so, if they had a safe place to keep them at home, and if it was felt by researchers that this would not harm participants. About half of participants chose to take the collages home, with the others preferring for the researchers to keep the collages safely.

Analysis

The overall analysis aimed to answer the following two questions. Firstly, what is the feasibility, value, and limitations of the collage method, used at two time points, to understand the experiences of young women living with HIV? And secondly, how does this compare to other methods of data collection? Data used for this analysis included a total of 31 individual collages (24 collages created by 24 participants in 2015, plus 7 collages

created by 7 of the same participants in 2017). The participants' verbal descriptions of the collages in the workshops and IDIs, and the researchers' reflective notes on the different methods (including the process of the collage method) were also incorporated. Firstly, analysis was conducted on notes and memos detailing the process of the collage method to understand the feasibility and limitations of the collage method. Secondly, analysis was conducted on the collages themselves by two researchers to understand the data that the collages generated in order to assess the value of the method for data collection. The researchers physically laid the collages out, arranged them into groups with shared themes, and then analysed the themes that emerged to understand the data that was produced by the collage method. These themes included: wide-ranging identities, high aspirations and optimism, resilience including through support from family and friends, and a focus on beauty and fashion. Thirdly, data collected from the collage method were compared with data generated from activities in the workshops and the IDIs. Inductive analysis was conducted on the transcripts from the workshops and IDIs, and the topics that emerged were grouped into themes, including finding out about their HIV status, disclosure, treatment, and impact of HIV on relationships. These were compared to the themes from the collage analysis in order to understand the value of the collage method in eliciting an understanding of the participants' lives that differed from that gleaned through the other methods.

Ethics

Pseudonyms were used in data collection, analysis, and in writing up results (including this article), to protect the anonymity of participants. After being provided with information about the studies, and a chance to ask questions, participants and their parents and guardians were asked to provide informed consent. Participants under 18 years gave written informed assent, while those over 18 years gave written informed consent. Ethical clearance was obtained from the review boards of the University of Zambia Humanities Research Ethics Committee, the London School of Hygiene and Tropical

Medicine, and the International Center for Research on Women. A discussion of some of the ethical issues that emerged has been published separately (Mackworth-Young., Schneiders, Wringe, Simwinga, & Bond, 2019).

Findings

Feasibility of the collage method

The individual collages were successful first activities in each of the workshops, thereby acting as an icebreaker. Participants were quickly able to understand the method, and engaged enthusiastically in the activity. In the first workshop, which was the first time the participants met, the researchers observed that the process of making the collages acted as a way for participants to get to know each other and develop friendships. As they shared scissors, glue, magazines, and cut-out pictures, they spoke to each other and shared stories while exchanging collage materials. Participants enjoyed making the collages, with many reticent to finish when told in the workshops that the activity was drawing to a close, with one protesting, "*I want mine to be just perfect!*" (Mavis, 2nd workshop, 2nd collage).

Value of collages for data collection

Participants said that they were able to express themselves through the collages. They felt that the individual collages "*held meaning*" as a form of self-representation. When reflecting about her collage later during the IDI, one participant expressed how much her collage captured herself and her life: "*That's exactly Sophie, through and through*" (Sophie, IDI, 2nd collage). Sophie explained that she could express herself and her experiences living with HIV through the collage in a way she found it difficult to do verbally: "*I want to show it (the collage) to my friend. I just disclosed to her, and I want her to understand what I've been going through*" (Sophie, IDI, 2nd collage).

The collages enabled self-expression of a wide range of identities and life-experiences, including, and beyond experiences of living with HIV. The collage method therefore provided an opportunity to give a holistic view of their lives, including showing the importance of faith, family, friends, school, and college, as well as their experiences with HIV: "*I'm positive, but my family is still with me and I can go to them for support*" (Mavis, IDI, 1st collage).

The collages overwhelmingly gave an impression of optimism, not being held back by living with HIV, and having high ambitions, despite challenges which participants may have faced (Figure 4.2). Words such as "*Happy and free*", "*Be successful", "Positively*", *"Stay Confident", "Always believe you got this"* and "*I believe in myself*" were written throughout the collages. This optimism was also linked to their HIV status: when describing her collage, one participant said, "*I have HIV but I'm still crazy, cool and confident"* (Mavis, 1st workshop, 1st collage). When probed during the IDIs about how HIV fitted into their collages, the participants often expressed how they never wanted HIV to hold them back. *"Even though I'm HIV positive… I will become whatever I want*" (Chanda, IDI, 1st collage).

Figure 4.2. 2nd collage by Natasha, demonstrating optimism and resilience

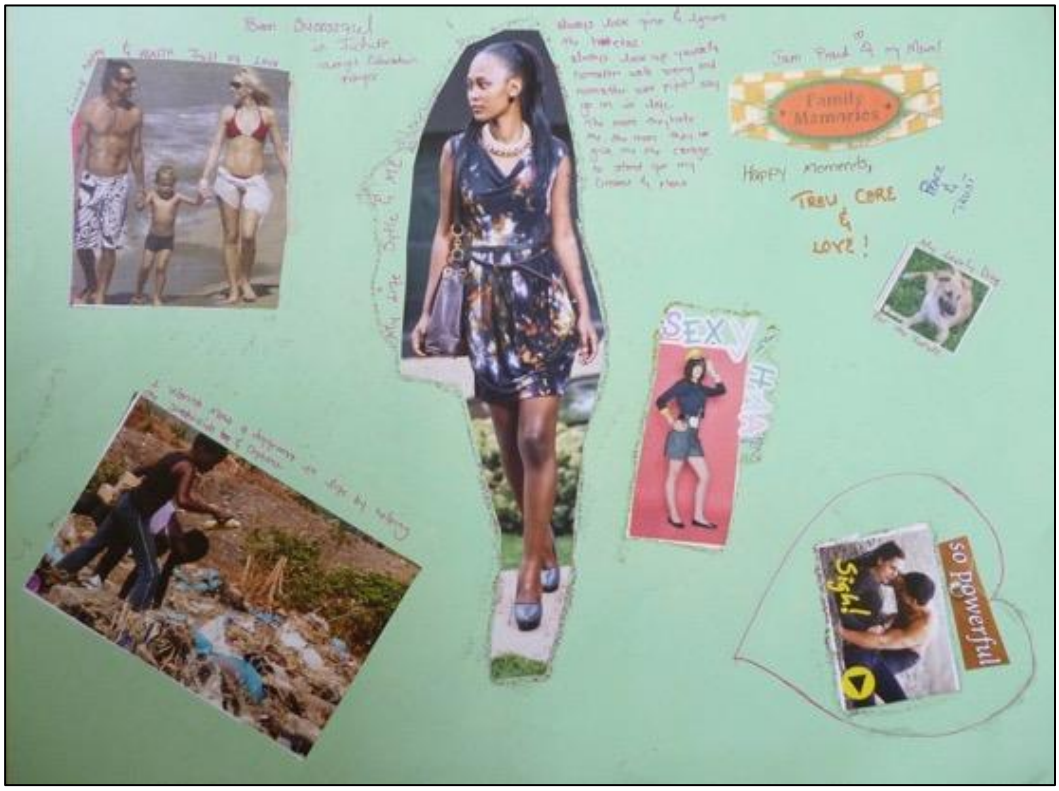
Usefulness of Repeated Collages at Two Time Points

Using the collage method with the same participants at two-time points, firstly in January 2015 and secondly in September 2017, gave the opportunity to make comparisons over time, and for participants themselves to reflect on the transitions occurring across a key period of development in their lives (Figure 4.2 and 4.3). When making the second set of collages, participants were almost three years older than when they had made the first set of collages; they were more mature, and also then familiar with the collage method. More complex thoughts and ideas were expressed in the second set of collages compared to the first set. The first set of collages relied more on images and conveyed more simplified desires and self-perceptions*: "enjoy singing", "love cooking" and "all thanks to every support given to me"* (Thandi, written on 1st collage); "*be successful in the future through education and prayer*" (Natasha, written on 1st college). In contrast, the second collages were more textually rich and offered more intricate and self-reflective messages:

Being successful in life is my greatest dream, and this will make mum feel proud of me. She has fought so hard to raise me as a single mum. It's not always easy, but her results will be good because I will make her proud (Natasha, written on 2nd collage; figure 4.2).

This demonstrates participants' development and maturation between the two time-points, as they grew older. It also suggests that using the collage method with the same participants a second time allows them to delve deeper and raise more complex or challenging issues than they did when they created their first collage, as several participants said they were already aware and comfortable with this as a medium of expression.

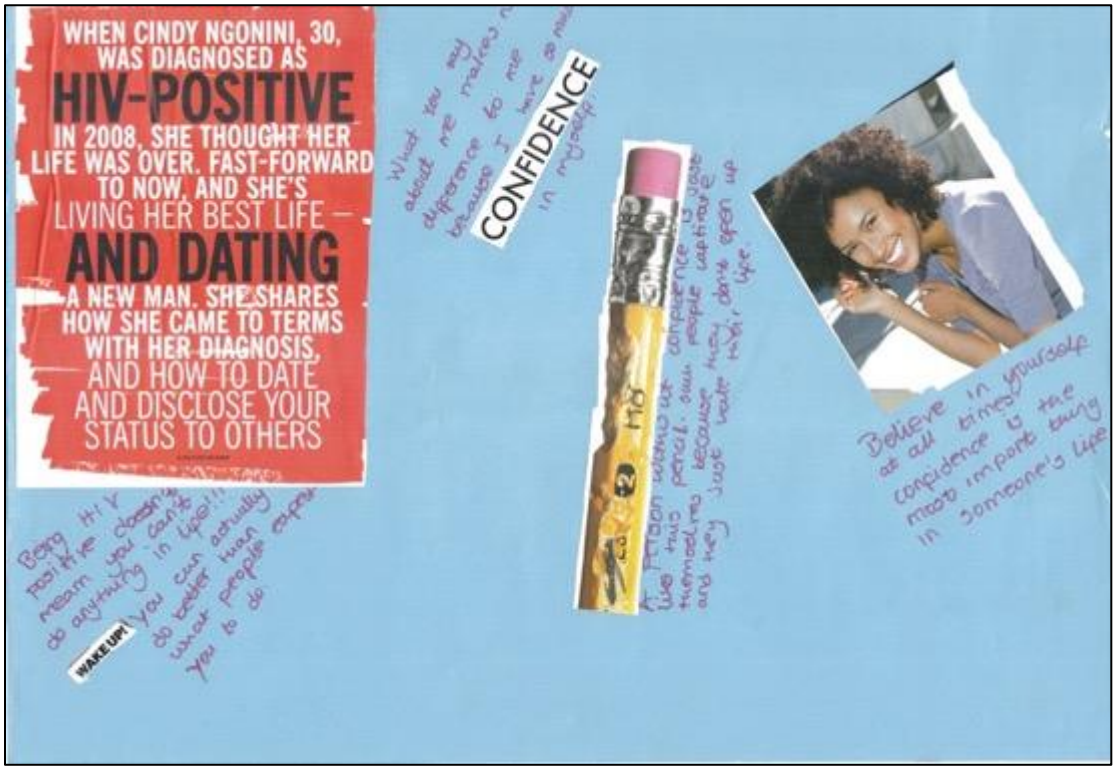
Figure 4.3. 1st collage by Natasha showing more simplified self-perceptions, compared to her 2nd collage (figure 4.2)



One participant made a direct before and after comparison in her second collage, showing the importance of confidence that she felt she had gained over the years (Figure 4.4). She included a photo of a chewed pencil to represent herself 'before', with the words "*a person without confidence is just like this pencil. Such people captivate themselves because they don't open up*

and they just hate their life." Then she included a photo representing herself 'after', of a beautiful, happy-looking woman, with the words saying: "*Believe in yourself at all times. Confidence is the most important thing in someone's life*." She linked this transformation to accepting her HIV status: how she has "*come to terms with her diagnosis*" and how this has allowed her transition into a confidant young woman without self-stigma (Sophie, written on 2nd collage; Figure 4.4).

Figure 4.4. 2nd college by Sophie showing before and after comparison, relating to growth in confidence

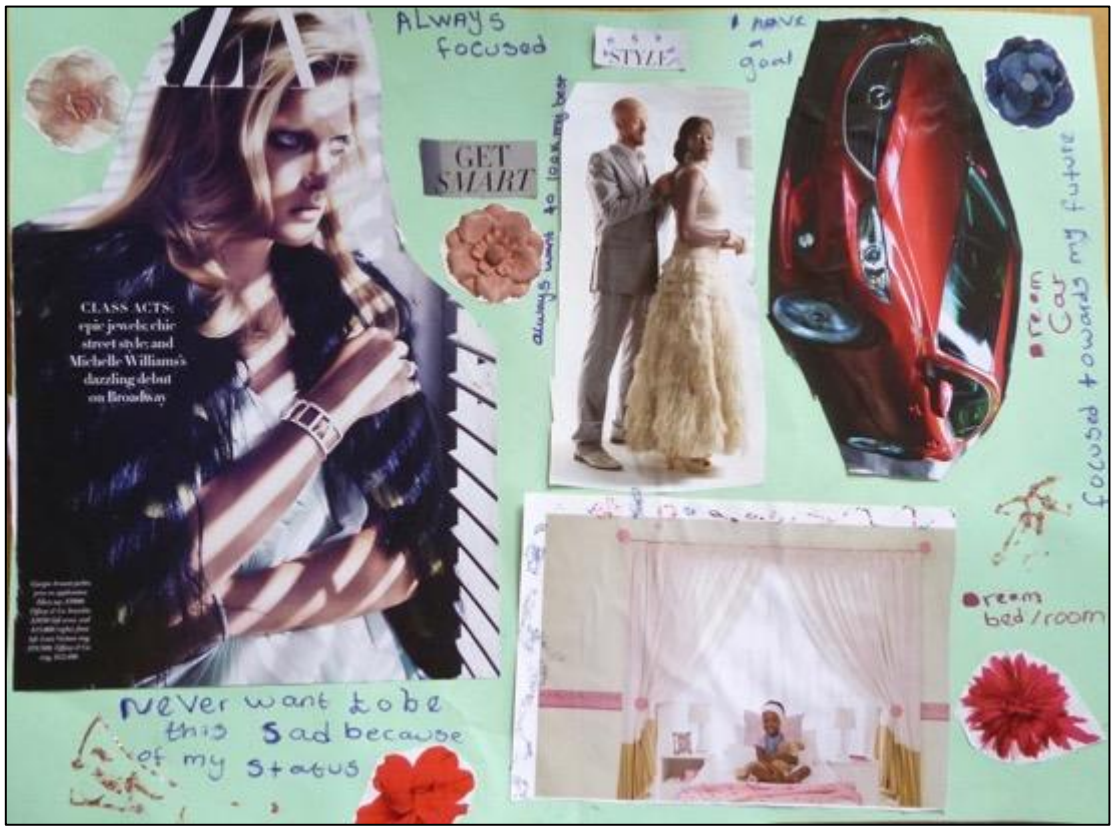


Comparison to other methods

Data from other methods of data collection focused more on HIV and the challenges they faced. For example in the workshops and IDIs, participants frequently expressed challenges around i) finding out their HIV status: "*I felt that my life had come to an end, it wasn't worth living*" (Thandi, 1st workshop); ii) disclosing their HIV status: "*I feel scared (to disclose): these people could tell other people*" (Rose, IDI); iii) taking their treatment: "*that is the biggest*

difficulty I have" (Mary, IDI); and iv) in their relationships: "*I want to go out with my friends, but in my situation, it's difficult*" (Rhoda, 1st workshop). Comparably, only a handful of the collages referenced the challenges that participants had faced living with HIV, and even in these situations, the emphasis was rather on their resilience in coping with challenges: I "*never want to be this sad because of my status*" (Mary, written on 1st collage; figure 4.5). The collage method, therefore, provided an opportunity to present optimistic and resilient aspects of their identity around HIV, but also broader identities beyond their sero-status. Differences in the content of the data generated by each method can partly be attributed to the differences in the questions and topics that were asked of the participants. Nevertheless, by providing sufficient time, open instructions and unconstrained space, the collage method enabled the young women to present representations of themselves that were often suppressed through other methods, such as the IDIs, where narratives around HIV-related challenges were more common.

Figure 4.5. 1st collage by Mary, showing resilience in coping with challenges related to HIV



Limitations of collage method

The individual collages were limited by the materials and especially by the images in the magazines provided. Since magazines can portray idealised versions of reality, they arguably encouraged the presentation of idealised versions of participants' lives in the collages. While researchers attempted to provide a range of magazines (including on fashion, home, food and travel), the emphasis on fashion and beauty in the magazines was reflected in the collages (for example in Figure 4.5). Almost all the collages in both rounds featured at least one main striking image of a beautiful-looking woman, and many of the participants spoke about how they wanted to look or be like these women.

Some participants expressed how the magazines provided them with plenty of inspiration and materials for their collages: "*I think I am finding too many inspiring things; I will end up using the whole magazine*" (Mavis, 2nd workshop, 2nd collage). However, others expressed that they found it difficult to find what they were looking for, as some felt "*all the magazines are about fashion*" (Thandi, 2nd workshop, 2nd collage). When the researcher asked participants what they would have liked to include that they didn't, as they were presenting their second collages to the other participants in the workshop, around half of the participants mentioned that: "*more (material) on aspirations for career and for the future*" would have enabled them to better express their aspirations.

Discussion

Using individual collages with young women living with HIV in this study proved feasible, enjoyable for participants, and elicited valuable data that both the participants and the researchers felt "*held meaning*" as a form of self-representation. Making the collages facilitated the active participation of young people in the creation of data, empowering them to tell their own

stories. Compared to the traditional research methods used alongside them, the collages gave the young women the space and the power to create, show and describe their own representations of themselves. Further, although this wasn't the primary aim from the outset, the collage method provided reciprocal benefit (Trainor & Bouchard, 2013) and therapeutic value (Kelly, 2014) for participants. This was through positive self-reflection, advancing identity development, and expression of their diverse, varied and complex identities that overlay their HIV status. The collage method not only gathered valuable data, but also went beyond traditional research methods by providing a space for the young women's personal processing and self-expression.

Participants were able to quickly engage in the collage method, without the need for extended instructions and despite having never previously produced them. This contrasts with some of the challenges described with other participatory arts-based methods with young people. For instance, with drawing methods, children can be hesitant to draw (Mayaba & Wood, 2015), whereas in the collage method, using the magazines as materials provided a starting point for the participants to create the collages. In this study, the second set of collages, which were created when the young women were older (aged 17-19 years), were more complex and self-reflexive. This suggests that when the method is used with older young people, it can elicit more detailed and multifaceted self-expression. Skilled facilitation was necessary to ensure participants engaged with the method successfully. This facilitation provided clear and simple instructions, an appropriate example of a collage that supported participants' understanding of the process, ensured the collages were created within the allocated time, and effectively used probing techniques when participants were describing their collage to others in the workshop. The method requires some resources including a space to create the collages, skilled facilitation, and materials including, scissors, glue, pens, card and magazines. Thus material, staff and spatial resources are necessary to carry it out.

The magazines provided undoubtedly set the parameters of the self-representations that participants were able to create. We attempted to address this limitation by providing participants with pens and markers to draw and write their own representations, as well as using clippings from magazines. In addition, we directly asked participants what they would have liked to include. Further, we looked at the magazines after the workshops to understand what the participants chose not to include in their individual collages. Being cognisant of the co-constructive nature of any qualitative data helps us understand the impact that the materials have on the collage creation. Through a social constructionist lens, we understand the collage data, like other qualitative data, not to be authentic representations of experience, but rather socially co-created through the interaction between the participant, the researcher, the materials available, and interaction with other participants (Blumer, 1969; Kitzinger, 1994; Seale et al., 2008). For future use of this method, providing additional forms of media, including printing images that go beyond those available in popular print media, could be incorporated. Additionally, encouraging more drawings and writing their own words in the collages could be ways to adapt the method to allow more freedom of expression, as demonstrated in the 'draw and write' exercises by Campbell et al. (2015).

For young women living with HIV, individual collages are an effective method to enable representations of optimism and resilience and identities that over-lay their 'HIV identity'. This compares to other methods, which focused more on HIV-related challenges. This aligns with Bond's finding of the importance for many people living with HIV to retain wider identities beyond one linked to HIV (2010). This is in a context where representations of young people living with HIV are often negative, with positive representations lacking and often not captured by traditional methods (Skovdal & Daniel, 2012). Here, the collage method gave young women the tools to reveal optimistic and resilient identities that were less likely to emerge through the other data generation approaches. This was through placing power in the hands of the participants to craft their own representations of themselves. This goes beyond more

traditional methods, which can miss complex and layered identities, and more optimistic self-perceptions, as they are frequently driven by the research objectives, often with a focus on an HIV identity. Adegoke and Steyn have demonstrated how other participatory methods, such as photo voice, are effective at capturing resilience amongst young people living with HIV, including how they frame positive goals, use social competence, coping skills, and express personal challenges (Adegoke & Steyn, 2017). The individual collages captured both of Wiegers' two forms of resilience: firstly to see beyond HIV, with optimistic messages and wider identities displayed; and secondly to manage the illness, through identifying the strategies and support they had adopted and received (for instance developing self-confidence, and relying on family and faith) to manage their HIV status (2008).

As others have noted with other longitudinal qualitative data collection methods (Bernays, Rhodes, & Jankovic Terzic, 2014; Seeley, 2015; Wouters & De Wet, 2016), we saw several benefits of using repeated collages with the same participants. Considering a developmental perspective, such repeated engagement can offer meaningful insights into the contextual effect of the substantive biological, psychological, and social change that takes place during adolescence and emergence into adulthood (Cicchetti & Rogosch, 2002; Holmbeck, 2002). Further, when creating their second collages, participants were familiar with the method, were older and thus able to express more complex thoughts as well as to be self-reflexive of the trajectories of their lives, offering richer data as a result.

We demonstrate that collage methods are a feasible, effective and enjoyable method to use with young women, and one that went beyond traditional research methods in actively involving them in the creation of their representations and the production of knowledge. Collages and other arts-based methods can empower young people to tell their stories in a less-directed way than other research methods, and enable them to express their full selves. This, in turn, can be used to inform programs and interventions as well as research. While needing to be being mindful of how the collages are

co-produced through the involvement of the researcher, the choice of materials and the interaction with other participants, collages are a valuable arts-based method in a growing toolkit for use in research and program development with young women living with HIV, and beyond, that enable the co-creation of the representations of their stories.

Acknowledgements

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Disclosure statement

No potential conflict of interest was reported by the authors.

Chapter 5: Navigating 'Ethics in Practice': An Ethnographic Case Study with Young Women Living with HIV in Zambia

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Thesis Title	An ethnographic study of the everyday lives of young women living with HIV in Zambia		
Primary Supervisor	Dr Virginia Bond		

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Where was the work published?	Global Public Health		
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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I designed the study and developed the study protocol with support from VB and AW. I conducted data collection. VB, MS and AW assisted me with the navigation of ethical issues as they arose throughout the study. The concept for the analysis emerged from discussions between MLS, VB, AW and myself. I led on the analysis, and wrote the first draft of the paper, with contributions from MLS. All authors commented on the paper and gave final approval.

SECTION E

Student Signature	[redacted]
Date	02/12/2019

Supervisor Signature	[redacted]
Date	10/12/2019.

Overview

"Who will I just be able to talk to about anything when you've gone?"

Thandi, participant observation, 2018

In Chapter 4, I discussed the importance of the development and critical reflection on specific research methods for young people. However, beyond methods, young people also require particular ethical considerations, which are heightened in the context ethnographic research on a stigmatised disease and in a low-middle income setting.

In this paper, I discuss some of the ethical issues that I encountered in the ethnographic study, how I navigated them, and my reflections on doing so. I discuss the limitations of ethical guidelines or procedural ethics and exemplify the importance of continual and deliberate reflexivity on "ethics in practice" (Guillemin & Gillam, 2004) within research, particularly ethnographic research. In conducting the study, I recognise the need to use "practical wisdom" (Jarvis, 2016) to navigate unpredictable and spontaneous ethical decision, as well as the importance of having local support and mentorship to discuss ethical issues as they arise.

This paper contributes to research objective 5:

5. To reflexively review ethical issues involved in conducting ethnographic research with young people living with HIV

Navigating 'Ethics in Practice': An Ethnographic Case Study with Young Women Living with HIV in Zambia

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Abstract

While 'procedural ethics' provides essential frameworks for governing global health research, reflecting on 'ethics in practice' offers important insights into addressing ethically important moments that arise in everyday research. Particularly for ethnographic research, renowned for its fluid and spontaneous nature, engaging with 'ethics in practice' has the potential to enhance research practice within global health. We provide a case study for such reflexivity, exploring 'ethics in practice' of ethnographic research with middle-income young women living with HIV in Lusaka, Zambia. We explore the ethical issues arising from the layered interaction of the population (young women), the disease under investigation (HIV), the method of study (ethnographic), and the setting (Zambia, a lower middle income country). We describe how we navigated five key practical ethical tensions that arose, namely the psycho-emotional benefits of the research, the negotiated researcher-participant relationship, protecting participants' HIV status, confidentiality and data ownership, and researcher obligations after the end of the research. We exemplify reflexive engagement with 'ethics in practice' and suggest that engaging with ethics in this way can make important contributions towards developing more adequate ethical guidelines and research practice in global public health.

Introduction

A growing appreciation of the ethical complexities in conducting global health research has resulted in the development of increasingly nuanced ethical guidelines in recent decades (Office for Human Research Protections, 2018). Certain populations are deemed to be at potentially higher risk of encountering ethical issues, including young people (Nuffield, 2015), people living with HIV/AIDS (Hlongwa, 2016), and populations living in low-and-middle income countries (LMICs) (Council for International Organizations of Medical Sciences, 2016). Additionally, there is widespread recognition that 'the emergent, dynamic and interactional nature of most qualitative research', including ethnographic methods, gives rise to a unique set of ethical considerations due to their intimate and longitudinal engagement with participants (Iphofen & Tolich, 2018, p. 1). Yet outside the field of bioethics and beyond the regulatory phase of seeking ethical approval for a study, such ethical issues are rarely centre stage in discussions about global health research. In this paper we hope to foreground such a discussion, at the intersections of an ethically salient population, methodology, disease, and setting, through exploring 'ethics in practice' within ethnographic research with middle-income young women living with HIV in Lusaka, Zambia.

'Procedural ethics', the process of institutional regulation of research ethics through ethical guidelines and oversight by research ethics committees (RECs), has offered important guidance for thinking about research ethics since the 1970s (Guillemin & Gillam, 2004; Kerasidou & Parker, 2014). The Association of Social Anthropologists of the UK and the Commonwealth (ASA) and the American Anthropological Association (AAA) have proposed core ethical principles to guide anthropological research across its various subfields and practical contexts. These principles are primarily oriented around the ethical principles of non-maleficence; informed consent; honesty and trust; respectful and fair relationships; privacy and avoiding undue intrusion; accessibility of results; confidentiality, anonymity and data protection (American Anthropological Association, 2012; Association of

Social Anthropologists, 2011). Others have emphasised the balancing act needed between procedural research ethics and the importance of community involvement in ethnographic research (Nyambedha, 2008). Additional frameworks have also been developed to provide more guidance on navigating the ethical challenges deriving from researcher-participants relationships in ethnographic research and the power dynamics between different actors in research (Iphofen, 2015). It is acknowledged that some ethical dilemmas arising from the positionality of the ethnographic researcher may remain unresolved, despite best intentions and careful attempts to mitigate them (Huisman, 2008). Further, there has been growing awareness of the ethics of post-research obligations, including access to effective interventions for participants and their wider communities, particularly in LMICs (Nuffield, 2002).

However, there has been extensive debate about the relevance, scope and form of such 'procedural ethics', particularly within the field of anthropology and for ethnographic research (Hansjörg, 2017; Molyneux & Geissler, 2008; Parker, 2007; 2012, ch 7). Heimer critiques the uniformity and universality of 'procedural ethics', which are usually formulated for American study sites and often do not translate well to other counties (2013). Qualitative, and especially ethnographic, research is characterised by 'fluidity and inductive uncertainty' (Mauthner, Birch, Jessop, & Miller, 2002, p. 2) and what may have seemed 'morally uncomplicated at the outset may turn out to be fraught with difficulty once a project is underway' (Iphofen, 2015, p. 18). As a result, the requirement for researchers to practise 'personal moral reflexiveness and integrity' in ethnographic research is therefore heightened and the onus of continuous ethical mindfulness, arguably, weighs more heavily on ethnographic researchers than on RECs (Molyneux & Geissler, 2008, p. 9).

Several scholars have stressed the value of thinking about ethics beyond the 'procedural' stage, and demonstrated the importance of reflecting critically on ethical guidelines and practice in order to enable more ethical research conduct. Kingori shows how the practice of ethics by frontline researchers is

set within the parameters of institutional interpretations, but these are generally peripheral to researchers' face-to-face interactions with participants and their own ethical values and motivations (2013). Similarly, Aellah *et al*. highlight the ways in which the 'momentary pursuit of morally right actions in personal interactions with other humans' is 'complex and spontaneous' (2016, p. 13). This dimension of ethics in research has been termed 'ethics in practice', referring to 'the day-to-day ethical issues that arise in the doing of research' (Guillemin & Gillam, 2004, p. 264). Applying this to ethnographic research, Jarvis illustrates the necessity of employing Aristotelian 'practical wisdom' when interpreting and contextualising international guidelines in cross-cultural settings (Jarvis, 2016). Researchers can exemplify such 'practical wisdom' by using practical judgment to do the right thing in the right way in a particular situation and context (Kinsella & Pitman, 2012). Together, this growing body of literature suggests that in order to respond adequately to the specific and sometimes unique ethical challenges arising in the context of international research, ethnographic researchers should engage deliberately with 'ethics in practice' through on-going and critical reflexivity. However, literature detailing examples of employing such critical reflexivity in international research contexts is limited, despite its potential to ensure more ethical research practice, enrich the development of ethical guidelines and frameworks and enhance mutual understanding between ethnographic researchers and RECs.

Research around HIV has, historically, also presented a range of ethical issues, including questions around human rights, resource allocation, consent around testing, sexual morality, and individual responsibility (Heimer, 2013; Venter, Allais, & Richter, 2014). The stigma surrounding HIV means that issues around privacy and confidentiality are especially important (Hlongwa, 2016). Madiega *et al*. describe how the repeated presence of researchers visiting households raised risks of inadvertently disclosing the HIV status of their participants (2013). This led to uncomfortable, yet necessary, decisions by research staff to assume alternative identities, including 'sister-in-law' or

'visitor', rather than 'HIV-researcher' to mitigate those risks (Madiega et al., 2013).

Much research in HIV has focused on lower-income groups. However, in some sub-Saharan countries, including Zambia and Tanzania, some middle- and upper-income groups have particularly high HIV prevalence (Central Statistical Office & Ministry of Health, 2014; Long & Deane, 2015; Parkhurst, 2010). Despite this group having a higher than average HIV prevalence, middle-income women are notably under-researched and relatively little is known about the factors that contribute to higher HIV prevalence among this population (Awusabo-Asare & Annim, 2008; Long & Deane, 2015). This ethnographic study thus aims to improve our understanding of the possible responses to HIV among middle-income young women so that more tailored and appropriate HIV prevention, treatment and care programmes and policies can be developed in the future to address the needs of this population.

Drawing on a case study of ethnographic research with middle-income young women living with HIV in Zambia, this paper gives a reflexive account of how ethical issues are navigated in practice, when 'procedural ethics' alone are inadequate to provide guidance. We describe the ethical issues arising from the layered interaction of the population (young women), the disease under investigation (HIV), the method of study (ethnographic), and the setting (Zambia, a LMIC). Through this, we exemplify and advocate for deliberately moving such reflections on the 'ethics in practice' into the foreground of scholarly discussion within global public health to enhance understanding of the kinds of ethical challenges that ethnographic researchers do and should actively engage with during research.

Methods

This study draws on ethnographic research, conducted by the first author (CMY), with seven young women living with HIV (aged 17-19 years) in Lusaka. The research took place over 12 months in 2017-2018, and aimed to understand the impact of HIV on the everyday lives of young women living with HIV, the results of which have been presented elsewhere (Mackworth-Young, Bond, & Wringe, 2018). The analysis, on which this study is based, emerged as a product of the reflections of the researcher's engagement with the ethical aspects of the research before, during and after the study. In order to capture the ethnographic reflective voice, this paper uses the first person, referring to the first author when discussing data collection and fieldwork. All authors contributed to the interpretation of the data and writing of this manuscript.

The research was conducted as part of a PhD project based at Zambart (a Zambian research institution) and the London School of Hygiene and Tropical Medicine (LSHTM). Zambart is committed to applied public health research and for more than two decades has been implementing research projects in Zambia based on long-standing relationships with local communities, policy makers and implementers working in the HIV and TB response. The rationale for this PhD research grew out of previous studies conducted by Zambart with young women living with HIV (Mackworth-Young. et al., 2017; Stangl et al., 2015). Further, the findings contributed to the design of further research studies including operational research that developed a support group intervention for young women living with HIV in Lusaka (Clay et al., 2018) and two randomised control trials with young people in Zambia, for a community-level delivery of sexual and reproductive health services and an HIV test and treat intervention (Shanaube et al., 2017) .

Participants

We were first in contact with the participants of this study in 2014, when we recruited them to participate in an exploratory qualitative study conducted in partnership with Zambart and the International Centre for Research on Women, when they were aged 15-16 years (Mackworth-Young. et al., 2017). In this study, we had recruited 24 young women living with HIV from two health facilities in Lusaka, met with their parents or guardians to discuss parental informed written consent, and, alongside a small research team, conducted in-depth interviews and participatory workshops with the participants. The study ended in 2015, but at their request, all participants were invited to participate in monthly support groups meetings for one year thereafter, until 2016, during which we sustained contact with them.

In 2017, we purposefully selected nine young women living with HIV from this original cohort to participate in the ethnographic study, from which this paper draws. They were selected based on being middle-income, defined as their parent or guardian having a formal job, and living in a more affluent area of Lusaka, where there is a lower population density and houses generally have a wall around them and their own supply of electricity and water. Due to the home-based, long-term and intimate nature of this ethnographic study, and the cultural context of close and inter-dependent familial relationships, we decided that it would be appropriate to involve both participants and their parents/guardians in the informed consent process. This was deemed culturally appropriate and was approved by the local Humanities Research Ethics Committee of the University of Zambia. The study protocol thus stated that both participant and parental/guardian consent would be necessary for participation, despite all but one of the participants being 18 years or older at the start of the study. Out of the nine young women asked to participate, seven participated (Table 5.1). Two of the nine women selected did not participate due to their parents/ guardians not giving their consent, both due to family issues at home. All participants were provided with a referral sheet with a list of appropriate people and organisations, including trained and experienced

counsellors, and that they could contact, and to whom they could be referred by the researcher if necessary.

Table 5.1. Participant characteristics at beginning of ethnographic study in 2017

Participant*	**Age**	**Key family member with whom she stays**	**Orphan status**	**Mode of HIV acquisition**	**Education**	**Year started ART**
Rose	19	Father and step-mother	Single orphan	MTCT**	Completed grade 12, studying to re-sit exams	2010
Thandi	18	Mother	Single orphan	MTCT	Studying at College	2012
Natasha	18	Aunt	Double orphan	MTCT	Complete Grade 12, applying for College	2008
Rhoda	19	Mother	Single orphan	MTCT	Completed Grade 12, applying for College	2005
Mavis	19	Grand-parents	Double orphan	Sexual abuse	Completed Grade 12	2017
Mary	17	Mother and Aunt	Single orphan	MTCT	Studying at College	2014
Sophie	19	Uncle	Double orphan	MTCT	Completed Grade 12, studying to re-sit exams	2008

*All names used are pseudonyms

** Mother to child transmission (MTCT)

Simultaneously to the ethnographic study on which this paper is based, at Zambart, in collaboration with the International Centre for Research on Women, we conducted an evaluation of a pilot support group intervention for young women living with HIV in Lusaka. The design of this intervention was based on requests and input from the young women in the previous qualitative study conducted in 2014-2015. Three of the young women who participated in the ethnographic study were asked to co-facilitate these support groups, alongside experienced counsellors.

At the beginning of the ethnographic study the participants' ages ranged from 17 to19 years (Table 5.1). All participants were orphans (with only one or no parent surviving), and all except one considered themselves infected with HIV by mother to child transmission (MTCT). All of them were regularly attending HIV clinics and were on anti-retroviral therapy (ART). All participants were middle-income, Christian and had taken part in previous research and support groups. They lived across Lusaka, with some occasionally spending large amounts of time outside Lusaka with family or for college. All participants had finished school, although two were resitting their final school exams during the ethnography. Two were in college at the beginning of the ethnography, rising to four at the end.

Data collection

Over 12 months, I conducted participant observation, spending significant amounts of time with each of the seven participants in their respective homes, workplaces, colleges, recreational spaces, health facilities and churches, in dozens of locations across Lusaka. This was primarily with research participants, but also with others with whom participants interacted, including their families, friends, and boyfriends. With each participant I conducted an average of 20 observations (range 12-24), totalling 276 h of participant observation. I spent time with participants at different times of day and days of the week to ensure a varied and detailed understanding of their everyday lives. I wrote up notes after each session with participants,

covering the space of the observation, conversations and interactions with the participants and others, and reflexive thoughts about the observation, including any ethical challenges arising.

The study began and ended with two participatory workshops. The first participatory workshop aimed to discuss what the research would involve and to ask for participants' input into the research design. At this initial workshop participants were given materials (A3 coloured card, a range of magazines, newspapers and pens) and asked to create visual collages to represent themselves, what they liked, what they had experienced in the past, and what they wanted in the future. The last workshop aimed to close the research collectively with all participants, present initial findings, and seek their input into findings and on-going analysis. Both workshops were recorded through written notes. At about six months into the study, I gave participants diaries (with combination locks to enable privacy), and asked them to write about their daily activities and feelings. These diaries were returned to me to read, scan and transcribe after one month. The authors have critically reflected on the use, benefits and challenges of participatory research methods in a separate analysis (Mackworth-Young, Wringe, et al., 2018).

Ethical clearance was obtained from the review boards of the University of Zambia Humanities Research Ethics Committee and the London School of Hygiene and Tropical Medicine.

Data analysis

The process of fieldwork was iterative, with cycles of data collection and analysis, and initial analysis informing subsequent data collection. 'Ethics in practice' emerged inductively as a key area of interest early on in data collection, building on an original focus on ethical issues that were considered during the design of the study, and later became a key focus in subsequent data collection. I deliberately and regularly reflected on the practical ethical

challenges that arose during the course of the study and how these were navigated when writing the participant observation notes, as well as in multiple conversations with the co-authors, including a Zambian ethicist (MS). After the completion of data collection, all data relevant to 'ethics in practice' were manually coded and extracted. Data included field notes from participant observation sessions, workshop notes, transcripts of participants' diaries and the visual collages created by participants. Ethical issues that were either seen to be consistent across participants, or that were unusual or notable, were collated for thematic analysis.

Reflexivity

I conducted the data collection, and led data analysis for this paper, as part of my PhD research, in collaboration with the other authors. I had lived in Lusaka, Zambia since 2014, when I first started working for Zambart, conducting research with the cohort of young women, starting with an applied study of their transitions to adulthood, that led to the development of support groups for the same group, and until the end of this ethnographic study in 2018. Although I learnt to speak basic conversational Nyanja (the most commonly spoken language in Lusaka), the majority of data collection took place in English. Participants and their families and friends spoke English fluently, and much day-to-day interaction took place in English. However, some conversations between family members were missed due to the language barrier.

The relationship between myself, the researcher, and the participants formed a central aspect of the study. The long-term established institutional relationships between Zambart and the local community, as well as my prior connection with the participants had enabled the development of important trust and rapport with them (and, to some extent, their families), which was built upon during this ethnographic study. With an understanding of the co-produced nature of data generation and analysis, I was continuously reflexive about how my identity as a young white-British woman influenced the

relationship that I had with participants and their families, as well as the data produced. My identity in part led to me being viewed as a trusted person by participants and their families, but also being a clearly visible outsider. Further, differences in age, power, wealth, and knowledge about research between the participants and me as the researcher led to inevitable power and relational dynamics. Reflecting on this relationship and how it influenced data collection forms the basis of some of the practical ethical challenges discussed in the results that follow.

Results

We present results on the 'ethics in practice' encountered during this ethnographic study in five broad ethical themes. These include the perceived benefits of participation and how these changed over the course of the study; the negotiated relationship between the participants and myself as the researcher; protecting participants from harm by telling 'white lies' about the research; balancing the protection of participants' confidentiality with ownership and autonomy over their data; and lastly considerations about obligations following the end of the research.

Perceived benefits of the research

During the informed consent process, several participants and their parents or guardians initially questioned what the benefits of the research would be to participants. In a context of HIV programmes, intervention and biomedical research, initially, some participants enquired whether the research would offer benefits that go beyond the obligations of ethnographic research, such as financial benefits to support college fees for the participants. During the informed consent process, I clarified that there were no direct benefits to the participants, including financial benefits to taking part in the study, although reimbursement was provided for transport costs to attend workshops, and

food and drinks were provided at workshops and whenever participant observation took place in recreational spaces, such as cafés or restaurants.

Throughout the course of the research, participants' understanding of the benefits and value of participating in the research evolved. Participants increasingly expressed valuing non-material benefits, particularly the psycho-emotional support gained from their relationship with myself as the researcher. My position as a young woman and as an outsider enabled participants to open up about parts of their lives that they otherwise felt they could not talk about. One participant reflected on this benefit of the research, when reflecting on the study as a whole:

> *I told you everything that was going on my life, even things that I didn't tell my mum. Of course I tell my mum lots of things, but there are just some things that I can't tell her, and that I needed to talk to someone else about, and you were always there to listen. It was so nice for me to have someone I could feel I could tell everything to. I didn't know I had so much going on in my life until I had the chance to talk to you and tell you everything about it.* (Thandi, participant observation)

Most of the participants expressed valuing the trusting, confidential and non-judgmental relationship with myself as the researcher:

> *Can I tell you a secret? I don't know why I always feel like I can tell you all my secrets, but I just do.* (Mavis, participant observation)

Many of the participants lacked someone who was able to take the time to listen actively, and they valued the fact that the research created a space for them within which they could reflect on their lives:

> *If you're talking to a friend, they always interrupt and tell me something about themselves, but you are a very good listener, and just listen to our stories.* (Rose, workshop)

Participant-researcher relationship

Participants were curious to also learn about my life, and, as such, I, as the researcher often became the 'researched', as the participants in turn questioned me about my life, asking to look at photos on my phone, and asking about my home, work and family. I appeared in participant's photos on their phones, including with their friends and families. There was a clear desire from participants to understand about my life: '*tell me about your house, your husband, really everything about your life*' (Rhoda, participant observation). To reciprocate the openness with which participants had approached the research, I felt it was important to share certain aspects about my life. In this way the enquiry became bi-directional, and the traditional boundaries between the 'researcher' and the 'researched' became blurred. Nonetheless, I constantly had to reassess when it was appropriate to allow the ambiguous boundaries between research and friendship to soften and when to draw the line in sharing about my life. For instance, although I visited participants' homes regularly, I declined when participants asked to visit my home, to ensure some boundaries over respective roles of researcher and participant remained.

Ethical issues emerged when the participants negotiated their relationship with me, as the researcher, to widen the scope of benefit they derived from participation, which was done in two ways. Firstly, while I emphasised my role as an observer, participants frequently sought my advice, including asking opinions on which course to apply for at college, or whether to date particular individuals. The 'official ethics' of remaining an observer were questioned, particularly when participants confided that they had not told anyone else about their situation, and sought advice from me: *'I haven't spoken to anyone else about this. Just in the diary and to you.'* (Mary, participant observation). My strategy in such cases, in order to limit the degree of intervention, was to use active listening, rather than give advice, including open questioning and reflecting questions back to the participant, and in this

way help participants to talk through and reflect on problems, without offering direct advice.

Beyond advice, some participants asked me to intervene actively in their relationships. The participants' awareness of the power and relationship dynamics between us led to my position as a trusted person by both the participants and their families being requested in several instances to assist in family disputes. For example, one participant asked me:

> *I have a favour to ask you. Could you possibly call my sister and tell her that we met, you met with me, and that you saw where I am staying, that I am staying with a friend, and that I am living somewhere that's nice and safe. Will you tell her that, because she trusts you, and it'll sound better coming from you than from me.* (Mavis, participant observation)

While I understood the importance to Mavis of restoring the difficult relationship with her sister, I could not gauge the implications of intervening in this complex relationship, and whether this would in fact serve the best interests of the participant. Additionally, the safety of Mavis' new home was uncertain, particularly as the co-residing father of her friend was an alcoholic, and so in this case the decision was to not intervene. This decision was made, in consultation with colleagues, including a Zambian ethicist (MS), with respect to upholding the primary principle to 'do no harm', commonly emphasised across ethics guidelines for anthropological research (American Anthropological Association, 2012; Association of Social Anthropologists, 2011). In this particular case, my active intervening may have resulted in unintended negative consequences for Mavis. However, I felt some 'moral residue' (Epstein & Hamric, 2009), that I was unable to assist Mavis in this matter, given the generosity of participants in terms of opening up about their lives. I discussed my decision with Mavis, and emphasised that this kind of intervention was outside the scope of my role as the researcher, which she said she understood.

Truth telling and 'white lies'

The context of participants' very limited disclosure of their HIV status raised ethical considerations for the research. Being an outsider to the community, my repeated presence with participants was both outwardly and privately questioned. I discussed with all participants and their parents or guardians the risk that the research might expose participants to unintentional disclosure, during the informed consent process, the introductory workshop, and regularly throughout the research. In the introductory workshop, participants were asked to decide collectively how to describe the research to others who did not know their HIV status in a way that protected their HIV status and that of other participants. It was agreed that we would describe the research to others who did not know their HIV status as anthropological research looking at the everyday lives of young women in Lusaka, and to adapt this to the specific circumstances for each participant, based on their personal choices.

Therefore, when meeting friends and family who didn't know the participants' HIV status, I used whatever cover-up story the participants' felt was most appropriate in each circumstance. This led me to adopt a range of different identities, including '*friend*', '*researcher on young women's lives*', '*someone I met through the support groups*', and even in one instance '*relative*'. During the informed consent process, for some, it was the worry of unintentional disclosure through the research that was the biggest concern in participating: '*the only thing that worries me is her brother finding out about her status*' (Rose's father, participant observation). Ironically, the research actually ended up being used as a cover-up story with this participant. When Rose's brother's wife discovered her ART and questioned her about it, put on the spot, Rose used participation in the research as the reason why she had ART, stating:

> *In the research I do workshops, where I have to show other people what the pills are, and how to take them.* (Rose, participant observation)

In this case, the research was both a potential risk of unintentional disclosure, but also used as a convenient cover-up story.

The one time that I was directly questioned about whether the research was linked with HIV was by the father of a participant's friend, with whom she was living at the time. The participant, Mavis, had actively chosen not to disclose her HIV status to her friend or the father, based on her witnessing their negative reactions to discovering that their domestic worker was living with HIV. Mavis explained the research to her friend's father as being anthropological research with young women in Lusaka, without mentioning HIV. Unprompted, the father asked me directly whether the research was looking at HIV. Making an on-the-spot decision, I responded, saying:

> *This research does not focus on anything like that (HIV) but it's more broadly trying to understand how young people in Lusaka live their lives* (Researcher, participant observation with Mavis).

Given the fear of unintentional disclosure and the negative consequences reported by those who had experienced this, protecting confidentiality was seen to outweigh the importance of truthfulness to participants' relatives, friends or community members in all circumstances. Participants reported being so used to telling cover-up stories to protect their HIV status that the additional stories around the research were seen as '*not a big deal*' (participatory workshop). They viewed it as essential, since they lived with '*poky*' or '*nosy*' people (participatory workshop), although they did express guilt and anxiety around telling lies every day, particularly to people who were close to them. For me, telling such 'lies' proved uncomfortable and left some 'moral residue' (Epstein & Hamric, 2009), despite being seen as essential to protecting participants.

Confidentiality and data ownership

Alongside the collection of their stories, participants produced material data during the research, through creating collages and writing diaries. The

question of ownership of data and data use led to ethical tensions between giving participants autonomy over their data, and my role, as the researcher, in protecting participants from harm. One example of this was the practical decision around whether participants were given the choice to keep the material data (diaries and collages) that they created. In this example, the potential for harm included family or friends finding their collage or diary at home, possibly leading to unintentional and harmful disclosure of a private identity, such as their HIV status or secret relationships. While I engaged in conversations about the potential harms to ensure that participants could arrive at an informed decision, the decision was made to place the choice in the hands of the participants. This was with the understanding that the participants were in the best position to assess the potential harms and their likelihood in each particular situation. This led to different decisions being made by different participants. Some saw tangible benefits to keeping their data, including having an outlet or method to express themselves:

> *I really want to keep the diary. It's been the only place I can openly speak about all the difficulties these last few weeks.* (Natasha, participant observation)
>
> *I want to show it (the collage) to my friend. I just disclosed to her, and I want her to understand what I've been going through.* (Sophie, participant observation)

However, others felt the risk of keeping their data was too great, and preferred the responsibility of data storage to remain in the hands of the researcher.

> *I think it's best if you keep it (the collage). I don't have anywhere safe for it, and I worry if my roommates found it, that they would ask a lot of questions.* (Mary, participant observation)

By providing participants with the choice, they were given the autonomy to weigh up the risks and benefits for their personal situation. However, the constraints within which this choice was being made must be noted. Many participants lived in spaces with extremely limited privacy, restricting their choice to keep their data. On the other hand, in the context of participants

having relatively limited spending money, the diaries with a combination lock were seen to be desirable personal items to keep. In order to ensure that participants were free in choosing to keep the diary specifically for its content, rather than simply for the sake of owning a diary, they were also offered the option of being given a clean diary (without their written data). One participant took up this offer, as she was worried about her family reading sensitive things that she had written, but none were keen to lose this desirable item by simply leaving it with me.

Obligations post-research

Heightened by the longitudinal and in-depth nature of the research and the resulting intimate relationships between the participants and myself, uncertainties around my obligations, as the researcher, towards the participants following the study posed further ethical questions. These included how the close and long-term relationship ought to be brought to a close. The participants expressed sadness at losing someone they were able to talk to and share worries, concerns, joys and aspirations with at the end of the research: '*who will I just be able to talk to about anything when you've gone?*' (Thandi, participant observation). The decision was taken to place a workshop at the beginning and end of the study, which served a symbolic purpose of formally marking and signalling the boundaries of the otherwise informal structure of the study. The closing workshop depersonalised and communalised the ending of the relationships between the researcher and the participants, and offered the opportunity to strengthen the peer support and friendships that had developed between participants during the course of this and earlier studies in which they had participated. While continued contact between participants and me was not actively encouraged, I enabled some contact after the research through a social messaging platform, to gradually close the relationship and the support this provided.

Throughout the study, participatory methods were used, including participants' input into the study design in the introductory workshop,

collage making and diary writing. This extended to the end of data collection: during the closing workshop, the participants were actively asked for their input into the interpretation and analysis of data, which fed into the iterative analysis of results around the main research question on understanding the impact of HIV on their lives. Beyond this, three of the participants of the ethnographic study had additionally been asked to co-facilitate support groups in a separate, but linked intervention evaluation. These young women were given additional training and experience in research and facilitation methods by the counsellors who facilitated the support groups, as well as payment for their co-facilitation role. Due to their long-term participation in and in-depth contributions to sequential research studies, this form of participant capacity building felt appropriate. Some of the young women were subsequently asked to facilitate other independent youth groups. However, despite these additional benefits to participants, I ended the research feeling some 'moral residue' (Epstein & Hamric, 2009) at the fact that many of the everyday concerns of participants and their families, such as financial worries over paying for college fees, remained unaddressed, as they were considered outside the scope of the research.

Discussion

Through identifying and exploring 'practical' ethical issues in this ethnographic study with young women living with HIV in Zambia, we provide a case study of critical ethical reflexivity in global health research. We highlight ethical tensions that arose from the interplay between studying a vulnerable population in a lower-middle income setting using ethnographic methods, and how these ethical issues were navigated. For researchers, we highlight the value of high levels of reflexivity throughout the research process for global health research, and we thus contribute to a small but important body of literature actively reflecting on 'ethics in practice' (for example Jarvis, 2016; Madiega et al., 2013; Mannell & Guta, 2017). For those involved in 'procedural ethics', this paper suggests that RECs have an

important role in gauging whether researchers have adequate ethics training and skills, and whether institutions have sufficient capacity and competence to critically engage with complex ethical problems as they inevitably arise in the context of their research. Using lessons from this study, we will now examine the relevant assumptions proposed by standard ethical guidelines, and suggest implications for future research practice and ethical guidelines.

Firstly, we demonstrate that participants' perception of the benefits of the research changed over the course of the study, with participants placing increasing emphasis on the value of psycho-emotional support provided through their relationship with the researcher. Further the study carved out designated space and time for the participants to engage in self-reflection, which may itself have served as psycho-emotional support. A number of participants specifically expressed enjoying this element of the research and valuing the activities associated with self-reflection, such as journaling. In contrast, considerations about the benefits of participation in research captured within standard ethical guidelines (for instance Council for International Organizations of Medical Sciences, 2016) are largely based on clinical, financial or material gains to participants. Previous work has highlighted the support gap in meeting the emotional needs of young women living with HIV in many settings (Chandra-Mouli, Armstrong, Amin, & Ferguson, 2015; Stangl et al., 2015), in particular an unmet need for well-run counselling and support group services (Li et al., 2017; Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). This study reinforces this support gap in Zambia, which was highlighted by the value attributed by the young women to the relationship with the researcher, and their expressed desire to speak more openly to someone about HIV and other issues in their lives. In settings where there is such a gap in psycho-emotional support, we therefore argue that current conceptions of what constitutes benefits of research need to go beyond what is included in standard guidelines to consider potential psycho-emotional benefits that ethnographic or other qualitative research may offer to participants.

Like others (Fichtner & Trần, 2018; Finch, 1992; Mannell & Guta, 2017), we highlight that in ethnographic studies, the enquiry can be bi-directional and the researcher's role involves continual negotiation. This recognition questions the applicability of objective and traditional role boundaries between the researcher and the researched for ethnographic research. We support Mannel and Guta's findings that this bi-directional questioning helped to ameliorate power relationships inherent in research encounters, but could sometimes present the researcher with uncomfortable choices, and so flexible boundaries are helpful to maintain roles as researcher and participants (2017).

In the context of research about a stigmatised disease with limited disclosure, we demonstrate the kind of moral tensions that may arise for researchers when having to balance personal moral principles of truthfulness against upholding professional confidentiality and protecting participants from harm. This is covered in more detail in a separate analysis from this study (Mackworth-Young, Bond, et al., 2018). Previous anthropological research has shown the need for data collectors to adopt untruthful identities to protect participants' HIV status (Madiega et al., 2013), and we concur with their findings around the 'moral residue' (Epstein & Hamric, 2009) and discomfort felt by data collectors, who nonetheless understand the necessity to tell untruths about themselves, the research and the participants. Ethical guidelines rarely give researchers advice on how to navigate these ethical challenges, although some relevant strategies have been proposed for practitioners (Guillemin & Gillam, 2015). Some teaching materials have provided case studies that stimulate researchers to think through the ethics of truth telling and lying when conducting community-based research (Aellah et al., 2016). While many decisions inevitably must be made in context, having sensitive and flexible frameworks for such decision-making could offer important support for frontline researchers.

Several of the ethical issues identified in this study relate specifically to young people. In order to ensure that the measures established to protect young

people from harm do not result in preventing their participation in research, young people's capacity for decision-making needs to be assessed within each particular context (Gibson et al., 2011). Researchers need to be cognisant of the constraints within which these decisions are made, for instance limited privacy and spending money seen here, or limited autonomy of young people within Zambian society documented elsewhere (Simpson, 2009). However, we have shown that when given sufficient information, room for discussion, and autonomy for decisions, such as whether to keep the diaries and collages that participants created, the young women showed capacity to balance the risks and benefits, and demonstrate that they, not the researcher, were best placed to make those decisions. In this study young people also showed capacity for being integrally involved in the research process. This extended beyond ownership of data to giving input into the research design, analysis and interpretation through participatory workshops. This finding supports and extends current ethical guidance recommending establishment of young people's advisory groups (Nuffield, 2015) to enable more participatory and integrated involvement of young people in the research process (Iphofen, 2015).

Beyond participants' engagement in analysis and interpretation of data, we highlight the ethical challenges involved in bringing an intimate and longitudinal research study to a close. Recognising the 'emotional labour' of research (McGarrol, 2017), ending intimate participant-researcher relationships can raise ethical issues for the participants and the researcher, especially when the research, as in most cases, has been unable to meet all the needs of the participants (Aellah et al., 2016). Addressing the obligations to end research in the most ethical way is particularly challenging for ethnographic research, for which specific guidelines are often deficient (eg. American Anthropological Association, 2012) or vague (eg. Association of Social Anthropologists, 2011, section 1.8). In this study, establishing a structured and formal closing to an otherwise fluid study, through the closing workshop, helped to depersonalise and communalise the end of the research and the participant-researcher relationship. Despite this, the ending of the

relationship was not clear-cut, and continued contact on a social messaging platform over several weeks was considered appropriate to avoid an abrupt end to the intimate participant-researcher relationship, thus continuing the 'emotional labour' of the research beyond the official end of the study (McGarrol, 2017).

Research ethics guidelines have increasingly highlighted the need for global health researchers to consider post-research obligations, including capacity-building obligations towards researchers or health-care personnel (Council for International Organizations of Medical Sciences, 2016). By involving participants as peer facilitators in a separate, but linked, support group intervention study, we support and extend CIOMS guidelines by advocating for the importance of including participants themselves in capacity building efforts, where appropriate and feasible.

Global health researchers need to be better supported and enabled to reflect actively on 'practical' ethical tensions, which they inevitably face throughout the research process, as this has the potential to contribute to the improvement of future research ethics guidelines and ethical research practice. This paper also suggests that 'procedural ethics' can play an important role in supporting ethnographers to go to the field well equipped. While this paper highlights the limits to what RECs can do to resolve the fluid, unpredictable, spontaneous micro-level ethical issues that arise in ethnographic research, we argue that RECs play a vital role in gauging whether a researcher or research institution has the skill and capacity to use 'practical wisdom' and engage with complex ethical problems as they inevitably arise in the context of ethnographic research. Specifically, when deliberation about approving such studies, RECs should assess whether the planning of a study involved meaningful consultations with local communities and institutions and the extent to which the researcher will be both supported by and embedded within a local research institution. This is important so that researchers will be able to reflect on and navigate ethical issues as they arise in real time, such as through regular discussions,

mentorship, supervision sessions, or ethics clinics. Therefore, RECs should be attentive to a proposal's ability to demonstrate that the researcher has thought through the strategies they will employ and the local support structures they will draw on when having to meet inevitable unforeseen ethical challenges in field.

This paper adds an important case study of ethical reflexivity in a specific context of overlapping vulnerabilities of population, disease, setting and method, which suggests ways of understanding how 'ethically important moments' can be navigated in practice (Guillemin & Gillam, 2004). In this time of heightened ethical guidelines and restrictions on research conduct, deliberately focusing on the 'ethics in practice' in this way helps navigate the ethical ambiguity of everyday research encounters.

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Chapter 6: "*My mother told me that I should not*": A qualitative study exploring the restrictions placed on adolescent girls living with HIV in Zambia

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SECTION A – Student Details

Student ID Number	1511419	**Title**	Ms
First Name(s)	Constance		
Surname/Family Name	Mackworth-Young		
Thesis Title	An ethnographic study of the everyday lives of young women living with HIV in Zambia		
Primary Supervisor	Dr Virginia Bond		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Journal of the International AIDS Society		
When was the work published?	November 2017		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/a		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	**Yes**

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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	VB and AS were co-Principal Investigators on the study, and led the design of the study. CMY, VB, KK, SC, CC and MC all conducted data collection, and together with KS and AS were all involved in data analysis. CMY led on writing the paper, together with VB and AW. All authors commented on the paper and approved the final version.

SECTION E

Student Signature	[redacted]
Date	02/12/2019

Supervisor Signature	[redacted]
Date	16/12/2019

Overview

"*Whatever a girl does is forbidden*"

Mary, in-depth interview, 2015

The previous chapters have focused on the methods (chapter 4) and ethics (chapter 5) of conducting research with young women living with HIV. This chapter 6, was the first of the results chapters that I wrote for this thesis. It assesses the restrictions that adolescent girls living with HIV face, arising from a moralising social context and the intersection of their age, gender, and HIV status. It draws on data generated during the qualitative study in 2014-15, which were subsequently analysed as part of this PhD to understand the impact of HIV on the everyday activities and relationships of adolescent girls. As mentioned earlier, in this paper I use the term 'adolescent girls', as the group was younger at the time of this qualitative study, contrasting to the rest of this thesis where I use the term 'young women'.

This paper details three key restrictive messages that adolescent girls living with HIV are told, and which influence their experiences and options, around disclosure, sexual activity and adherence to ART. It emphasises how this messaging can provide incomplete information to young people, reducing their capacity to make informed and supported choices. The messaging can lead to adolescent girls living with HIV worrying about disclosure, having limited information about safer sexual practices, and staying silent and feeling guilty when they have adherence challenges. The chapter concludes with suggestions for family-based interventions to support parent-child communication.

This paper contributes to research objective 1:

1. To understand how HIV impacts young women's relationships, and everyday activities

"My mother told me that I should not": A qualitative study exploring the restrictions placed on adolescent girls living with HIV in Zambia

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Abstract

Introduction: Adolescent girls in sub-Saharan Africa are disproportionately affected by HIV due to a range of social and structural factors. As they transition to adulthood, they are recipients of increasing blame and shame for HIV infection and 'improper' sex, as well as increasing scrutiny, restrictions and surveillance. This study used a qualitative and participatory approach to explore the messaging and restrictions imposed on adolescent girls living with HIV in Zambia.

Methods: Thirty-four in-depth interviews and four participatory workshops were carried out with 24 adolescent girls aged 15-19 years old and living with HIV in Lusaka, Zambia. Key themes explored included experiences living with HIV, finding out about HIV status, disclosure, experiences with antiretroviral treatment, and support needs. Data were organized, coded and analysed using a grounded theory approach to thematic analysis. This analysis uses data on participants' experiences of living with HIV and their interactions with their parents, guardians and healthcare providers.

Results: Family and healthcare providers, partly in a quest to protect both the health of adolescent girls living with HIV and also to protect them from blaming discourse, imposed restrictions on their behaviour around three main topics: *don't* disclose your HIV status*, don't* have sex, and *don't* miss your medicines. These restrictions were often delivered using tactics of fear, and usually disconnected from other options. Participants responded to these messages in several ways, including internalizing the messages, changing their behaviour either to comply with or resist the restrictions, by remaining silent and anxious when restrictions were broken, developing concerns around their own health and sexual and reproductive aspirations, and by sometimes experiencing stigma when restrictions could not be maintained.

Conclusions: Restrictive messages were delivered to adolescent girls living with HIV through the broader social discourses of stigma, religion and global

and local narratives about HIV. Programs aiming to support adolescent girls living with HIV need to work together with parents and healthcare providers to reflect on the impact of sanctioning messages, and to encourage more enabling and empowering messaging for adolescent girls living with HIV.

Introduction

The importance of adolescent health is increasingly being recognized in sub-Saharan Africa (Dellar, Dlamini, & Karim, 2015; Patton et al., 2016; PEPFAR et al., 2015), although the focus on preventing new HIV infections means that the needs of adolescents living with HIV (ALHIV) are not receiving sufficient attention (Chandra-Mouli et al., 2015). With increasing access to effective antiretroviral therapy (ART) enabling vertically-infected children to survive (Bernays, Jarrett, Kranzer, & Ferrand, 2014; Mofenson & Cotton, 2013), alongside high incidence rates particularly amongst girls aged 15-19 years (Abdool Karim et al., 2013; Santelli et al., 2013; Santelli et al., 2015; Schacht et al., 2014; Vandormael, Newell, Barnighausen, & Tanser, 2014), adolescents are now a key group in sub-Saharan Africa affected by HIV. An estimated 2.1 million adolescents aged 10-19 years are living with HIV globally, including 79,000 in Zambia (UNAIDS, 2014a, 2015), with more girls than boys infected. Nearly 6% of girls aged 15-19 in Zambia are living with HIV, around twice the proportion of adolescent boys of the same age (National AIDS Council, 2014).

ALHIV across sub-Saharan Africa have been the subjects of narratives focused on 'promiscuity', personal blame and shame and the circumstances of infection, based on global, local, religious and familial discourses around HIV (Bond et al., 2003; Parsons, Bond, & Nixon, 2015; Vale, Hodes, & Cluver, 2016; Vale & Thabeng, 2016; Winskell, Hill, et al., 2011). Even with widespread access to ART, HIV-related stigma remains pervasive in many settings (Bond et al., 2016; Roura et al., 2010; Winskell, Hill, et al., 2011). Despite the majority of ALHIV having been perinatally infected, connotations associated with shame and 'improper sex' also apply, and typically emerge during adolescence (Winskell, Hill, et al., 2011). The combination of being young, female, and having a highly stigmatised disease that is mainly perceived to be transmitted sexually drives morality narratives for adolescent girls living with HIV.

Adolescence is a period of transition from being viewed as a child to an adult, with increasing autonomy and responsibility, but alongside restrictions, rules and expectations regarding social behaviours (Patton et al., 2016). Young women in particular are often restricted in their activities (Reynolds, 1991; Wamoyi et al., 2011; Wamoyi & Wight, 2014). ALHIV have been described as developing increased levels of self-surveillance to fit in alongside their peers (Philbin, 2014). Increased care and surveillance from family members and healthcare providers is often protective but heightens the onus on restrictions and self-control (Busza, Dauya, Bandason, Mujuru, & Ferrand). The messages that ALHIV receive, and the restrictions that they are placed under, warrants more scrutiny. It is important to understand how these restrictions influence the parameters within which ALHIV behave and make choices, in order to better target interventions to provide information, support and empower choice. Focusing on the transition from adolescence to adulthood, we used a qualitative and participatory approach to explore the experiences of adolescent girls growing up with HIV in Lusaka, Zambia.

Methods

Study population

Twenty-four adolescent girls living with HIV between the ages of 15 and 19 were recruited to participate in the study from two urban, government health facilities in Lusaka. One health facility was located in a high-density area, serving a predominantly low-income population, and the other was a centre for paediatric excellence accessed by a mixed-income population. Participants were recruited at the health facilities during paediatric antiretroviral treatment (ART) days. All participants underwent an informed written consent process: for participants under 18 years old, informed written consent was sought from their parents or guardians first, and then informed written assent was sought from the participants; for participants over 18 years, their informed written consent was sought. As a condition of

participation, all parents and guardians and all participants were aware of the HIV status of the participant for whom they provided consent.

Data Collection and Analysis

Data were collected between January and April 2015 through a total of 4 participatory workshops and 34 in-depth interviews (IDI). First, four 6-hour participatory workshops were held with two groups of 10 and 14 participants each. Participatory tools, including concept mapping (Trochim, 1985), collages (Butler-Kisber & Poldma, 2010) and vignettes (Gourlay et al., 2014) were used in the workshops. Two rounds of IDIs were then conducted with 17 participants purposefully selected from the workshops. The IDIs used 'network tools' (Wallman, 1984) to describe the participants' 'affective networks' of who knew their HIV status, and their 'effective networks' of who provided them with support. The workshops gathered collective narratives from group interactions, while the IDIs provided the opportunity for participants to share in-depth individual experiences and, for some participants, to share traumatic experiences.

In both the workshops and IDIs, participants discussed finding out about their HIV status, experiences with disclosure, experiences with treatment and at the ART clinic, and support needs. All participants knew the research was only open to adolescent girls living with HIV: at the start of the workshops, a discussion was held about shared confidentiality. The workshops gathered collective narratives from group interactions, while the IDIs provided the opportunity to gather in-depth data on some individual experiences. Three trained counsellors (SC, CC, MC) and one young woman living with HIV were involved in the research design, data collection and analysis. Data were captured through audio recording, transcription and translation of interviews, note taking in the research workshops and photos of workshop materials. In research notes and transcriptions, pseudonyms were used to protect participant anonymity. Audio recordings were deleted after transcription. Visual data were stored in a locked cabinet accessible only to

the research team. After the research ended, and based on requests from research participants, nine support group sessions with each group of the same participants, stretching over a period of a year were held.

Data were organized and coded using ATLAS.ti Version 7. We used a grounded theory approach to thematic analysis, using analytical memos to develop ideas. Visual data were analysed by physically grouping the collages and network diagrams into inductive themes. Using an inductive approach to analysis, the theme of restricting messages and the responses of participants to these messages emerged from the data, rather than being a predetermined theme.

Ethical clearance

Ethical clearance for the study was obtained from the review boards of the International Center for Research on Women in Washington, DC, USA, and the University of Zambia Humanities Research Ethics Committee in Lusaka, Zambia. Permission to conduct the study was also given by the Ministries of Health in Zambia. London School of Hygiene and Tropical Medicine ethics committee granted permission for analysis of the data.

Results

Participant characteristics

Participants ranged from age 15 to 18 years, with the majority (14/24) aged 15-16 years. The majority of participants were in school at the time of the study, with one not in school due to financial constraints. Most participants (17/24) reported acquiring HIV perinatally, two reported infection through sexual abuse, and five did not indicate the mode of acquisition. Most of the participants had been taking ART for several years. Many of the participants described Christian religion as being important in their lives. Eleven of the

participants were cared for by their parent; thirteen of the participants had another family member as their main caregiver. Although participants were selected from both middle and low-income backgrounds, stratified analysis by socio-economic background showed similarities in experiences of restrictions and messaging between the two groups.

Experiences of restrictions

Participants were not asked directly about experiences of restrictions and messaging. However, participants reported high levels of parental and familial surveillance, which they linked to their age, gender and HIV status. They described being told repeatedly how they should or shouldn't act by parents, guardian, healthcare providers, and less frequently by their peers. These messages focused on three key 'don'ts': *don't* disclose your HIV status; *don't* have sex; *don't* miss your treatment.

Don't disclose your HIV status

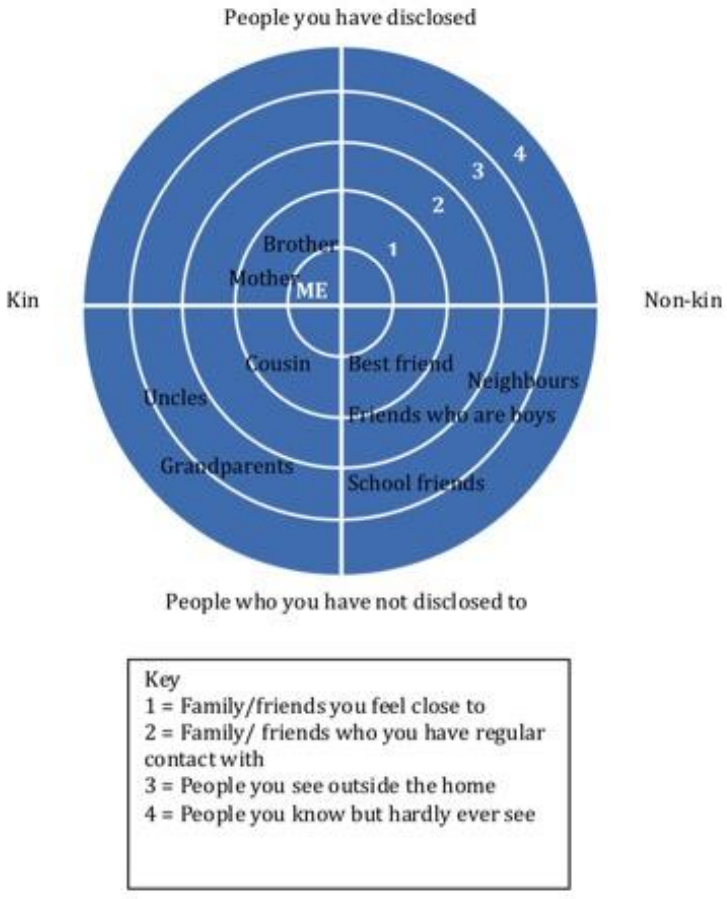
All the participants had extremely limited disclosure networks (Figure 6.1), with almost half having never themselves disclosed to any member of their family or non-family network. Participants' parents or guardians had mostly disclosed the participants' status on their behalf, with participants often excluded from the decision-making of who to tell and how. The participants' parents discouraged their children from disclosing their status to others, including other family members. Many of the participants stated that the reason why they didn't disclose their status was because their parents or guardians had forbidden them from telling other people about their status: "*I want to tell my father's family: they don't know I take ART. But whenever I want to tell my father's family, my mother tells me not to tell them" (*18 year-old girl, workshop).

Parents and guardians discouraged disclosure in order to avoid anticipated stigma for their children, but also, for their families, and themselves. This was

particularly in the context of perinatal infection, where the adolescent's disclosure could also be disclosure of the mother's or father's own status. When asked about where they would want to get support around disclosure, the participants largely said from the clinic, as their parents so strongly discouraged disclosure:

> "*Mum warned me about telling them, so I think maybe someone at the clinic could help me out...I need to talk to mum, mum needs to understand that I need some kind of comfort from them*." (15-year old girl, IDI)

Figure 6.1. Affective network diagram for a 15-year-old girl living with HIV showing the family and non-family members who had and had not been disclosed to.



The restrictions on disclosure set by parents and guardians conflicted with healthcare providers encouragement to disclose to partners in order to prevent transmission of HIV. These messages, mixed with the participants' concerns of anticipated stigma if their status was known more widely based on their perceptions of how people living with HIV are treated by others, often left participants confused and anxious around disclosure. Disclosure to boyfriends was particularly feared: *"If it were to end and then he would start telling people"* (15-year-old girl, IDI).

When a limited number of participants did disclose more widely, in some cases this led to stigma. One participant who reported disclosing more widely later changed schools on account of stigma (e.g. taunting, name-calling) she experienced from peers who found out her HIV status. The fear of unintentional disclosure also sometimes interfered with medication adherence.

> "*Yes, that was after I went into boarding grade 10, term one: I had stopped taking my medicines because I was scared that people would see and all. So, when I got back home, that is when I had complications. The doctor said your medicine is not working so you go on the second line"* (17 year-old).

Don't **have sex**

Participants reported being very strongly discouraged from having sex or boyfriends, not only by their parents or caregivers, but also by healthcare providers at the clinic, and sometimes also their HIV-positive peers during workshops. *"People say when you are sick of HIV/AIDS you are not supposed to have a boyfriend."* (15 year-old girl, IDI). Healthcare providers, during consultations and at support groups at the clinic, as well as family members, discouraged sex often in relation to fears around re-infection and infecting others.

> "*But they* (Grandmother and Aunt) *forbid me from having sex with men. That is what they stop me from doing. Because that man can have HIV*

as well and I can re-infect him and he can also re-infect me, we exchange. So you will not find me with men mostly, no" (16 year-old girl, IDI).

At the research workshops, some of the participants strongly encouraged other participants to abstain from sex, talking about avoiding peer pressure to have sex, and the *"dangers"* of what can happen if you have sex: "*I would encourage us all to abstain, not to use condoms."* (17 year-old girl, workshop). Peers, therefore, appeared to both encourage and participate in restrictions to dissuade having sex, suggesting that they had internalised the restrictive messages they were receiving from their parents, guardians and healthcare providers, as well as abstinence messages at church. A few participants said that at the support groups held at the clinics, they discussed having healthy and safe sexual relationships. However, others said that when such topics were raised, the healthcare providers running the support group closed the conversation down, saying they should not be thinking of such things: *"She* (community lay worker) *started saying... 'As long as you are not married, we're not even going to talk about sex. We're not going to talk about marriage or dating.'"* (17 year-old, IDI). When given the opportunity to ask questions to a doctor during the research workshops, sexual relationships was overwhelmingly the most popular topic.

For most of the participants, restrictions and silence around sex created much anxiety. In describing their hopes and dreams for the future, getting married and having a family was central to the participants' aspirations: *"I'm passionate about having a family in the future"* (17-year-old). Pictures of families were consistently depicted in the collages created by the participants during the workshops (Figure 6.2). During the workshops, participants often described how HIV will not stop them from achieving their sexual and reproductive hopes and dreams: *"Even though I am positive, there is nothing that can stop me from marrying"* (15-year-old). However, the messages around abstinence and the restrictions around sex linked to fears around reinfection or infecting others conflicted with these aspirations. This led to concerns that they may never have a relationship or get married: "*I thought*

maybe I was never going to get married because of my status" (15-year-old). Additionally, participants described their fears around the possibility of transmission of HIV to potential partners and children.

Figure 6.2 Collages created by participants during research workshops: two examples showing family playing a central role.

Don't miss your medicine

Family members and healthcare providers alike impressed the importance of adhering to medicines upon participants. Participants reported that they, along with their parents and healthcare providers had good knowledge about the importance of ART for maintenance of good health and avoiding illness and death: "*I know that I am sick and this is the medicine which can make me survive"* (15 year-old girl, IDI). Guardians and healthcare providers at the clinic were often quoted as the reasons why the participants continued taking their medicines: "*It is because my mother tells me that I shouldn't stop taking the drugs"* (16 year-old girl, IDI). Support from family and healthcare providers was reported to be valuable in reminding participants at the time they need to take their medicines, providing information about the importance of adherence, and giving encouragement to sustain their treatment taking.

However, messages of adherence were sometimes conveyed using tactics of fear, such as talking about potential consequences of non-adherence, to strongly encourage the participants to adhere to their medicines:

> "*Let me just say that. I used to skip. So when I sat, then I was like: now if I die or I get meningitis cause Aunty* (adolescent councillor at the clinic) *told me that if you don't drink your medicine, you get blind and you get deaf. So I was like: ah I might start getting blind. No let me just start taking well. And I just started taking every day"* (17 year-old girl, IDI).

These messages were rarely accompanied by information about how ART works and why adherence is important: treatment literacy amongst participants was low, and the reasons for adherence were sometimes misunderstood. Some participants complained of being told too often about the importance of adherence, and it becoming like "*a song"* that's repeated. A couple of participants complained about the support groups at the clinics focusing too heavily on adherence, at the expense of other concerns:

> "*When we are told all the time* (about adherence)*, it becomes boring… For me, when I'm told once, I think I can get it there and then. I don't need someone to remind me over and over again"* (16 year-old girl, IDI).

When the participants were non-adherent, this often led to secrecy. Because adherence was so strongly impressed upon the participants, many feared to tell either their families, or healthcare providers at the clinic, or both if they did miss their medicines, leading to secrecy and feelings of guilt:

> "*No wonder I don't tell people at home* (that I have missed my medicines)*. I just wait for the time when I come here* (to the clinic) *so that I can tell them. Then they give me advice on what to do"* (15 year-old girl, IDI).

Reasons for non-adherence were often practical, and related to the inability to take their medicines secretly at the time they need to take their medicine: "*I usually have difficulties taking my medicines at 18 hours because I'm usually in class, when I go for tuitions*". Despite this, both minor and major non-adherence were kept secret. Family members or healthcare professionals discovered about non-adherence only when participants' health was severely affected.

Discussion

Based on qualitative research, we highlight how restrictive messages emerged as key to influencing the experiences of adolescent girls living with HIV in Lusaka, Zambia. Our results identified three common restrictions communicated by families, healthcare providers and sometimes peers that can impede adolescent girls living with HIV from making informed choices about disclosure, sexual relationships and treatment. These messages were: *don't* disclose your status; *don't* have sex; and *don't* miss your medicine. Participants responded to these messages in several ways, including internalizing them, modifying their behaviour, resisting them, or becoming anxious and silent.

The complex factors involved in decision-making to disclose one's HIV status in Zambia have been previously described (Bond, 2010; Denison et al., 2015). Additional to these factors, we highlight that restrictions from parents and guardians around disclosure, in part to protect themselves as well as their family, particularly their mothers, from anticipated stigma, weighs heavily on their disclosure decisions. This is particularly important because HIV is often interlinked with family networks (Vale et al., 2016; Vale & Thabeng, 2016): most ALHIV live in households with another person also living with HIV, often their parent (Shanaube et al., 2017). We also highlight that in some cases, deviating from the normative script and breaking the restriction on disclosure endorsed by parents and guardians led to experienced stigma (in the case of the participant changing schools because of taunting and name-calling). This highlights the conundrum adolescent girls living with HIV face as they decide whether to disclose and whose advice to listen to, parents, guardians, or healthcare providers.

The emphasis placed on abstinence for young people, and particularly adolescent girls living with HIV, corroborate with previous findings. Countries with strong conservative, Christian influence, including Zambia, have narratives of 'religiously-infused moralizing', parallel to the 'ABC' prevention messages that have remained prevalent since the beginning of the HIV epidemic (Simpson & Bond, 2014; Winskell, Beres, Hill, Chigozie Mbakwem, & Obyerodhyambo, 2011). This messaging for ALHIV to 'control their sexuality' through abstinence is often disconnected from other HIV prevention strategies. Providing limited sexual and reproductive health options particularly for ALHIV, can lead to adolescents feeling unprepared for sexual experiences, and can run the risk of stigmatizing those adolescents who do not have the opportunity to remain abstinent (Busza et al., 2013; Fernet et al., 2011; Winskell, Beres, et al., 2011). These restrictions appear in stark contrast to the global rhetoric of possibility, opportunity and autonomy that dominate global discourse around HIV, particularly in light of treatment as prevention (UNAIDS, 2014b). Rather than opportunity, and despite

advances in HIV prevention including treatment as prevention (World Health Organization, 2015), adolescent girls living with HIV have a tangible fear of infecting a partner or child, to the extent that they feel they may not fulfil their aspirations of having a family. Engagement with healthcare providers, parents, and guardians is needed to provide age-appropriate sexual and reproductive health information that situates abstinence within other prevention options for ALHIV to choose from (Vujovic et al., 2014; Winskell, Beres, et al., 2011).

Several participants in this study reported issues with adherence, despite having adequate information and a strong desire to adhere, supporting findings from previous studies that have shown that information is necessary but not sufficient to ensure good adherence over time (Bernays, Paparini, Gibb, & Seeley, 2016). Restrictions that assign moral responsibility and instil fear may inadvertently dismiss the social challenges that adolescents face in adhering, and encourage silence around non-adherence (Bernays et al., 2017; Bernays et al., 2015; Mupambireyi et al., 2014). Adherence support provided by family members and healthcare providers should therefore recognize the broader social and environmental challenges of adherence for ALHIV, acknowledging a margin of flexibility for adherence, and understanding the fluidity of adherence as they grow up with HIV (Fetzer et al., 2011). Such support could provide a more enabling environment for adherence, rather than one inadvertently encouraging resistance or secrecy.

Our research is limited in several ways. Firstly, we were not able to collect data from parents, guardians or health care providers, so our analysis is based only on the perspectives of the adolescent girls who participated. Future research with these stakeholders could shed light on how and why they communicate in the way they do and how to foster supportive and empowering relationships and communication. Secondly, we were not able to include adolescent boys living with HIV in the study and thus could not directly explore whether restrictive messaging differs by gender. In addition, our study did not include adolescent girls not living with HIV, which provides

challenges in understanding whether the messaging, especially around sex, differs for adolescent girls with unknown or negative HIV status. Lastly, due to the qualitative nature of the study and the small sample size, we were not able to fully explore how restrictive messaging may have varied among adolescent girls living with HIV by various characteristics, including socioeconomic status, type of guardianship or mode of HIV infection. While our findings did not suggest major differences by these characteristics among our study participants, future studies with larger samples are needed to fully examine these relationships. Despite these limitations, our study provides important information on the experiences and needs of adolescent girls living with HIV in urban Zambia and suggests key areas for further research and intervention development and testing.

Parents, guardians and extended family members are crucial in the decisions that adolescents make around their health and HIV (Denison, McCauley, Dunnett-Dagg, Lungu, & Sweat, 2008; Wamoyi, Fenwick, Urassa, Zaba, & Stones, 2010; Wamoyi et al., 2011; Wamoyi & Wight, 2014; Wamoyi, Wight, & Remes, 2015). Providing balanced and complete information empowers adolescents to make informed and supported choices, while messages that singularly provide restrictions laden with moral responsibility can impact the view of the self, with feelings of guilt, blame and resistance to messages (Nguyen, 2013; Philbin, 2014). Family-based interventions in households with ALHIV, like those being tested by Denison et al. in the Copperbelt region of Zambia (Denison et al., 2015), may help to support parent-child communication to help ALHIV to imagine and fulfil their sexual and reproductive health aspirations (Wamoyi et al., 2014). Determining the best combination of interventions to fully support the needs of ALHIV in a comprehensive manner requires further research.

Conclusions

This research has described some of the restrictions placed on adolescent girls living with HIV and the impact this had on their experiences. Policies aiming to support adolescent girls living with HIV need to take into account these restrictions and how they are communicated, internalized, or resisted by the adolescents they are meant to protect from stigma and harm. Programs should focus on working together with parents, guardians and healthcare providers to develop supportive relationships where messages can be delivered to ALHIV in an open way that provides options and optimal support for achieving a healthy transition to adulthood and fulfilling their goals for starting safe and healthy families of their own.

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Competing interests

None of the authors have any conflict of interest that might conflict with this research.

Chapter 7: Secrets and silence: agency of young women managing HIV disclosure

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Thesis Title	An ethnographic study of the everyday lives of young women living with HIV in Zambia		
Primary Supervisor	Dr Virginia Bond		

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I designed the study and developed the study protocol with support from VB and AW. I conducted data collection. I led on the analysis, and wrote the first draft of the paper. All authors read and commented on the final paper.

SECTION E

Student Signature	[redacted]
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Supervisor Signature	[redacted]
Date	16/12/2019.

Overview

> *"Yes, of course, lying is bad, and the Bible tells us not to do it, but sometimes lies can be your life-saver."*
>
> Rhoda, participant observation, 2018

In chapter 6, I explored the social restrictions placed on young women living with HIV, through analysis of qualitative data generated in 2015. It was partly this analysis that led to my desire to investigate within the ethnographic study, not only the constraints placed on young women living with HIV, but how they are navigated, and what impact they have. In chapter 6, I discussed the tension around different disclosure messaging that young women living with HIV face, with their parents discouraging disclosure, while healthcare professionals strongly encouraged it. In this chapter, I now delve much more deeply into experiences around HIV status disclosure.

In this chapter, I draw on data generated by the ethnographic study in this PhD research, as well as the conceptual and theoretical literature discussed in chapter 2. I explore how young women living with HIV in Lusaka practiced secrecy and silence to maintain an identity beyond HIV, and control over knowledge of their HIV status. Whilst these coping strategies reflected their agency, the accompanying feelings of guilt and demonstrated how their agency was limited by the social nature of HIV-related stigma.

The findings presented in this paper challenge the conventional pejorative view of secrecy and silence, to argue that they can be practiced as constructive strategies to control the flow of information and protect one's identity, in the context of persistent HIV-related stigma. This leads to questioning public health and health professionals' assumptions that disclosure to sexual partners should be universally advised and practiced. The findings also lead to recommendations for establishing and extending support groups to provide a space where young women living with HIV can be free and open with peers.

This paper contributes to research objectives 1 and 2:

1. To understand how HIV impacts young women's relationships and daily activities
2. To understand the strategies that young women practice to cope with HIV

Secrets and silence: agency of young women managing HIV disclosure

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Abstract

Drawing on a 12-month ethnography with young women living with HIV in Zambia, we explore their everyday strategies to avoid unintentional disclosure of their HIV status. Young women practiced secrecy with sexual partners, through hiding their antiretroviral therapy and using veiled language around HIV. Whilst remaining silent about their HIV status enabled them to maintain identities beyond HIV, this secrecy triggered feelings of guilt and anxiety, suggesting that their agency was "bounded" (Evans, 2007) by the context of persistent stigma. These strategies to hide their HIV status question public health narratives urging disclosure, and support disclosure-counselling approaches that champions choice.

Introduction

Young women living with HIV in sub-Saharan Africa often experience persistent stigma, commonly leading to limited disclosure networks (Mburu et al., 2014). Though encouraged by counsellors, the process of disclosing HIV status can provoke anxiety and has the potential to have either a positive or negative impact, including on individuals' identities and relationships (Toska et al., 2015). Much research with young people living with HIV has highlighted the challenges, such as stigma, that they face when considering disclosure, but often does little to extend our understanding of the factors and choices that young people make to moderate or mediate these negative impacts of HIV (Skovdal & Daniel, 2012; Theron & Theron, 2010). Since youth is a period of social change, relationship formation and identity development (World Health Organization, 2017b), the negative social impact of HIV disclosure can have especially strong effects on young people, and strategies for coping often take on a social form (Skovdal & Ogutu, 2012).

Young people affected by HIV have demonstrated individual strategies of tapping into their inherent strengths to become agents in care and support (Khanare, 2012). If young people living with HIV seek social support, this has been shown to reduce anxiety and depression (Seffren et al., 2018), support adherence (Denison et al., 2015), and enable progression through the HIV continuum of care (MacPherson et al., 2012). Disclosure to others is best understood as a process, which often includes targeting who to tell based on relationship quality and minimising risks of rejection, rehearsing how to disclose, and 'testing the waters' through incremental clues (Cusick & Rhodes, 1999). In a study in the US, young people living with HIV described strategies to manage the impact of the disclosure process on their identities, including getting to know a new sexual partner before disclosing to them in order to postpone and lessen the negative impact of disclosure (Frye et al., 2009). However, we have limited understanding about the everyday strategies that young women living with HIV undertake to mediate the potential challenges of unintentional HIV disclosure.

Disclosure and secrecy

One strategy to avoid the challenges associated with HIV disclosure in certain contexts is secrecy. The majority of young women living with HIV have limited disclosure networks, and are careful over who they choose to tell about their HIV status (Fielden et al., 2011; Mburu et al., 2014). In a study in Uganda and Kenya, over half of adolescents living with HIV had never told anyone their HIV status (Nostlinger et al., 2015). Family members or caregivers of young women living with HIV often strongly discourage disclosure, to protect not only the adolescent, but also themselves or their families from anticipated stigma and potential discrimination, especially in cases of mother-to-child transmission (Mackworth-Young. et al., 2017).

However, the value of secrecy as a strategy to navigate the potentially negative consequences of stigma is challenged in a context where the personal and public healing effects of disclosure are emphasised (Nguyen, 2013, p. 440). Numerous accounts describe the liberating effect of disclosure (e.g. Paxton, 2002). This is linked to empowerment speak of "coming out" and discourses of therapeutic citizenship, where people living with HIV can demand and access antiretroviral therapy (ART) only once they have "confessed" (Nguyen, 2010, pp. 1, 35). Disclosure is therefore encouraged, not just for individual liberation and prevention of the onward transmission of HIV, but also for wider societal mobilisation and contestation of stigma (Paxton, 2002). However, as critiqued by Hardon and Posel, this emphasis on disclosure and the pejorative notion of secrecy risks that the "prescription to be open about these issues will become monochromatic, blunt and unduly coercive, based on a misreading of more nuanced ways of knowing and telling, ignoring the more complex psychology and anthropology of making and keeping secrets" (2012, p. 3). We draw on Hardon and Posel's notion of secrecy as a deeply relational social practice, where what we reveal and what we withhold is shaped by agency bounded by social and structural factors (2012).

"Bounded" agency

Bourdieu theorises agency as the interactions between agents and their environment, thereby positioning choices within, and responsive to, social processes (Bourdieu, 1977). Women's agency has been considered as being along a continuum, where a woman's position varies over time and between relationships (Stoebenau et al., 2016). Popular discourses of young people and HIV are often situated within a framework of vulnerability and a lack of agency, which can overlook strategies that young people employ in their daily lives (Pincock, 2017). Cognisant of the particular social and structural constraints that young people face, Evans introduced the concept of "bounded agency", which is "socially situated agency, influenced but not determined by environments" (Evans, 2007, p. 17). Through "bounded agency", individuals are understood as actors within structures, with space open for action but within the constraints of the "social landscape" (Evans, 2007, p. 2). Some of these constraints are difficult to move, while others can be circumnavigated, altered or resisted. We build on Evan's concept of "bounded agency" to explore how young women living with HIV adopt secrecy as a strategy of resistance to norms concerning HIV status disclosure in the context of a particular social landscape.

Managing identity

Employing agency through the practice of secrecy in the context of a stigmatised disease can be seen to impact one's identity. The concept of identity was explored by Goffman in his seminal work on stigma, which theorised how individuals who are unable to conform to society's standards of normality are seen to have "spoiled identities" (1963, p. 31). Chronic or acute health conditions can be seen as a "disruption" to identity (Bury, 1982, p. 167), which then requires review, maintenance and repair (Corbin & Strauss, 1987). This resonates with understandings of the ways that changes in HIV status can impact on identity, including through abrupt biographical disruption, and loss of a communal self with changes to relationships and

support networks (Freeman, 2017; Russell & Seeley, 2010; Seeley et al., 2012). However, we have more limited understanding of how people maintain or protect their identity throughout the course of living with HIV, including through the choices made around HIV status disclosure. Goffman's work has been criticised for centring on the stigmatised, without a focus on those who impose stigma, thus situating stigmatised individuals as victims who lack agency and overlooking how social life and relationships are altered by stigma (Kleinman & Hall-Clifford, 2009). Broader understandings of stigma acknowledge the socially embedded context, which enable structural discrimination that leads to individual stigma (Kleinman & Hall-Clifford, 2009; Link & Phelan, 2001). We draw on and beyond Goffman's notion of stigma to explore how, in the context of a stigmatised disease, young women use their agency within cultural and structural contexts to practice secrecy in order to navigate disclosure within their relationships and therefore manage their wider identities.

Income level can contribute to identity formation, as well as being an important factor determining the strategies that individuals may use to manage their identities, including secrecy. Despite having high HIV prevalence in some sub-Saharan African countries, such as Zambia (Central Statistical Office & Ministry of Health, 2014) and Tanzania (Long & Deane, 2015), middle-income populations have been notably under-researched, with the HIV epidemic remaining firmly rooted in a poverty narrative (Fenton, 2004). Middle-income populations face particular vulnerabilities, such as high sexual risk behaviours and high HIV prevalence, and are overdue focused research (Long & Deane, 2015). Further, middle-income groups may have particular motivations for secrecy around HIV, including protecting particular identities, such as college students or employees, and particular strategies for doing so. This research gap, alongside practical and language considerations for data collection, underlies the purposeful selection of middle-income young women living with HIV for this ethnographic study.

In this article, we explore the intersections between agency and identity to understand the everyday strategies employed by middle-income young women living with HIV in urban Zambia to manage disclosure of their HIV status. We explore how secrecy and silence are practiced as strategies to manage their identities in the face of pervasive stigma, and the impact that this has on their lives.

Research methods and setting

This ethnographic study aimed to understand the impact of HIV on the everyday lives of young women living with HIV. The lead researcher (initials removed for peer review) conducted twelve months of participant observation with seven young women living with HIV (aged 17-19 years) in Lusaka in 2017-2018. This study arose out of an earlier qualitative study in 2014-15 and subsequent support group intervention in 2016 with a larger cohort of young women living with HIV (Mackworth-Young. et al., 2017). Building on this earlier contact, young women from that cohort who were middle-income (defined as having a parent or guardian working in a formal job, and living in a middle-income area of Lusaka) and spoke English were purposefully selected to participate in the ethnography. Seven young women participated in the ethnography (Table 7.1). They were all on HIV treatment, identified as Christian, and had completed secondary school.

Table 7.I. Participant characteristics at the beginning of the ethnography in 2017

Participant [a]	**Age**	**Key family member who they stay with**	**Orphan status**	**Mode of HIV acquisition**	**Education**	**Year started ART**
Rose	19	Father and step-mother	Single orphan	MTCT [b]	Completed grade 12; studying to re-sit exams	2010
Thandi	18	Mother	Single orphan	MTCT	Studying at College	2012
Natasha	18	Aunt	Double orphan	MTCT	Complete Grade 12, applying for College	2008
Rhoda	19	Mother	Single orphan	MTCT	Completed Grade 12, applying for College	2005
Mavis	19	Grandparents	Double orphan	Sexual abuse	Completed Grade 12	2017
Mary	17	Mother and Aunt	Single orphan	MTCT	Studying at College	2014
Sophie	19	Uncle	Double orphan	MTCT	Completed Grade 12, studying to re-sit exams	2008

[a] All names used are pseudonyms;

[b] Mother to child transmission (MTCT)

Fieldwork mostly occurred in Lusaka, the capital city and largest urban centre in Zambia. This research largely took place in low-density, middle-income areas of Lusaka, where the young women lived, studied at college, shopped, met with friends, and went to church and to the clinic. In these areas the main roads are tarred and smaller roads are dirt. Most areas have a main shopping centre, a government health facility, as well as dozens of schools, informal shops, cafes, bars and churches. A walled fence usually surrounds each house

or collection of houses in these areas, with a gate at the entrance, and a small yard around the house. Inside most houses in these middle-income areas, there is a kitchen, living room with sofas and a television, a bathroom with running water, and two to three bedrooms, shared by all household members. Most participants shared their bedrooms with cousins or other family members, and sometimes also with visitors when they stayed. The participants' bedrooms usually had one double bed (usually shared with other female family members), a tall cupboard and chest of drawers full of clothes and shoes, with bags or suitcases of clothes or other possessions in bags on top. Participants' ART was usually stored in their bedrooms, either in their bedside table, or hidden in a drawer amongst their clothes. Participants studying in college stayed in boarding houses, sharing dormitories with one to seven other young women, with shared bathrooms and limited private space.

Participant observation involved the lead researcher spending time with the seven young women across a range of settings (including home, recreational, colleges and clinics), sometimes in the company of their family, friends and boyfriends, and sometimes on their own. Between 12 and 24 blocks of time were spent with each of the young women over the twelve months. Each session of observation was arranged by phone with the participant, usually initiated by the researcher, ensuring no more than a few weeks passed between each session with each participant. Less frequently, participants initiated meeting up by suggesting the researcher join a particular activity that they were doing. Field notes were written up soon after each participant observation, capturing the detail of places, discussions, relationships with others and personal reflections.

The lead researcher mostly spent time with the young women individually as opposed to seeing them together. The exception was participatory workshops held at the beginning and end of the fieldwork period when all the young women and the lead researcher came together. The first workshop discussed the purpose of the research and how to introduce the research to

others, and the second validated the preliminary findings with the young women. To illustrate the range of data collection methods, below is a description of the data collection with one participant, Rhoda, over the course of the 12-month ethnography. Rhoda was asked to participate and gave consent in September 2017. She participated in the introductory workshop with the other participants. The researcher had 17 sessions of participant observation with her, including at her home (n=3), at her place of work (n=3), in recreational spaces including cafes and shopping areas (n=6), at church (n=1), at the clinic, including a peer education session (n=1) and at an NGO (n=3). Rhoda participated in the closing workshop with the other participants in September 2018.

Additional to the ethnography with young women living with HIV, 14 young women with negative or unknown HIV status were recruited to attend a one-day participatory workshop, which aimed to compare their experiences to the young women living with HIV to understand what experiences might be specific to living with HIV, or more generally related to being a young woman. Nine young women were recruited through convenience sampling through colleagues of the authors in Lusaka, and these young women themselves recruited a further five young women through snowball sampling. The selection criteria were being aged 18-21 years, living in Lusaka, being middle-income and having a negative or unknown HIV status. In the workshop, discussions explored the role and place of secrets and disclosure of information in the context of their social relationships.

Conducting the ethnography over twelve months allowed time for findings to initiate both further enquiry and deeper analysis, developed through reflective memos and conversations with the research team. The theme of secrecy as a strategy to prevent unintentional disclosure emerged out of this process. This then influenced subsequent data generation, which consequently included a specific focus on this topic, including discussions around secrecy in the workshop with young women who had negative or unknown HIV status. At the closing workshop with the young women living

with HIV, the participants were asked to collectively analyse the initial results on secrecy, unintentional disclosure, the strategies they used to hide their HIV status, and the impact these had on their lives. This included brainstorming in pairs about the strategies that they used to hide their HIV status, and a 'card-storm' activity, writing and discussing words they used to discuss and conceal HIV. In the workshop, participants discussed how the word "*lies*" was a strong word with negative connotations, but, since it was the word that they collectively chose to use to describe their experiences around HIV disclosure, we have used the term in this analysis. After the completion of data collection, data relating to this thematic area were coded manually, using the following broad codes which were developed inductively during data analysis: unintentional disclosure; stories told to hide HIV status; hiding ART; veiled language; researcher's experience of secrecy. Data were then grouped and analysed thematically. The themes that emerged form the structure of this manuscript: i) secrecy in sexual relationships; ii) secrecy around ART; iii) secrecy in language; iv) secrecy through stories; v) fear and anxiety around secrecy; and vi) secrecy beyond HIV.

Ethical clearance was obtained from the review boards of the University of Zambia Humanities Research Ethics Committee and the London School of Hygiene and Tropical Medicine, and approval was granted by the Zambian Ministry of Health. Participants were asked for their written consent to participate in the study, as well as their parents or guardians, due to the familial and intimate nature of the ethnographic study, which involved spending large amounts of time in participants' homes. The risk of unintentional disclosure of the young women's HIV status was discussed with participants during informed consent and in the introductory workshop. In the introductory workshop, the young women reached a consensus to describe the research to others who did not know their HIV status as anthropological research looking at the everyday lives of young women in Lusaka, thereby maintaining confidentiality about HIV status. The researcher also agreed to adapt this to the specific circumstances for each participant, if they felt that for particular individuals a different story would be more

appropriate in a particular context to hide their HIV status. For example, one participant told her uncle that she had met the researcher at her workplace, and another told her friend that she met the researcher at church. Pseudonyms were used in writing participant observation notes and results. The navigation of ethical issues by the researcher in the study was explored separately through a detailed analysis reported elsewhere (Mackworth-Young. et al., 2019).

There are several limitations to the study. Firstly, the research only considered the experiences of young women, thereby not representing the views of young men who are living with HIV, which remain underrepresented in ethnographical research (eg. Simpson, 2009), and are needed to understand gender differences. Secondly, I decided not stay with any of the participants in their households overnight for ethical and practical reasons, and this may have limited the extent to which I could immerse myself totally in their lives. Lastly, although I learnt basic Nyanja, and could converse with the participants and their families, not being fluent in the language meant that I missed some of the nuanced content in these conversations. However, with this group of middle-income young women, English was the predominant language, so, on the whole I could understand and participate fully in their social interactions.

Findings

Silence in sexual relationships: "I won't tell him about my status"

All the young women were in relationships at some point during the study, mostly long-term steady boyfriends, but also, less commonly, short-term sexual relationships, which were occasionally concurrent. For the young women, their boyfriends were central and exciting parts of their lives. However, their HIV status was a consistent worry to them in their

relationships. They worried about whether, how and when to disclose their HIV status, what reaction they would receive, and how to protect themselves and their boyfriends if and when they had sex. Most participants did not disclose their HIV status until their relationship "*became serious*" (Thandi, participant observation), which to Thandi meant being a close and exclusive couple, but not yet sexually active. However, they continuously feared that their boyfriends would find out about their HIV status. Even when participants made a conscious decision to disclose their status to their boyfriends, the continued fear of potential negative consequences plagued their thoughts. After Mary had told her boyfriend that she was living with HIV, even though he had reacted well, she said:

> *You know, I think hard about things, and I really wonder whether I will ever get married in my state. Maybe he'll accept it for a while, but one day, he might just think differently about it, and realise that he doesn't want to be with me because of that thing. And then it makes me think whether anyone would want to marry me. It's something I think about a lot.* (Mary, participant observation).

Unintentional disclosure of their HIV status was described as "*the worst thing that could happen to me*" (Mary, participant observation), with the fear and the potential negative consequences of unintentional disclosure being most heightened with young women's boyfriends or other sexual partners. Most of the young women had experienced unintentional disclosure, either before or during the study, often with damaging and adverse social consequences. For one participant, Rhoda, when her ex-boyfriend discovered her HIV status unbeknown to Rhoda after they had broken up, he told multiple friends about it, causing Rhoda significant worry and hurt:

> *I really hated it that these people found out about me without my choice. We are always learning in workshops that you have to think about how to disclose: who, when, where, why, how. Now I really hope I don't see these people ever, because of discrimination and all that. He made me feel like I was trash.* (Rhoda, participant observation).

Rhoda's hurt about this experience was not only through the discrimination that she feared and experienced, but through her loss of control over the knowledge of her HIV status. Rhoda continued to describe the impact that this had on her, and her views on future disclosure:

> *I always used to be wary of telling boyfriends (that I was living with HIV), because I thought that they might bring it up if we ever fought. But now it has really made me lose my trust. If I have another boyfriend, I really won't tell him anything about my past and my status. I will wait until I really know him, and I am really sure before telling him. But if it does ever happen again, I now know I can deal with it.* (Rhoda, participant observation)

Rhoda's HIV status was subsequently discovered later by fellow students in her boarding college, and the ensuing gossip forced her to move to another boarding college.

Where the choice around how and when was removed from the young women through unintentional disclosure, they sometimes experienced damaging and traumatic social consequences, exemplifying Goffman's "spoiled identity" (1963). This silence and secrets about their HIV status were therefore unstable and temporary, maintained until someone finds out. The fear of unintentional disclosure was linked to a fear of rejection, and being labelled as different from others. This rejection was experienced by some when unintentional disclosure did occur, leading to impacts on the young women's identity as viable girlfriends, friends or students, with disruptive and traumatic consequences. Links can be drawn with Abu-Lughod's understanding of female agency through Bedouin veiling (Abu-Lughod, 1986). She described how, though choosing visual concealment by veiling, women negotiated hierarchical social relationships, enacting agency through a desire for conformity to a social ideal (Abu-Lughod, 1986).

Secrecy around ART

All participants were taking ART during the study, and most had started ART several years before (Table 7.1). They recognised that being on ART helped them "*look healthy*" (Thandi, collage) and conceal their HIV status through their bodies, maintaining their identity as a "*healthy*" young person by reducing the risk of excessive weight loss. However, for many participants, ART was also the most potentially conspicuous everyday sign that they were living with HIV, and so they went to great lengths to conceal their medicines. For those who did not have a private space, either at home or in boarding college, keeping their ART in a secret space was described as "*the biggest difficulty I have*" (Mary, participant observation). The participants who stayed at boarding colleges had similar strategies to each other for storing their medicines in their shared dormitories with up to seven other students. For instance, Mary kept "*a small supply of medicines inside a small medicine bag, in my backpack, which is kept on my bed, the top bunk*" (Mary, participant observation). Her longer-term supply of ART was kept in a bottle at the bottom of her trunk, hidden under her clothes, where she felt it was least likely to be found by her roommates. But she described the challenges she faced transferring a new supply of pills into her small medicine bag in her shared dormitory without anyone seeing or asking questions.

Transporting ART from the health facility where the young women collected their new supply usually once every three months was seen as a potential risk of disclosure. In a peer education workshop observed at a health facility with one participant, common strategies of hiding or disguising ART once they had received it from the health facility were discussed. These included: throwing away the cardboard packaging of the ART before leaving the health facility; stuffing the bottles of ART with either paper or tissue to stop the noise of the pills rattling in the bottles; and emptying the ART into small plastic bags. The young women in the study similarly shared the strategies that they used for getting their ART ready to take at the same time each day without raising suspicion in the closing workshop. This included collecting the pills earlier

than they needed to take them, then keeping them on their person (e.g. in their bras or in their pockets, wrapped in a tissue) until the designated time so as not to raise suspicions by going to their bags, or wherever they stored their ART, at the same time each day.

During the study period, many participants moved households to stay with different family members for periods of time from one night to several weeks or months. While in their main home, most participants had established somewhere private and safe to keep their ART. However, when they stayed with other relatives, many of whom did not know that they are living with HIV, hiding their ART became "*really very difficult*" (Sophie, participant observation). For some, their backpacks were the only private and safe space, as "*everybody knows that you certainly should not go into other people's bags*" (Sophie, participant observation). Some therefore carried their ART with them in their bags, wherever they went. For Rose, while staying with her brother, her ART were discovered by her sister-in-law, who looked through her clothes where the ART was hidden while Rose was out of the house. This led to an array of questions, leading Rose to feel that she was forced to invent a story, saying that she was given the medicines so that she could teach others about HIV and ART in support groups that she was facilitating. When a friend of Mary's discovered Mary's ART, the friend confronted Mary with a bottle of ART. Mary "*felt scared that her secret was out*", but then conversely "*felt a great sense of relief*" when her friend told her that she was also living with HIV, and that the bottle of ART she was holding was in fact her own (Mary, participant observation). This led to a close bond being developed between the two friends, who have since supported each other.

In other settings, non-HIV-identifying spaces for clinical and social HIV programs attempt to create a "normalising environment" (Fielden et al., 2011). The young women in this study attempted to create such an environment in their home lives through concealment of their ART, thus encompassing use of space in their identity management. In both settings, we see the attempt to erase what Goffman refers to as the "stigma symbols" or

visual reminders of HIV (1963, p. 59). This is particularly relevant in contexts of limited private space, as seen here with shared bedrooms, communal storage space and collective belongings. This supports others who extend Goffman's focus on how the social order of stigma is maintained, to understand how the stigma norms may be challenged or resisted (Tyler, 2018), while remaining cognisant of the structural and contextual boundaries that this can occur within (Kleinman & Hall-Clifford, 2009). Here we see secrecy and concealment of ART as a resistance to HIV stigma, within the boundaries of limited privacy.

Silence in language: Veiled language around HIV

Verbally, participants used concealed language around HIV and ART, never once mentioning the word HIV during participant observations. Instead, words such as "*dosed*", "*in my state*" and *"atopinga*" (i.e. 'topping up' with medicines) were used to refer to their being HIV positive, while others living with HIV were described as being "*in my shoes*", "*she's like me*" or "*in my state*". ART was rarely referred to as such, rather as "*meds*", and taking their ART was described as "*drinking*". In a card storm session in the closing workshop, the young women described more cryptic ways of talking about their ART with particular individuals who knew their HIV status. These included: "*chocolate"* or "*toffee*" (Thandi, with her mother); "*cherry*" (Mavis, with her boyfriend); "*daily manna*" (Mary, with her friend who is also living with HIV); *"your beans*", "*therapy*", or *"snacks*" (Rose, with her mother); and "*manure*" or "*catalyst"* (Sophie, who explained that she uses these words because the ART feeds your body and stimulates reactions in your body to keep you alive). They also sometimes referred to their ART as other medication, such as "*panadol*" (or paracetamol), to cover up what the medicines were really for. This contrasted to openness about other chronic diseases: one participant, Natasha, talked openly about her cousin's epilepsy medication, but then used veiled language about ART:

> *She takes her epilepsy medicine twice a day, and then that other one once a day at 20 hours.* (Natasha, participant observation).

One participant, Sophie also referred to ART as "*chitupa"* (translated as 'my identity card'), when speaking with her friend from church who was also living with HIV, implying that she viewed ART as a central part of her identity.

This veiled language was a form of HIV silence practiced by the young women almost subconsciously, using it with those who know their HIV status even in private spaces where there was no chance of being overhead. It became so normalised that as the researcher, I adopted the use of this veiled language when with participants and their families. As the researcher, my embroilment in the young women's silence and secrets raised complex ethical and practical implications, discussed in detail in a separate analysis (Mackworth-Young, Bond, et al., 2018). The practice of veiled language supports Squire's findings of how language can be used to evade the actualities of the condition, through the use of acronyms or coded language for HIV (Squire, 2013). It can be seen to lead to HIV being rendered publicly silent, being pushed into the realm of private suffering (Squire, 2013). However, among those living with HIV, this choice of veiled language can create a "secret fraternity of sickness" (Moore, 1996, p. 62), and can enable oblique and potentially supportive discussion of HIV issues between those with knowledge of each other's HIV status (Squire, 2013). Here, the use of veiled language provided the young women with the ability to talk about HIV and ART, and their experiences of it, without being explicit, through the use of analogies and metaphors. This veiled language allowed the young women to speak without explicitly saying, to refer without naming, to infer without implicating, and by doing so, made the interaction of HIV in their relationships both safer and more ambiguous.

Secrecy through stories: "*I tell lies every single day*"

Beyond using veiled language, secrecy was practiced more explicitly in the young women's language through the use of stories, or in their words, "*lies*". Participants said they *"tell lies every single day*" (Mavis, workshop), including around their presence at the ART clinic, how their parents died, and what

their ART was. When they went to the clinic, participants often had to invent stories to cover up where they were:

> *(My friend) kept on calling when I was at the clinic, asking where I was. So, I just had to say that I was in town doing a few things. But then she wanted to join me in town, so I had to lie again.* (Mavis, participant observation).

Thandi, who was studying clinical medicine at college, described the challenges of excusing herself from classes when she went to the clinic, without being able to explain the reason why. Many of the young women spoke about telling multiple stories in order to cover up previous stories that they had told, and the challenges that ensued of having to try to remember who they had told what.

Since inventing cover-up stories was so commonplace for participants, they described adding another thing that they may have to conceal information about, namely this research study, as "*not a big deal*" (workshop). For them, this did not mean that being forced to invent stories did not impact them or their lives; rather it had become such a commonplace aspect of their everyday lives. During this research, participants frequently invented stories about the research and the researcher to hide their HIV status. For instance, Rhoda, when going to her house, told the researcher,

> *If anyone asks, you should just tell them that we met at my work, at the printing shop. My Grandmother, she knows of course, but just if anyone else asks, it's best to tell them that.* (Rhoda, participant observation).

Other participants described me, the researcher, as "*a friend*" to people who asked how they knew each other. As such I, as the researcher, became embroiled in the "*lies*" that participants told to conceal their HIV status. This supports Madiega *et al*.'s findings of researchers being described as "church friends", "sisters-in-law" or "relatives" by participants and, while this was deemed necessary, it left some moral residue with the researchers (2013, p. 25). Cognisant of the ethical importance of protecting participants' confidentiality, which was perceived to override the ethical need for

transparency within research, such strategies may be essential to ensure active participation of young people living with HIV in such research.

The young women drew strength from employing responsive agency through telling such stories, keeping secrets and staying silent as a strategy to maintain relationships and their identities beyond HIV. As others have presented (Bond, 2010; Hardon & Posel, 2012), the young women in this study used secrecy as a social practice to control how others see them. The boundaries between what is revealed and what is withheld are fluid and shaped by personal choice (Hardon & Posel, 2012). Here, these strategies largely enabled the young women to avoid unintentional disclosure of their HIV status. However, social and structural factors constrain these choices, sometimes very tightly indeed, and the choices can have challenging consequences.

Fear and anxiety around secrecy: *"I feel really bad lying"*

When asked in the closing workshop how they felt about having to practice secrecy to hide their HIV status, two participants wrote:

> *We are both honestly okay with having to lie/ cover up about our status because people have different understandings about HIV so we lie to protect our social life and also to avoid stigmatistation*. (Mavis and Mary, workshop).

However, in participant observations, these strategies were sometimes seen to create guilt around telling "*lies*" and anxiety that their lies might be discovered. Participants particularly worried that close friends, family and boyfriends would unintentionally find out about their HIV status:

> *The bad part is that I can't tell (my best friend). But I don't like it because there's no lie that can stay hidden forever. One day she is going to find out, the way she always borrows my clothes and goes through my stuff. I'm sure she's going to find out.* (Mavis, participant observation).

This fear turned out to be well founded, as later this best friend did discover Mavis' status, leading to her telling other friends, speaking in negative terms about Mavis, and the end of their previously close friendship.

When participants did "*lie*" to hide their HIV status, they sometimes expressed guilt around telling "*lies*":

> *I feel really bad lying to that woman. I just didn't know what to say, so I made that up, but I should have just told the truth.* (Rhoda, participant observation).

Rhoda brought the topic up again several hours later, saying

> *I still feel bad about lying to that woman. I always feel bad when I lie. It makes me feel so guilty inside. May God forgive me.* (Rhoda, participant observation)

When the researcher then asked: "*do you have to lie because of your status*", Rhoda replied, "*yes, a lot, all the time*". During participant observation of a peer education session at an ART clinic that one participant was attending, a group of young people living with HIV discussed the benefits, the challenges and the Christian morals around telling "*lies*" to hide one's HIV status:

> *Yes, of course, lying is bad, and the Bible tells us not to do it, but sometimes lies can be your life-saver.* (participant observation of peer education group with Rhoda).

While non-disclosure through the social practice of secrecy was, for some of the young women, an enactment of agency, the guilt and anxiety which these elicited demonstrates that the young women's agency was tightly "bounded" (Evans, 2007) by the social context of persistent stigma. The regret about not being able to disclose to close friends, boyfriends and others shows how despite making choices around disclosure processes, and practicing strategies to manage their identity, their agency was bounded by social and structural factors. Here we see that silence and secrecy were practiced as a form of resistance, although only one that was attempting to navigate, rather than alter a social environment characterised by stigma.

When participants did not have to practice secrecy, because they had chosen to disclose their HIV status to certain people, they described the peace this provided:

> *It's so nice to be with someone who knows. I don't know how to describe it; it's just so peaceful. She just understands; I don't need to explain or tell stories.* (Mavis, participant observation).
>
> *I felt like a weight had been lifted off my chest, I felt so much lighter.* (Rhoda, participant observation)

Mary, who had disclosed to four close friends, described the benefits of this disclosure:

> *This is the most important bit, having friends who support you and accept you for you who are.* (Mary, participant observation).

Other participants emphasised the freedom they gained from disclosing to friends:

> *I took my friend to the clinic to disclose my status to her: I knew she wouldn't believe it if I just told her. We've been close friends for years, we were at school together, but I just never felt like I could tell her before now. When she realised, she told me that she was also HIV-positive. I couldn't believe it. But we're now closer than ever, we've shared all our stories, and it's so nice that I can be completely free with her.* (Sophie, participant observation).

This freedom, support and relief that the young women experienced with those they had chosen to disclose to, as well as with others living with HIV supports other evidence demonstrating the value of psycho-emotional support for young people living with HIV (Mupambireyi, 2017; Mupambireyi et al., 2014).

Secrecy and silence beyond HIV

The young women living with HIV went to great lengths to conceal their HIV status through secrecy and lies. However, Sophie's statement that "*everybody knows that you certainly should not go through other people's bags*" illustrates that everyone has things that they do not want to reveal. In the workshop

with young people with unknown or negative HIV status, several of the participants agreed that they "*don't like announcing things about ourselves*" (Winnie, workshop). They said they would assess whom they could trust to share certain issues with. In particular, they would avoid talking to their parents about relationships, and would avoid telling friends some things to avoid judgement and envy: "*I don't want to share things with friends because of jealousy*" (Mwangala, workshop). One young woman declared that there were some particular major, and challenging, aspects of her experience and identity that she selects to keep silent about:

> *I share most things with everyone, but there are some secrets, some big secrets, that make me scared to even think about. There are some secrets that even make me cry when I think about them*. (Tila, workshop).

Ill health was one issue that the young women in the workshop were clear that they would want to keep private, including, but not restricted to HIV:

> *You would definitely hide your HIV status or any other disease or health status* (Brenda, workshop).

These young women with negative or unknown HIV status therefore were also acting within boundaries of choosing to keep certain identities and parts of their lives secret (Hardon & Posel, 2012). Being young bounded their options more tightly, as did being female, with young women known to face greater restrictions and social judgement on their choices and activities (Mackworth-Young. et al., 2017). These restrictions include where they can move, who they can interact with, and the social connotations between young women, HIV and unsanctioned sex (Mackworth-Young. et al., 2017). The young women with negative or unknown HIV status admitted that they thought the boundaries would be more restrictive for those living with HIV. We suggest that being middle income, gave these young women (those with positive, negative and unknown HIV statuses) more options, compared to lower-income young women, including greater access to safe spaces through support groups peer education networks and financial ability to pay transport costs, thereby widening the boundaries within which they enacted agency.

Conclusions

The young women living with HIV in the ethnographic study disclosed their HIV status on a need-to-know basis, choosing to keep it secret from others to protect themselves from potential stigma arising from disclosure that they deemed unnecessary. Through this, they drew strength from employing responsive agency by using secrecy and silence as strategies in response to social relationships to retain choice over who, how, where and when to disclose their HIV status. Where they were able to maintain the secret, they had the agency to shape and define what being HIV positive meant to them. However, the findings build on Evans' concept of "bounded agency" (Evans, 2007) to show how the young women's agency to practice secrecy and silence was tightly bounded by the social context of persistent stigma. Despite the accompanying guilt and anxiety, for some, secrecy and silence were seen as necessary to avoid the potentially traumatic consequences of unintentional disclosure.

Our findings question the pejorative dimension of secrecy and silence which are often opposed to the cherished social values of truth and honesty (Stadler, Scorgie, van der Straten, & Saethre, 2016), to argue instead that they can be used as active strategies to protect one's identity in a context of a stigmatised disease and limited private space. We demonstrate the potential constructive power of secrecy and silence to control the flow of information, to protect against stigma, and as strategies to manage identity. Secrecy and silence, especially through the use of veiled language, presented the young women with a level of ambiguity to navigate their lives with HIV, enabling a balance between people knowing and having the possibility of people not knowing. Maman et al. have shown that non-disclosure of HIV can be a marker of other problematic aspects of a relationship (Maman, Groves, McNaughton Reyes, & Moodley, 2016). Indeed, Mavis' decision not to disclose to her friend and Rhoda's decision not to disclose her boyfriend, led to traumatic social consequences when each unintentionally found out their status. The young women's judgement to withhold their HIV status was thus a reflection of the

quality of the relationship and the predicted outcome of HIV disclosure. Secrecy was used as both a conscious and an intuitive strategy, particularly in environments with restricted privacy and high mobility for this middle-income group, with several attending boarding college and sharing rooms with other students, as also identified by Mutwa et al. (Mutwa et al., 2013). These accounts show how secrecy and silence can be used as constructive practices, as "resistance against exclusion" and to safeguard against moral judgement (Dongen & Fainzang, 2002, p. 150).

This adds to an increasing body of knowledge that aims to shift towards greater nuance within assumptions and practices around the disclosure process (Fielden et al., 2011; Galano et al., 2017; Hardon & Posel, 2012). Unlike some other secrets, within the context of HIV, privacy about HIV becomes a secret that *must* be shared. Viewing the silence practiced by young people with regard to their HIV status as subversive (Hardon & Posel, 2012) holds them to a higher threshold of transparency than we ask of others. In the context of Undetectable= Untransmittable (U=U) (The Lancet HIV, 2017), and in view of evidence from South Africa showing that the disclosure of young people's HIV-positive status to sexual partners does not lead to safer sex (Toska et al., 2015), assumptions that disclosure to sexual partners is universally constructive for young people living with HIV are questionable. This is particularly the case for this group of middle-income young women, who have access to high standards of care, including routine viral load testing, and so can regularly monitor their viral load. These prescriptive disclosure assumptions underlie international guidance on HIV that frequently emphasises the importance of disclosure, and reflects global narratives urging disclosure to sexual partners (World Health Organization, 2013b). In some settings, non-disclosure of HIV status is criminalised (Hurley, 2018). Yet, for the young women in this study, disclosing to boyfriends was potentially the most damaging for their identity. This more nuanced approach interrogates global and local counselling guidelines that recommend disclosure, especially to all sexual partners. As Hardon and Posel argue, rather than "calls to normalise HIV/ AIDS through routine practices of disclosure…

a culturally sensitive balance between truth-telling and silence may sometimes be more appropriate" (Hardon & Posel, 2012, p. 5).

Previous research has shown that young people manage a 'truth economy', choosing what information to share with healthcare providers (Bernays et al., 2017). Where healthcare providers singularly encourage disclosure without due attention to possible harmful outcomes, there is a risk that this could lead to damaging the wider supportive relationship young people may have and could possibly lead to withholding other information and avoiding clinical spaces for support. Disclosure counselling should adapt to account for the importance of this agency and support young people with such strategies to manage their identities. Counsellors should therefore acknowledge and support settings and cases where it may be "neither morally appropriate nor tactically advantageous to disclose" (Hardon & Posel, 2012, p. 9).

The value of psycho-emotional support is demonstrated by the freedom, support and relief the young women experienced with those they had chosen to disclose to as well as with other young women living with HIV. Support groups with other young people living with HIV have been shown to provide a valuable safe space, where they receive social support and can feel "normal" through being "among others who are just like me" (Barker et al., 2019; Mupambireyi et al., 2014, pp. p. 110, 106). They can provide a much-needed space for young people living with HIV to be open, free from necessitated secrecy and fear and without worrying about the consequences, in contrast to the rest of their lives when they are bounded by the social context of persistent stigma. Support with the disclosure process can equip young women living with HIV with the skills to make decisions around who, when, where and why to disclose their HIV status, and strategies both for choices to disclose as well as not disclose (Evangeli, Lut, & Ely, 2018). With an overwhelming focus on treatment adherence in adolescent programs (Bernays et al., 2017), this support and advice on disclosure is often overlooked, but strongly needed. Further, such support could alleviate some

of the guilt and anxiety experienced by the young women living with HIV around the secrecy and silence that they practice.

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Declaration of interest statement

None of the authors have any conflict of interest that might conflict with this research.

Chapter 8: Coming of age with HIV: A temporal understanding of young women's experiences in Zambia

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Student ID Number	1511419	**Title**	Ms
First Name(s)	Constance		
Surname/Family Name	Mackworth-Young		
Thesis Title	An ethnographic study of the everyday lives of young women living with HIV in Zambia		
Primary Supervisor	Dr Virginia Bond		

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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	This paper draws on data from two studies. The first study was led and designed by VB and AS, with data collection conducted by MC and myself. The second study was led and designed by me, and I conducted data collection. I led on analysis and writing for the paper, including writing the first draft. All authors commented on the paper and gave final approval.

SECTION E

Student Signature	[redacted]
Date	02/12/2019

Supervisor Signature	[redacted]
Date	05/12/2019

Overview

> *Researcher: And did your mother also have HIV?*
> *Sophie: Yes. (pause) And she told me I contracted the virus from her.*
> *Researcher: Ok. And did she have more children after you?*
> *Sophie: Yes, she's got two… Both are girls.*
> *Researcher: Both are girls. And do you know if they have HIV?*
> *Sophie: No, they are not. She was taking medicines when she was pregnant with them. Since I think they now always do that for the women who are HIV positive.*
>
> Sophie, in-depth interview, 2015

Chapter 7 provided insights of the impact of HIV on the everyday experiences of young women, including the everyday negotiation of a stigmatising social environment. In this chapter, I now look beyond the young women's everyday experiences to how their experiences are situated within and determined by socio-historical time. This draws on literature explored in chapter 2 around time, temporalities and the historical context which the young women, who participated in the ethnographic research, grew up in.

This paper draws on both the data generated by the ethnographic PhD study in 2017-2018, as well as data generated in the earlier qualitative study in 2014-2015, with a focus on the seven young women who participated in both studies. Drawing on both these data sources provided longitudinal data on these young women that was important for the temporal analysis conducted in this chapter, over a period when the young women were growing up and going through life transitions. I draw on a temporal framework developed by Bonnington et al. (2017), to analyse the experiences of young women living with HIV across three temporalities: everyday, biographical and epochal time.

In this chapter, I argue for reframing this group of young people living with HIV as a "biogeneration" (Reynolds Whyte, 2014), as their HIV infection, survival and experiences are intimately enmeshed with their biosocial

environment, and are particular to their specific generation. The results in this chapter further emphasise the value of support groups that include processing key biographical moments (such as loss and grief, disclosure of HIV status and future aspirations of having families) as well as everyday challenges of adherence and relationship management.

This paper addresses research objectives 1 and 3:

1. To understand how HIV impacts young women's relationships, and everyday activities
3. To understand how HIV impacts the lives of this particular generation of young women, and how this changed over time

Coming of age with HIV: A temporal understanding of young women's experiences in Zambia

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Abstract

Young perinatally-infected women living with HIV in Zambia grew up alongside antiretroviral therapy (ART) roll-out and expanding prevention programmes. We used Bonnington's temporal framework to understand how HIV impacted the experiences of these women over time. Data were drawn from two sequential studies with a cohort of young women living with HIV: a qualitative study in 2014-16 and an ethnographic study in 2017-18. Data from workshops, in-depth interviews, participant observation and diaries were analysed thematically, guided by three temporalities within the framework: everyday, biographical and epochal time. In everyday time, repetitive daily treatment-taking reminded young women of their HIV status, affecting relationships and leading to secrecy with ART. In biographical time, past events including HIV disclosure, experiences of illness and loss shaped present experiences and future aspirations. Lastly, in epochal time, the women's HIV infection and their survival were intimately interlinked with the history of ART availability. The epochal temporal understanding leads us to use Reynolds Whyte's notion of 'biogeneration' to conceptualise these women, whose experiences of living with HIV are enmeshed with their biosocial environment. Support groups for young women living with HIV should help them to process biographical events, as well as supporting their everyday needs.

Introduction

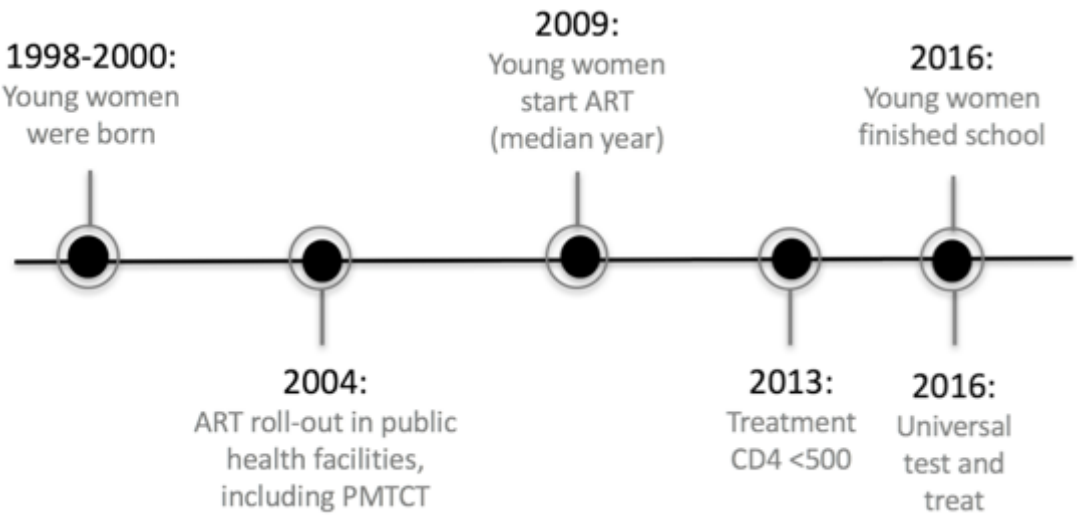
Young people living with HIV are viewed as a focal population in the HIV response (World Health Organization, 2018). However, our understandings of their lives are often drawn from cross-sectional studies or research with limited follow-up periods (Salam, Das, Lassi, & Bhutta, 2016). This is despite adolescence being characterised as a period of ongoing physical, cognitive, emotional, and social changes (Patton et al., 2016). A deeper understanding of their experiences over time as they grow up with HIV is needed to ensure that interventions are well targeted to young people as they develop.

In Zambia, where an estimated 65,000 young people (aged 15-24) are living with HIV (UNICEF, 2019), the epidemic has "touched the lives of all Zambians" (Simpson & Bond, 2014, p. 1067). HIV was first identified in Zambia in the 1980s, and by the 1990s the epidemic had escalated, leaving the country grappling with affected families, HIV care, and education programming in the absence of effective treatment (Simpson & Bond, 2014). In 2004, antiretroviral therapy (ART) became available in public health facilities, enabling transformations for some people living with HIV from ill-health to relative wellness (Simpson & Bond, 2014). Those who were saved by the introduction of ART have been described as constituting a "biogeneration", due to their shared relationship to ART when this biotechnology became widely accessible (Reynolds Whyte, 2014, p. 11).

Young people currently aged 15-24 years were born in the period where HIV had escalated, but before widespread availability of treatment. They grew up through changing HIV policies and treatment availability (Figure 8.1). These include the national policy change to using ART to prevent mother-to-child transmission from 2004 (World Health Organization, 2004), expanding treatment availability to CD4 counts below 500 after WHO recommendations in 2013 (World Health Organization, 2013a), and universal test and treat in 2016 (National HIV/AIDS/STI/TB Council, 2016). Young people's lived

experiences of growing up with HIV are intertwined with this shifting context as it changes over time.

Figure 8.1. Timeline of the developments of the young women in the study, mapped against changes in HIV treatment policy in Zambia



Although time is an "inescapable dimension of all aspects of social experience and practice" (Munn, 1992, p. 93), HIV experiences have often been understood within a singular view of time (e.g. before or after testing, or after an intervention), rather than one where overlapping temporalities affect the contexts and concerns of people living with HIV (Bonnington et al., 2017). Illness can cause a "biographical disruption", radically disrupting one's day-to-day arrangements and understandings of oneself, and one's past, present and future (Bury, 1982). Bonnington's concept of overlapping temporalities – everyday, biographical and epochal time – was used to examine the manifestation of stigma for people living with HIV at stages of the HIV care continuum (Bonnington et al., 2017). Although a growing body of research has looked at the experience of health and disease through a temporal lens (Beynon-Jones, 2017; Golander, 1995; Reddy et al., 2006; Seeley, 2015), few researchers have considered the experiences of young people living with HIV in terms of their past and present lives, in the particular era within which they were born.

In this paper, we use Bonnington's temporal framework to understand the impact of HIV on the experiences of young women living with HIV through three temporalities: everyday, biographical and epochal (2017). In this analysis, everyday time involves the immediacy and repetition of daily experiences of HIV. Biographical time concerns the link between past, present and future events and processes related to HIV. Lastly, epochal time encapsulates the historical shifts, including how global, national and local developments in responses to the HIV epidemic, including treatment availability, influenced the experiences of this generation of young Zambian women living with HIV.

Methods

This analysis draws on two sequential studies: a qualitative study and an ethnographic study, both undertaken with young women living with HIV in Lusaka, Zambia. The qualitative study ran from 2014 to 2015 with 24 young women living with HIV aged 15-18 years, and aimed to understand the challenges they faced and their support needs. Participants were recruited from two health facilities (Table 8.1), and data collection included four participatory workshops and 34 in-depth interviews (IDI). Details of the methods used for this study have been presented elsewhere (Mackworth-Young. et al., 2017). In 2015-16, after the close of the study, support groups were established at each health facility, and were held monthly over a period of a year; in total 20 meetings were held.

In 2017-18, middle-income young women from this qualitative research study were purposefully selected and asked to participate in an ethnographic study. The selection criterion of being middle-income was principally chosen because, although middle-income populations are rapidly growing in Zambia and have a high HIV prevalence in Zambia (Central Statistical Office & Ministry of Health, 2014), they have been under-represented in research (Long & Deane, 2015). Additionally, the middle-income young women spoke

English, which enabled the researcher to conduct the ethnographic study without the need for a translator. The seven young women who consented to participate were then aged 17-19 years (Table 8.1). Data were generated through participant observation over 12 months in participants' homes, workplaces, colleges, recreational spaces, health facilities and churches in dozens of locations across Lusaka. The research began and ended with participatory workshops to gather their experiences collectively and receive their input into the research design and analysis. The introductory workshop included discussions with participants to gather their input into the research design, focus and objectives, and establish how best to present the research to others. Discussions also included participants' views and preferences with regards to different research methods, for instance choice of methods for keeping diaries. The closing workshop included discussing initial results with the participants, and undertaking participatory activities to develop and refine some key findings. Additionally, participants created visual collages to represent themselves, and wrote in diaries about their activities, experiences and feelings. Details of the data collection of the ethnographic study have been presented elsewhere (Mackworth-Young. et al., 2019).

Data from the two studies were analysed together, focusing on the sub-group of young women who participated in the ethnography (the second study). In conducting analysis, attention was paid to the longitudinal nature of the data and changes to participants' lives over the four years during which data were collected. Workshop notes, IDI transcripts, notes from support group meetings, participant observation notes, transcripts of the diaries and the visual collages were manually coded analysed using Bonnington's temporality framework (2017). Sub-themes emerged inductively, and data on each sub-theme were collated and analysed together. For example, under biographical time, the sub-themes included HIV's impact on past, present and future moments: i) HIV disclosure; ii) experiences of illness and loss; and iii) future aspirations.

Ethical clearance was obtained from the University of Zambia Humanities Research Ethics Committee, the London School of Hygiene and Tropical Medicine and the International Centre for Research on Women. Ethical issues that emerged have been discussed separately (Mackworth-Young. et al., 2019).

Table 8.1. Participant characteristics

	Participants in qualitative research 2014-15 (N=24)	**Participants in ethnographic research 2017-18 (N=7)**
Age (years)		
15	9	--
16	5	--
17	5	1
18	5	2
19	--	4
Income-level		
Middle income	10	7
Low income	14	--
Reported mode of HIV transmission		
Perinatally infected	17	6
Sexual abuse	2	1
Not specified	5	--
ART[1] status		
Taking ART	19	7
Not taking ART	1	--
Not specified	4	--
School status		
In school	23	--
Not in school	1	--
Completed school	--	7
In college	--	2

[1]Antiretroviral treatment (ART)

Findings

HIV experiences in everyday time

HIV impacted the young women in everyday time through repetitive daily experiences. The daily act of taking ART was the clearest reminder of HIV in their lives. While the young women were able to follow the daily routine of treatment-taking, it protected their health and largely prevented any bodily signs of HIV. This allowed the young women to "*feel comfortable*", "*look healthy*" (Rhoda, participant observation, 2016) and to enjoy everyday activities with their peers, including going to school and college, shopping, studying, and daily chores. However, it was often an unwelcome reminder of HIV in their lives:

> *I didn't like having to take them every day, every day being reminded that I have this thing.* (Rose, participant observation, 2016).

For several participants, this repetitive everyday act was such a constant reminder of living with HIV that for periods in their lives they "*stopped taking… ARVs"* (Rose, participant observation, 2016). Barriers that prevented the everyday treatment-taking included feeling healthy and not seeing the need for the medicines, difficulties maintaining secrecy in storing and taking ART in non-private spaces (such as boarding colleges or church camps) to avoid undesired disclosure of their HIV status, and frustrations at taking too many medicines.

HIV also impacted the young women's daily experiences through the effect on their friendships and their familial and sexual relationships. For close family and friends who knew their HIV status, this shared knowledge of their HIV status fostered a closeness and support, "*filled with love*" (Natasha, diary, 2018). For some, this closeness was manifested daily through family and friends being protective of the young women. Sometimes this was experienced as over-protective: "*My sister is always worried when I go out"* (Mavis, participant observation, 2017). Knowledge of their HIV status also engendered support, including being reminded to take their medicines by

close family: "*Usually she reminds me: 'have you been taking your medicine'?*" (Rhoda, IDI, 2015).

However, the young women's wider family, friends and sexual partners did not know their HIV status. This led to fears of involuntary disclosure, clouding relationships and making the daily taking of ART a social risk. The young women went to great lengths to hide their ART and the daily pill taking, with some collecting their ARVs before the allocated time and keeping it on their person to avoid anyone noticing them going to the storage place at the same time each day. To maintain relationships with family, friends and partners, the young women had to carefully plan their everyday activities, particularly those related to obtaining and taking their treatment, in order to protect their HIV status. These findings were similar for the young women regardless of mode of HIV infection.

HIV experiences in biographical time

HIV influenced the young women's lives at key moments across their past, present and future aspirations, and in turn the past influenced present and future experiences and aspirations.

The most significant past moment when HIV impacted the young women's lives was when they found out about their HIV status. Those who had been perinatally infected with HIV were mostly unaware of their HIV status during their childhood, and were told that they were living with HIV when they were around 10-14 years old, usually by their parent or guardian, or, for one participant, by a health professional. Many saw this as a pivotal moment that shaped their biography:

> *I'm kind of seeing my life changed, because I don't have the freedom that I used to have before* (Thandi, IDI, 2015).

Some found this moment of disclosure a difficult time: "*I was very scared… thinking it's not worth living life*" (Thandi, IDI, 2015), and several felt anger and blame: "*I was angry with the situation, the whole thing*" (Natasha, 2015).

Despite the initial disclosure being a shock, the young women in this study expressed a gradual acceptance of their HIV status. Over time, the increase in self-confidence was noticeable, and was attributed, in part, to their attendance of support groups:

> *Even if people say things about me, or anyone could discriminate against me, it doesn't matter, because I now have so much confidence in myself* (Sophie, participant observation, 2018).

Some participants who had family members living with HIV recalled periods of illness at various points during their lives. Mary's father and sister had died when she was young, and so, when her mother was ill, she worried about the prospect of being orphaned:

> *To be made an orphan, a double orphan, is really worrying. Who would look after me?* (Mary, participant observation, 2017).

Many of the young women had previously had limited opportunities to talk about impact of loss of close family and friends, due to social silence around death in general, and particularly AIDS-related death, especially around children. Subsequently, many continued to carry a heavy emotional burden.

> *My father died, then my mother two years later. I still remember my mother in hospital. I don't really talk about it. It's so hard, but I will manage. I just have to do the best for my young sisters.* (Sophie, participant observation, 2017)

Despite their often-challenging past experiences, having HIV did not seem to reduce the aspirations of these young women, and perhaps made them more determined. Their aspirations often included the desire to study further and have successful careers:

> *I would want to go to school and study, either Clinical Medicine, Nursing or Midwifery. I pray that I get a scholarship from any sponsoring organisation.* (Rhoda, diary, 2018).

Rhoda did later receive a scholarship to study nursing. The young women also had strong desires to have a family, as depicted in their collages: "*I want to have my own family – with my husband and children"* (Natasha, collage, 2015).

However, these reproductive desires conflicted with narratives the young women received from healthcare workers and sometimes family members, warning against engaging in sexual relationships: "*they say 'we're not even going to talk about sex'"* (Mavis, IDI, 2015). Several of the young women had serious concerns around having children: "*I worry if it's possible to give birth to a negative child*" (Natasha, participatory workshop, 2015).

HIV experiences in epochal time

HIV influenced the young women's experience within the biosocial epoch in which they grew up. All but one of the participants were born with HIV. For those perinatally infected with HIV, both their HIV infection and their survival to adulthood were intimately interlinked with the socio-historical availability of ART. They largely understood that they had been infected in this way because their mothers had not had access to, or had not taken ART, during pregnancy. Most of their mothers would not have known their HIV status at the time, their pregnancies being prior to the introduction of routine antenatal HIV testing.

> *Researcher: And did your mother also have HIV?*
> *Sophie: Yes. (pause) And she told me I contracted the virus from her.*
> *Researcher: Ok. And did she have more children after you?*
> *Sophie: Yes, she's got two… Both are girls.*
> *Researcher: Both are girls. And do you know if they have HIV?*
> *Sophie: No, they are not. She was taking medicines when she was pregnant with them. Since I think they now always do that for the women who are HIV positive.* (Sophie, IDI, 2015)

This recognition that their relationship with HIV was different from their younger siblings, suggests their acknowledgement of the impact of changes in the biosocial context over time on the availability of testing, treatment and prevention technologies and their experiences with HIV. For some, the fact that they had been infected with HIV, but not their siblings, made them feel sad and alone:

> *So how am I supposed to take this if my brother isn't positive and I am?* (Thandi, IDI, 2015).

However, over time, the young women largely grew to accept their HIV status, and the difference from their siblings:

> *But when time goes on you pass by it, you see, it's not like your life will be different (because of your status). It will be just the same.* (Thandi, participant observation, 2018)

All the young women were taking ART at the time of the study, and most had started ART when they were children. Most had experienced periods of severe illness before starting ART, and they recognised that having access to, and taking ART had kept them alive: *"medicine has brought good health, not being sick"* (Card storm activity, workshop, 2015). Although several participants had had periods of non-adherence, they recognised that the availability of ART enabled them, and others living with HIV, to live a healthy life:

> *Most people who are on treatment are successful on treatment, just like those who are healthy* (Thandi, workshop, 2015).

Further, they saw the value of ART for their future: "*ARVs keep you going because you're looking ahead"* (Mary, workshop, 2015).

Interlinking across temporalities

The experiences of the young women were not distinct within each temporality but were enmeshed and overlapping, as exemplified by their experiences around ART (Figure 8.2). The historical availability of ART changed their experience of HIV from one of illness to survival:

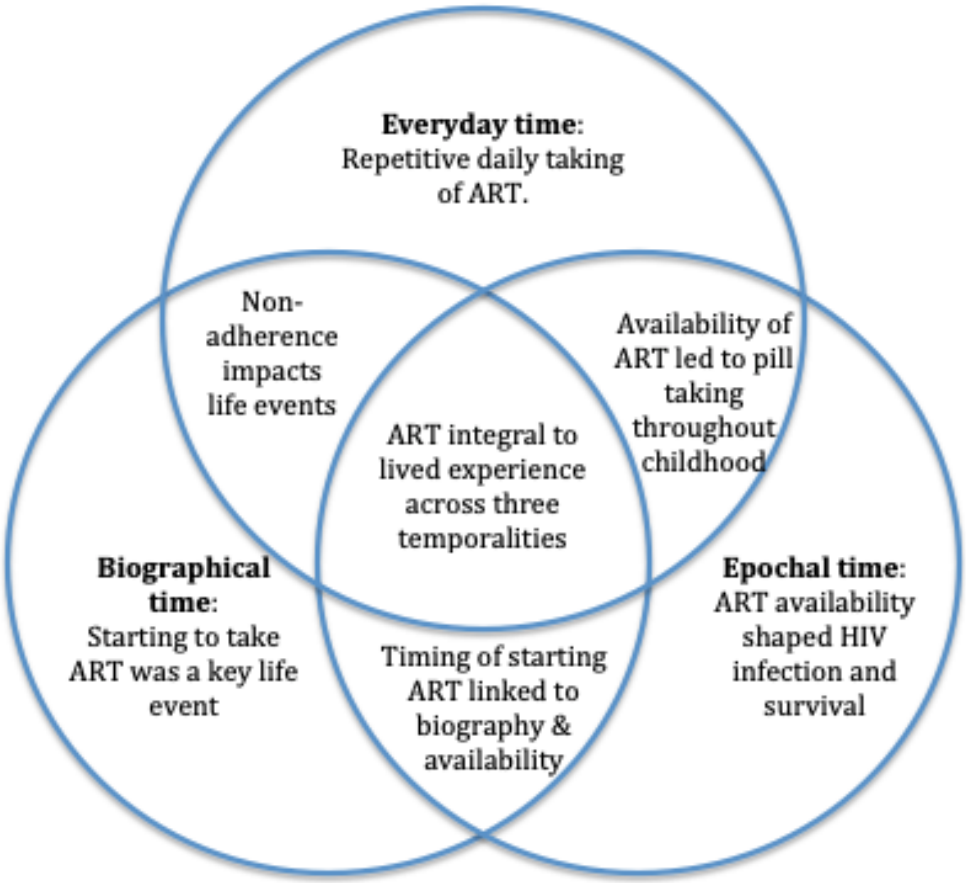
> *I was feeling weak, and I started losing blood, everything was just bad. They took me to hospital... That's when I started taking my medicine... And that changed my life.* (Thandi, IDI, 2015)

The availability for the young women to start treatment during their childhood not only shaped their biography, but also their daily experiences.

Further, the daily pill-taking, when disrupted, could impact major biographical moments and processes, such as their education:

> *My mum always asks 'Are you managing to take them (ARVs) every day?' I always say yes because if I ever say no, mum will stop me from going to college* (Mary, participant observation, 2018).

Figure 8.2. Overlapping temporalities in terms of experiences with ART



Discussion

Through the lens of everyday, biographical and epochal time, we provide an understanding of the impact of HIV on this generation of young women. We provide evidence that their experiences go beyond the social management of day-to-day pill-taking, to the impacts of past disclosure, illness and death on

their current lives and future familial aspirations, bounded by the time in which they were born and now live. As noted by Bonnington (2017), these temporalities interlinked, as the young women's daily experiences influenced experiences in biographical and epochal time. For instance, daily adherence to ART could threaten not only young people's relationships (Bernays et al., 2017), but also valued aspects of their biographical lives, such as college attendance for these middle-income young women. "Disruptive events" (Bury, 1982) such as HIV disclosure impacted the young women's biography, emotionally and socially. The impact changed over time, through increased self-confidence, and even over-confidence for some that they felt they were healthy enough to stop taking their daily ART.

The young women who were perinatally infected with HIV recognised that they were born at a very particular time in history, where ART was not yet widely available to prevent mother-to-child transmission, but was available during their childhood, which enabled them to survive. We build on Reynolds Whyte's term 'biogeneration', which she uses to describe the previous generation of adults who were expected to die from AIDS in the 1990s and survived due to medical intervention in the early 2000s (Reynolds Whyte, 2014). We here expand it to refer to this generation of young people perinatally infected with HIV. For the young women in this study who were perinatally infected, both their HIV infection and their survival are fundamentally interlinked with the historical, social, political and biomedical environment. This links to Foucauldian notions of biopolitics, of how the bodies of young women living with HIV are themselves the site of biomedicine and politics (Foucault, 1997). It further connects to Fassin's exploration of the impact of politics on individual's bodies, deeply situated in the social history of the South African HIV epidemic (Fassin, 2007). This research builds on Fassin's work to demonstrate how the impact of HIV on young women is necessarily placed in the context of local and global politics. Their bodies, their illness and their health are inextricably tied to their close family histories as well as wider bio-medical developments. By viewing young women living with HIV as a particular 'biogeneration', we acknowledge their

lives and HIV infection to be deeply situated in political bio-medical and social history, including ART availability and family history of HIV infection.

As optimum interventions are being developed to support this 'biogeneration' of young people living with HIV (for example, Cluver et al., 2018; Graves et al., 2018; Li et al., 2017; Mavhu et al., 2017), our data aid understanding of their experiences, providing valuable evidence as to how to provide comprehensive support. Increasingly support groups are being set up to support young people living with HIV (Bateganya, Amanyeiwe, Roxo, & Dong, 2015; Cowan et al., 2019; Mavhu et al., 2017). However, some have been critiqued for focusing too heavily on adherence, with little room for discussion about other critical topics including the multitude of challenges they face related to HIV and more broadly, or openness about the practical and emotional challenges and strategies to manage daily adherence (Bernays et al., 2016; Bernays et al., 2017). Our findings suggest that support for young women living with HIV should acknowledge the fundamental biographical moments that have shaped, or will shape, their lives, including illness, death, learning about their HIV status, and decision-making around having children. Including topics such as 'loss and grief' and 'disclosure' in support group curriculums has been shown to be effective at enabling young people living with HIV to process challenging moments in their biography together with others who have had similar experiences (Clay et al., 2018; Stangl et al., 2018). Further, discussing future aspirations that these middle-income young women held, including around education and employment, supports them to consider future opportunities regardless of their HIV status. Providing information on treatment as prevention and PMTCT is key to ameliorate fears about having healthy families in the future, and support aspirations of young women living with HIV to have children (Bernays, Tshuma, et al., 2019; Clay et al., 2018).

Temporal analyses provide a breadth of understanding of young women's experiences of HIV, beyond one snapshot in time. By means of analysis through epochal time, we suggest reframing this cohort as a specific

'biogeneration': a generation whose lives and experience of HIV is intimately interlinked to the history of ART availability in Zambia. We thereby understand some of their experiences as being particular to their generation, and our response to support them should be targeted and adaptive as they grow up with HIV. We recommend support groups with a focus on collectively talking about significant biographical challenges as well as day-to-day issues that young women living with HIV face within this specific epochal time, to provide holistic support for them now and as they grow up with HIV.

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Declaration of interest statement

No conflict of interest.

Chapter 9: Discussion

Within this final chapter, I synthesise the thesis findings, aligning how they contribute to each of my six objectives presented in chapter 1. I then detail the applied, methodological and theoretical recommendations that arise from them. I critically reflect on the strengths and limitations of the study, before stating the ways in which I have disseminated the findings from the research. I end with a conclusion to sum up the thesis.

Synthesis of findings

Objective 1: To understand how HIV impacts young women's relationships and everyday activities

The findings from this thesis highlight the restrictions faced by the young women living with HIV, and detail how they form part of the social environment through which the young women navigated their lives. The findings demonstrate how these restrictions arose from the interplay of their HIV status, their young age, their female gender and the moralising social context. One restriction was the strong encouragement to delay or abstain from sexual relationships. This was in the context of a strong, conservative, Christian background, alongside fears of HIV transmission, which underlaid sexual abstinence messaging. Abstinence messaging has been widespread since the beginning of the HIV epidemic, especially for young people, across many sub-Saharan African countries (Squire, 2013; Winskell, Beres, et al., 2011). The young women were also repeatedly told that they must adhere to their ART, often without discussion of the social context which can prevent or enable adherence, including persistent stigma, fear of unintentional disclosure, and limited private space. Messaging around adherence occurs within the context of a hierarchical healthcare system, where healthcare providers sometimes may suppress discussions of the social and

environmental challenges young people face around adherence, leading to many young people remaining silent around adherence challenges (Bernays et al., 2016; Bernays et al., 2017). In both of these examples, the messaging was inflexible with no room for alternatives or acknowledgement of the young women's broader lives. For example, the messaging rarely acknowledged the importance of intimate relationships to the young women, or the social context necessitating secrecy that could challenge their adherence.

In terms of HIV status disclosure, the young women were presented with varied advice, according to who was giving it. Whereas their parents encouraged them not to disclose their HIV status in order to protect their wider identities, and their parents' own HIV status, health professionals encouraged disclosure, especially to sexual partners, in order to prevent onward transmission of HIV. This disclosure messaging could lead to a tension between the public health and health professional mantra of "always disclose" (particularly to sexual partners), and the fear of disclosure, that might lead to disruptions to their social relationships and identity, and of going against their parents' wishes. This advice about disclosure is given within the context of HIV being situated within family networks (Vale, Hodes, & Cluver, 2017), public health concerns around transmission of HIV (Toska et al., 2015), and persistent stigma accompanied by the threat of a "spoilt" identity (Goffman, 1963). The contradictory messaging around disclosure becomes particularly stark during adolescence. The young women gained increasing autonomy in many areas of their life, but their actions, behaviour and identity were still tied to their parents or guardians' restrictions. For young people who have been perinatally infected by HIV, their HIV status will always be enmeshed with their parent's story and history (Vale et al., 2017). This entangled biography in part leads to the restrictions placed on young people living with HIV, as their HIV-disclosure often leads to the unintentional disclosure of their parents' HIV status. These restrictions in turn impacted the young women's everyday experiences of HIV, constraining where and how they could keep and take their ARVs, and how HIV altered

their relationships. Relationships with family and friends changed in several, sometimes overlapping ways, with some becoming more supportive, others over-protective, and others filled with fear of unintentional disclosure. The findings of this thesis described the sometimes traumatic consequences when some of the young women's friends or boyfriends found out about their HIV status, leading to the end of friendships and relationships, feeling forced to move accommodation in college, and more public knowledge of their HIV status than they wished.

These restrictions are imposed because of the young women's social context, but also because of the particular intersection of their age, gender, income-level and HIV status. The findings showed that being young restricted their options more tightly, as did being female, with the young women saying they felt they faced greater restrictions and social judgements on their choices and activities than their male counterparts. Further, while all young women were restricted in their behaviours and relationships (for example, young women with negative and unknown described keeping secret particular parts of their lives), this was heightened for those living with HIV. However, the financial background of these middle-income young women provided and enabled a supportive. Their access to financial resources enabled access to peer education and support groups, through financial ability to pay for transport costs.

While these restrictions influenced the everyday lives of the study participants, the findings also emphasised that HIV was only one aspect of these young women's lives, even if it was one that permeated their experiences. This supports work by Smith and colleagues that shows that while HIV pervaded throughout the lives of young people living with HIV in the US, they wanted to engage in school, church, work and social life alongside their peers (2016). They were able to "claim normalcy" in this way as the "scars of HIV" (for example poor self-esteem, fear of rejection or worries about daily treatment-taking) were kept invisible (Smith et al., 2016, p. 845). The young women in this thesis had identities as girlfriends, students,

Christians, friends, and family members; they got excited about getting good grades, singing at church and having fun with friends; and they worried about college fees, and their relationships with their boyfriends. HIV was one part of their identity, but one that infused through their other identities, enmeshed with their hopes and fears. Their identities as students were interwoven with challenges of missing classes to attend clinic appointments; their identities as Christians was intermingled with worries about how to take their medicines while on church camps; and their relationships with boyfriends were tinged with concerns about disclosure and their future aspirations and fears of having HIV-negative children. These findings add weight to Smith and colleague's conclusion that everyday activities may be outwardly "normal", but inwardly tainted by HIV (2016). HIV was an ever-present framing of their lives, interlinked with their activities and emotions, but simultaneously was not the only lens through which their lives were seen and experienced. The findings here emphasise that the impact of HIV can only be understood within the context of young women's daily relationships and lives.

Objective 2: To understand the strategies that young women practice to cope with HIV

In this thesis, I explored how the young women navigated the behavioural restrictions detailed above, and their restrictive social environment through practicing "bounded agency" (Evans, 2007). The young women developed coping strategies to navigate the persistent stigma that they faced and feared, and in order to maintain identities separate from HIV. Through strategies of keeping secrets and maintaining silence, the young women were largely able to retain choice over how, where, to whom, and when to disclose their HIV status. This builds on Hardon and Posel's questioning of secrecy as a pejorative notion, suggesting that secrecy can rather be used as an everyday social practice to control what we reveal and what we withhold to those around us (2012). Ways of knowing and telling are nuanced, with varying degrees of openness and concealment, and with acts of concealment being

inherently relational (Hardon & Posel, 2012). In this thesis, I develop this argument to demonstrate how non-disclosure through secrecy and silence was a mechanism through which the young women could control their stories, and control the social risks not only to their own lives, but also to those of their parents, whose own stories were enmeshed with their own through their shared HIV status. This builds on and contributes to the literature around resilience of young people and people affected by HIV. In particular, my findings counter the dominant narrative that emphasises the challenges faced by young people affected by HIV. Instead the findings support previous work that emphasise and encourage a focus on young people's resilience in navigating HIV-related challenges (Adegoke & Steyn, 2018; Skovdal & Daniel, 2012).

The young women in this study demonstrated both forms of resilience described by Wieger (2008): firstly seeing beyond their HIV status, and secondly managing the illness through identifying and practicing support and strategies. The young women presented optimistic and resilient aspects of their identity, beyond their sero-status, in the visual collages that they created (Chapter 4). Bond previously highlighted the importance for many people living with HIV to retain a wider identity beyond their HIV status (Bond, 2010). She detail how non-disclosure can help to maintain public/ private boundaries, while disclosure "can fix identity", as once an individual has disclosed their HIV status, it is not possible to retract this information, or reverse the subsequent identity change (Bond, 2010, p. 6). For the young women in this study who had grown up with HIV, the identities that they held most dear were outside of their HIV status (for example, as girlfriends, friends, students, or Christians), even if their HIV status was intimately interlinked to many aspects of their lives. Where they were able to practice the coping strategies of secrecy and silence around their HIV status, they had the agency to shape and define what being HIV positive meant to them.

However, the findings from this thesis suggest that there is a balance to be drawn between emphasising young people's agency to practice strategies

that enable them to navigate their HIV status, and understanding the constraints to this that were imposed through the social context. I build on Evan's concept of "bounded agency" (2007) to show that the young women's space for choice occurs within the constraints of the social context of persistent stigma, and potentially distressing consequences when friends, boyfriends and family did discover their HIV status unintentionally. The young women's agency was therefore tied to social structures that were contextually and temporally specific, as well as tied to the agency of those with whom they have relationships. What HIV came to mean to the young women is relationally framed, changing in part due to the dynamic reactions of the significant people in their lives (for example, their parents or boyfriends) and bound in a particular moment in time. These findings draw on Goffman's work on stigma (1963), but extend his focus on how the social order is maintained, to demonstrate how young women navigated stigmatising social environments, and found ways to resist HIV-related stigma. However, while these young women could alter and amend the prevailing definitions of HIV, they are not totally unshackled from the predominant social norms that bound how HIV is perceived and their agency to navigate within this. I conclude that these strategies are vital to enable the young women to maintain an identity beyond HIV, to preserve relationships with family, friends and boyfriends, as well as to navigate their lives in college, home or at work, within the current social context in Lusaka. However, their agency to practice these strategies is structurally, socially, relationally and temporally bounded.

The repercussions of these strategies meant that the young women sometimes felt guilty about keeping part of their identity a secret, anxious that their secret might be discovered, and regretful that they were not able to disclose to some close friends, family and boyfriends. More stigma reduction efforts could alter the social environment within which these young women lived and through which they had to navigate. For example, family-based interventions can reduce stigma and improve support options for young people living with HIV (e.g. Denison et al., 2015). This thesis contributes

nuance to the debate around agency of young people, discussed in chapter 2, and aligns with Evan's concept of "bounded agency" (2007) to recognise the choices the young women make as displays of resilience within a tightly constrained social context.

Objective 3: To understand how HIV impacted the lives of this particular generation of young women and how this changed over time

The temporal analysis, conducted in this thesis highlighted how intimately interlinked the young women's lives were with the history of ART availability in the Zambian socio-historical context. The young women in this study, and others of their generation, were born at a very particular time in history, where ART was not yet widely available to prevent mother-to-child transmission, yet was available early enough during their childhood to enable them to survive. Reynolds Whyte introduced the term "biogeneration" to refer to a generation living with HIV who thought they were going to die, but who were saved through the introduction of ART, due to their shared relationship to ART when this biotechnology became widely accessible (2014). Based on the findings of this thesis, I propose applying this term, "biogeneration", to this generation of young people living with HIV.

Applying the term "biogeneration" to these young people living with HIV emphasises how intimately interlinked their bodies, lives and experiences are with the social, political, historical and biomedical context. This builds on Fassin's work around the bodily experience of politics, history and biomedicine in the context of the politically charged pre-ART AIDS epidemic in South Africa (2007). In this thesis, we see that the young women's bodies themselves were the sites of politics and biomedicine, and this impacted their lived experiences across their biography and on an everyday basis. Their bodily experience of HIV infection, and their survival with HIV are interlinked with the political and biomedical timing of policies relating to availability of

ART, specifically policies of prevention of mother-to-child-transmission (after they were born), and policies determining ART becoming publicly available (during their childhood). The participants of this study, as members of this particular "biogeneration", were focused on trying to thrive, rather than trying to survive, distinguishing them from the generations that had gone before them.

Further, this generation of young people living with HIV who were born during the late 1990s is almost a closed cohort. There were markedly fewer HIV infections at birth by 2018, due to the impressive success of mother-to-child prevention programs (e.g. Fasakin et al., 2018). Globally, the number of children newly infected with HIV has halved, from 240,000 in 2010 to 130,000 in 2018, which has been achieved through the increase in the proportion of mothers receiving ART globally from 43% in 2010 to 85% in 2018 (UNAIDS, 2019a). This leads to far fewer children growing up with HIV. Global targets have ambitious aims to reduce mother-to-child transmission even further to 20,000 children newly infected with HIV by 2020 (UNAIDS, 2019a). The generation of young people living with HIV to which the participants of this study belong are exceptional by being the singular substantive generation of young people to have been born with HIV. Theorising this generation of young people living with HIV as a "biogeneration" is a novel theoretical contribution that solidifies our conception of this generation as unique, and emphasises how the biosocial and historical context impacts their lived experiences.

Objective 4: To explore and critique participatory methods with young women living with HIV

In chapter 2, I critiqued the literature that has promoted the practice and development of participatory methods with young people, and emphasised the importance of including young people as active participants in research. This thesis involved applying and critiquing a range of participatory methods,

including collage making, diary writing and participant observation. In this thesis I conducted a deep-dive critique of the collage method (chapter 4). There was a lack of existing literature that detailed the feasibility of using collages for research purposes as well as considering the value of the data for understanding participants' lives, and the challenges and limitations of this approach in comparison to other methods. This chapter concludes that the collage method proved to be feasible, enjoyable for participants, and was a form of self-representation that elicited valuable data, providing a methodological contribution to the field of arts-based research, and participatory methods with young people. It builds on a body of literature that promotes arts-based research (Campbell et al., 2015; Khanare & De Lange, 2017; Mayaba & Wood, 2015; Rodriguez Vega, 2018; Tay-Lim & Lim, 2013; Theron et al., 2011; Thomson, 2008). While collage methods have been used elsewhere (Khanare & De Lange, 2017; Mayaba & Wood, 2015), Chapter 4 in this thesis provides a description and critique of the method to push forward its development and use in research and programs, especially for young people. In particular, the findings from this thesis show that collage methods can provide a space for young people to be authors of their own stories, and through this, it provides some therapeutic value for participants, as well as generating informative data. In enabling more freedom of expression, the collage method opened up space for the young women in this study to discuss aspects of their lives beyond HIV as well as parts that were optimistic and forward-looking. This contrasted with the data generated through IDIs in the earlier qualitative study in 2014-2015, in which the interview environment and pre-written topic guide constrained discussions to focus more on challenges related to HIV.

The diaries that were given to the young women had less success as a method of data generation. All the participants were very enthusiastic to receive the diaries, and they were kept as coveted possessions. Some of the participants wrote detailed descriptions in their diaries about a range of aspects of their lives, although mostly focusing on issues with their boyfriends. However, others wrote very brief entries, including notes from church or about routine

and fairly mundane aspects of their everyday lives. The diaries provided limited additional insight into the young women's lives to those already gathered through other methods in the study. Only once was HIV mentioned in any of the diaries. This was by Natasha, referring to how a potential boyfriend knows about her HIV status; she wrote: "*He is so close to me, he knows about me being HIV positive*." One interpretation of this minimal mention of HIV is that other parts of the young women's lives were more prominently important to them, and when given open instructions in writing the diaries, other aspects of their lives were felt to be more notable to write about. Another interpretation is that the process of writing down their experiences of HIV shifted their conversations with me, as the researcher, into a different realm, in which the security of confidentiality and discretion was looser. No longer were they talking directly to me, free of any physical record, they were writing something for me that could be found by someone else. The diaries therefore carried a higher risk of potential exposure then the young women's conversations with me, as what was written would become permanent and undeniable. In this study, I consider both these interpretations to be relevant.

Bernays et al. have critiqued diary methods with young people living with HIV in Uganda, specifically the use of audio diaries (2019). They detailed challenges in the use of audio diaries, including participants not using them for their intended use, their gathering of limited data relevant to the study aims, large variation in their use between participants, and no participants choosing to use the method again when offered, leading to conclusions that methods need to be selected with consciousness to the local context (Bernays, Paparini, et al., 2019). There was more success in using audio diaries with young people living with HIV in another setting, namely Zimbabwe (Mupambireyi & Bernays, 2019). In this setting, smartphones were more plentiful, and so the audio diaries attracted less attention; additionally participants had more private space to use the audio diary (Bernays, Paparini, et al., 2019). The findings from this thesis concur with the observations made by Bernays et al. (2019), in that while some participants chose to share details

of their lives in their diaries, including around less openly discussed aspects of their lives such as sexual relationships, others shared limited information of their lives beyond what was gathered through other data collection methods. The participant observation methods already gathered in-depth data on everyday activities, and the diaries did not contribute many additional insights. While the participants in this thesis said they enjoyed using the diaries, they had limited effectiveness as a data generation tool to contribute to the aim of understanding experiences with HIV, in the context of a range of participatory methods.

The main body of data was generated through participant observation. The choice of method was based on trying to gain close access to the young women's everyday experiences, and develop close relationships with them to enable sharing more intimate and hidden aspects of their lives, which may not have been revealed using other methods. DeWalt and DeWalt describe participant observation as being characterised by having an open non-judgemental attitude, being interested in learning about others, being a careful observer and a good listener (1998). The section from my participant observation notes with Mavis demonstrates that this was effective at enabling and facilitating the young women to share intimate, personal and often secret aspects of their lives:

> "*It was such a nice scene: we were very relaxed, intimate and chatting away. Mavis was extremely open with me as we spoke. She kept on saying: "can I tell you a secret?" And then she would say: "I don't know why I tell you all these secrets, but I just do. I think it's because I see you as my friend, and I know that you will never tell anyone else. With other people I always worry that they will tell, or at least judge me. Somehow, I just feel very open with you, and able to share everything."* (participant observation notes with Mavis, 2018)

With the understanding that young people practice a "truth economy" (Bernays et al., 2017) in choosing what to tell to whom, and whilst acknowledging that I only saw the parts of their lives that the young women chose to show or tell me, I felt this method involving longitudinal relationship

development was effective at enabling the participants to share more intimate aspects of their lives.

My relationship with the participants and their families was integral to the methods of the ethnographic study, both in terms of its feasibility, as well the data that were generated and the analysis that was conducted. This relationship was multidimensional in several ways, four of which I explore here. Firstly, the relationship was both the means and the site of data generation. The close relationship that I had with the young women meant that they shared details about their lives, and these stories became the data of the study. Knowing that I had promised them discretion and was obliged to maintain this, helped them open up about aspects of their lives that they said that they kept closed to others. This, in part, led to the focus in this thesis on exploring issues pertaining to secrecy, as well as the ethical issues around confidentiality and telling 'white lies' to protect participants.

Secondly, the participants gradually perceived the relationship as the primary benefit of the research. For example, Thandi said: "*It was so nice for me to have someone I could feel I could tell everything too*" (Thandi, participant observation, 2018). Telling adults certain things sometimes led to immediate consequences, including restrictions being imposed on their actions and activities (as described in chapter 6). Telling friends or boyfriends certain things, such as their HIV status, held risks with fragile friendships and relationships (as seen in chapter 7). However, my role may have been perceived to have been somewhere between that of a peer and of and an adult, although with the added dimension of being a foreigner, an outsider to their community, and a researcher, with the promise of confidentiality. This unusual identity, perhaps led to participants confiding in me around particular parts of their lives that they didn't share with some others:

> "*I told you everything that was going on my life, even things that I didn't tell my mum. Of course, I tell my mum lots of things, but there are just some things that I can't tell her, and that I needed to talk to someone else*

about, and you were always there to listen." (Thandi, participant observation, 2018).

This is, in a way, ironic as their means of securing confidentiality with me was through engagement in research, where they understood that their stories and their words would be made public, albeit anonymously.

Thirdly, my relationship with participants was a negotiated space where participants attempted to push the boundaries by asking me to intervene in their lives. For example, Natasha called me one time to ask if I could tell her Aunt that she would be with me one day, as an excuse to enable her to go to a friend's barbeque. I refused since it would be a breach of trust between her Aunt and myself, but it was interesting to reflect on how the young women saw the relationship with me as the researcher as an advantage of their participation in the research.

Finally, the relationship developed into a two-way exchange about life experiences. The study was based on my understanding of the young women's everyday lives, but the young women and their families were quickly curious about me and asked about aspects of my life, my family and friends, and requested to see photos on my phone. I shared stories and photos about my family and friends; the young women were particularly interested to talk about how I was expecting a baby, with several suggesting that I should name the baby after them. Some requests to see aspects of my life I declined, for example when participants asked to visit my home, in order to ensure some boundaries over respective roles of researcher and participant remained. However, the traditional boundaries between the 'researcher' and the 'researched' became blurred. This negotiation of the relationship, and the ethical issues that emerged from this were often dominant in my thoughts during fieldwork. The multidimensional aspect of the relationship was often at the forefront of my mind and conversations with others before, during and after fieldwork. This led to the specific focus in this thesis of investigating the ethics-in-practice of the research and the researcher-participant relationship.

Objective 5: To reflexively review ethical issues involved in conducting ethnographic research with young people living with HIV

This thesis provides a critical exploration of the ethical issues that arose during this ethnographic study, contributing to the global health literature on research ethics. Chapter 5 of this thesis was conceived and written in response to on-going reflexivity, questioning and conversations around the ethical issues encountered while conducting the research, which went beyond the 'procedural ethics' of approval of the protocol by the appropriate research ethics boards. Previous researchers have offered reflexivity on the 'ethics in practice' of conducting research (Jarvis, 2016; Kingori, 2013; Madiega et al., 2013). In this thesis, I add to this literature by providing a case study of ethical reflexivity at the intersection of the particular population (young women), a stigmatised disease (HIV), a fluid method of study (ethnography) and a lower middle-income country (Zambia). Through this, I provide a demonstration of the ethical issues that emerged 'in practice' and how these were navigated, offering guidance and suggestions for other researchers in similar fields. Such ethical critique highlights that reflexivity is important and necessary to continually improve the ways in which we conduct research with young people living with HIV.

As the researcher, my background and identity were inevitably intimately interlinked to data collection, analysis and interpretation (Pool & Geissler, 2005). This is understood and acknowledged to be a central aspect of the anthropological method (Iphofen, 2015; Kawulich, 2005). As Kawulich notes, "participant observation is conducted by a biased human who serves as the instrument for data collection", and one must therefore be cognisant of how the researcher's identity may affect observation, analysis and interpretation (2005, p. 5). The fact that I had lived in Lusaka since 2014, and had known all the participants since 2015, meant that I had some understanding of the setting and their lives from the beginning of the ethnographic study, but this

understanding was through the lens of being as an outsider to the setting and their lives. My identity as a young white British woman led in part to me being viewed as a trusted person by participants and their families, but also a clearly visible outsider. This was evident, for example, when I went to church with Natasha and her family. The priest pointed me out as the only white person at church and spoke about how he thought it was good I was "*getting involved*" (participant observation with Natasha, 2017). It was also evident when I met with Mavis at a shopping mall, and two strange men at different times came up to talk to us, intrigued by me as a white person, and it took a bit of time to persuade them to leave us so we could speak alone. Mavis afterwards said how she knew how frustrating it was when, because of your race, *"random people feel it's ok to butt into your conversation*" (Mavis, participant observation, 2017). Her boyfriend was mixed race and she said that he experienced similar things with strangers.

Differences in age, power, wealth and knowledge about research between the participants and me as the researcher led to inevitable power and relational dynamics. Marshall and Batten have explored issues of ethics and power in research, and describe the inevitability of power dynamics in cross-cultural research relationships, where "researchers have traditionally held power in forms of money, knowledge and 'expertise' over their human subjects" (2004, p. 5). These power dynamics were continuously in play during the research for this thesis. For example, when I met with participants in cafes, I would always buy the participant and myself a drink and sometimes some food. However, some participants would always insist that they would get me the next one when we met next time, alluding to some semblance of reciprocity in the relationship. I always did pay, as I wanted to ensure that participation in the research didn't bring a financial cost to the young women, and I also believed that their offering to pay to be more of a gesture than a genuine desire. This nod to reciprocity was seen in other aspects of my relationships with participants: when Mary and I went shopping together, we each tried on clothes, told each other what we thought of them, and we each bought some clothes for ourselves. When I went to visit Natasha's house, I would bring eggs

from my chickens at home, and Natasha and her family would give me avocados from their tree when I left. While I usually brought a drink and some food for participants and myself when we met in public settings, when I visited participants' houses, in this private setting I was almost always offered some food prepared in the household. The power dynamics inevitable in research were arguably lessened compared to other studies because all the participants and their families were middle-income. Although there were certainly significant power dynamics present, there were some aspects of our relationships that involved elements of reciprocity.

In the protocol for the ethnographic study, I had written that I planned to spend the night with some of the participants towards the end of the data collection period in order to gain as much in-depth knowledge of the young women's everyday lives as possible. I had thought that spending time with the young women during the greatest range of activities throughout the day and night would provide the most in-depth understanding of their lives, their relationships, and the impact of HIV on their everyday activities. When I presented my proposal at Zambart prior to data collection, my Zambian colleagues honed in on this part of my proposed methods, and questioned whether this would be feasible. They predicted that things in the house would be changed around in order to enable me to stay and that everyone would be on their 'best behaviour' if a white person was spending the night. We discussed how this could be problematic for two main reasons: firstly, it would put an unnecessary burden on the household, and secondly, since behaviours, activities and interactions might change due to my presence, I wouldn't gain the insights that I would have been looking for.

As a result of this, I decided to assess the situation when I started fieldwork, and to only ask participants with whom I felt staying the night would be the most appropriate. When I started spending time in the young women's homes, I saw more clearly how space was limited, with several people often sharing a room and sometimes a bed. I realised that spending the night with most participants would be practically unfeasible and would indeed place too

much burden on the families, which would raise ethical issues. Indeed, I felt it would have been quite a major imposition on the participants and their families, whom I expected would move family members to different bedrooms in order to provide a bed for me, in part because of my ethnicity and status as an outsider. I also wondered whether the additional insights that I could gather from spending the night in their homes would justify the effort and the imposition. This was especially because, as my colleagues at Zambart suggested, the behaviour and activities of the young women and their family would likely be significantly altered if I were to spend the night, rendering the data that I could gather less insightful. I did suggest the idea to two participants, whose living arrangements were the most conducive to me spending the night with them: I knew both of their families well, had been to their houses several times, and had seen that there was adequate space for sleeping in their houses. However, their reactions confirmed that it would not be feasible or ethically appropriate, as seen from my participant observation notes:

> *"I was quite tentative mentioning the idea of me staying the night, partly as I was nervous bringing it up, and partly because I wanted to make it easy for Natasha to say that it wouldn't work if she wanted to. She said that she'd think about it, but I really got the impression that it wouldn't be easy. Having now seen the living space, and their bedrooms, I realise that so many of them sleep in the same room, and that if I stayed, they would really have to shift things around and almost definitely move people out of their beds. It made me really question whether the upheaval and effort participants and their families would have to go to is really worth the extra data that I would gather from staying the night."* (participant observation with Natasha, 2018)

I initially felt disappointed at the decision to not spend the night with participants, thinking that I may have missed a deeper understanding of their everyday lives, including insights into evening, morning and night-time routines and activities. In an attempt to gain some of this understanding, within the limitations of not spending the night with participants, I made an

effort to ensure I saw them at different times of the day and different days of the week, to try to gather as comprehensive a picture of their lives and interactions as possible, given the constraints. In the end, I felt relieved that I did not impose on participants in this way, and was confident that I was still able to understand their everyday lives as a whole. I concluded that because of my ethnicity and outsider status, there were certain boundaries with the young women that were hard to transcend.

During the data collection period, I spent much time considering, discussing with my supervisors and colleagues at Zambart, and deciding how best to navigate various ethical issues that I encountered, largely related to the relationship with the study participants. My primary supervisor was based at Zambart. I was also based at Zambart during the design and development of the ethnographic study, during fieldwork, as well as before embarking on my PhD. This enabled me to have regular discussions with colleagues on emerging challenges, including navigating the researcher-participant relationship as well as ethical issues. In particular, discussions with colleagues within the Zambart social science team, provided me with significant support. I quickly learnt of the importance of local supervision and support during my fieldwork, in terms of being able to ask questions related to the local context and how to navigate any problems that emerged. Examples of the importance of this local support included telling me what was appropriate to wear when going to church with a participant and her family; suggesting cafes to meet up in when a participant asked to meet in an area of Lusaka that I did not know very well; and discussing how best to navigate the situation when one participant asked me to intervene in her difficult relationship with her sister.

Recommendations

The sixth objective of this thesis was to generate policy, practice and research recommendations to improve support for, and research with, young women living with HIV.

1: The value of support groups for young people living with HIV

The findings of this PhD demonstrate that the limited disclosure that young women living with HIV practiced, while essential in managing their identity, left many feeling anxious and isolated. Findings showed that the young women really valued opportunities where they could be open and free to speak about their lived experiences. Support groups with other young people living with HIV can provide that opportunity. They provide a safe space where young people living with HIV can be open about their HIV status, where they don't have to keep secrets or stay silent, and where they can share experiences and advice with others who are like them.

There is some emerging evidence to show that support groups are effective in improving medical and psychosocial outcomes. Recent results from the Zandiri trial demonstrated that a support group intervention had measurable impact on young people's viral load (Cowan et al., 2019). The efficacy of this support group intervention is arguably due to the support groups' provision of psychosocial support by engaging with the dynamic social and structural challenges that young people living with HIV face, beyond the biomedical (Bernays, Tshuma, et al., 2019). These include financial and emotional security of their familial relationships, high youth unemployment, engagement in the education system, persistent stigma around HIV, and a stretched healthcare system with weak mental health provision (Bernays, Tshuma, et al., 2019).

The findings from this thesis support and build on this evidence around the value of support groups in engaging beyond biomedical adherence and recognising the social and structural context that can enable or constrain young people's ability to adhere to ART and live full lives. HIV impacts young people living not only through everyday influence on their activities, relationships and emotions, but also through longer-term biographical impact. These findings suggested that support groups that cover topics such as grief and loss, future aspirations, and reproductive hopes and fears, could be particularly valuable in enabling young people living with HIV to process challenging moments in their biography together with others who have had similar experiences. They can support young people in their process of overcoming and refashioning their past, present and future alongside current understandings of HIV.

Following on from the qualitative study that we conducted in 2014-15, Zambart, the International Centre for Research on Women, and 3Cs Regional Consultants designed, implemented, and conducted an evaluation of a support group intervention for young women living with HIV, as a pilot (Stangl et al., 2018). This demonstrated the feasibility of a support group curriculum that included topics of healthy relationships, loss and grief and planning for the future, as well as topics more directly about their experiences living with HIV, such as ART and disclosure (Clay et al., 2018). Including such discussions around future aspirations, such as education, employment and having a family, supports young people to consider future opportunities with their HIV status. The findings from this thesis around young women's concerns about having healthy families, support the importance of providing information on treatment as prevention and PMTCT to ameliorate these fears, and support their familial aspirations. This is particularly important, in the current context of Undetectable=Untransmittable (U=U) (The Lancet HIV, 2017), and can provide a grounded and relevant incentive for adherence to ART to young women living with HIV. In summary, I recommend support groups for young women living with HIV to provide a very necessary safe space where they can be open, not have to keep secrets, and be able to discuss

aspects of their past biography, present experiences and future aspirations with HIV.

2: Counselling to support disclosure choices

The findings from this thesis demonstrate the real challenges that young people living with HIV face in disclosing their HIV status, and the sometimes traumatic and damaging impact on their identity when unintentional disclosure of their HIV status occurred. The findings showed that messaging around disclosure was often contradictory during adolescence, with young women's families usually strongly telling them not to disclose to protect their and their family's identity, but health professionals starting to strongly encouraging them to disclose, especially to sexual partners, to attempt to prevent transmission of HIV. The young women became increasingly autonomous as they developed, including becoming increasingly separate from their parents and guardians. However, their HIV status remained, and will always remain enmeshed with their parent's story and history too. Being in control of whether, when, to whom and how to disclose their HIV status provided the young women with a degree of agency, albeit bounded by social and structural factors, to manage their identity. Where the young women were able to maintain this agency, the outcome of intentional disclosure of their HIV status was usually, although not always, constructive, with those who they told often becoming more supportive and understanding.

These findings suggest that the messaging that the young women received from healthcare professionals to always disclose to sexual partners to prevent transmission of HIV may be misplaced. For the young women in this research, intentional or unintentional disclosure to boyfriends had potential damaging impact on their identity. Evidence from South Africa demonstrates that young people living with HIV disclosing their HIV status to sexual partners does not lead to safer sex (Toska et al., 2015). Further, this is in the context of U=U (The Lancet HIV, 2017), where there is now strong evidence

demonstrating that an undetectable viral load prevents HIV transmission in condom less sex (Rodger et al., 2019). This must also be understood within this group of middle-income young women, who have access to high standards of care, access to ART and routine viral load testing, all of which are important to enable U=U (Bereczky, 2019). Giving young people control over disclosure may therefore be justified through the control that they are able to exert through optimal adhering. Given this context, I support others that suggest that the public health, legal and healthcare professional's mantra of disclosure as essential to all sexual partners may be out-dated and misplaced (Galano et al., 2017; Hurley, 2018; The Lancet HIV, 2018).

Bernays et al. have shown that young people manage a "truth economy" in choosing what information to share with healthcare providers (2017). Building on this, the results from this thesis suggest that singularly encouraging disclosure without open conversations about the possible harms and benefits, has the potential of damaging the wider supportive relationship healthcare providers might have with young people. The findings from this thesis support others that suggest that there is a delicate path between concealing and disclosing one's HIV status, and that there are risks as well as advantages of both, which individuals weigh up and consider when making choices (Stutterheim et al., 2017). Whilst counselling young women living with HIV, a sensitive balance between disclosure and silence should be discussed, with an acknowledgement that different situations may require different approaches and that there will be cases where it may not be appropriate or beneficial to disclose, including to sexual partners. International guidance on HIV disclosure, as well as practice by healthcare professionals, should take a nuanced approach that supports young people's informed choices, without singularly encouraging disclosure to all sexual partners.

3: Development and reflexivity on specific methodological and ethical practices for young people

The findings show that research with young people is more effective when the methodologies that are used to generate data include them as active contributors through participatory approaches. They lead to recommendations to use participatory methodologies in research and programming that meaningfully involve participants in co-creating the representations of their stories. Using such methods is particularly important for groups, such as young people, including those living with HIV, who can be marginalised by more traditional research methods (Leavy, 2015). Certain populations, such as young women living with HIV, can be intimidated by the power dynamics inherent in interview settings or group workshops (Leavy, 2015). I recommend continued practice and development of participatory arts-based methods with young people, as well as on-going critique of these methods. This is important to improve the ways in which research is undertaken, and to ensure that the methods used are as inclusive and participatory as possible and contribute to an understanding of the lives of participants and their identities as full and complex individuals.

Research with young people requires not only development and reflexivity around methods, but also with the practice of ethics. Through critical analysis and reflection on ethics-in-practice, I recommend that researchers should be reflexive around ethical issues they may face in research practice and in their thinking of potential ways to navigate them. Research is necessarily fluid and dynamic, and unplanned ethical issues may arise during the study, including during data collection, requiring reactive response. In ethnography, the lead researcher is often in close contact with these ethical issues, and with thinking how to navigate them, compared to other research methods, where the principle investigators and lead researchers may be more distant to such issues. However, I argue that such reflexivity during the course of all research studies is critical in a range of disciplines and research methods. I highlight the value of local support systems for fieldworkers to openly discuss, and

receive support on challenging ethical issues. I also suggest there is value in sharing this reflection with other global health researchers and ethicists in order to share potential unforeseen ethical issues, and possible ways of navigating these, and to develop more appropriate ethical guidelines and research practice in global health.

4: Conceptualisation of young people living with HIV as a "biogeneration"

As discussed above, I recommend that the generation of young people perinatally infected with HIV should be conceptualised using Reynolds Whyte's term, "biogeneration" (2014). Based on this, I recommend that researchers, policy-makers and programmers use this term to refer to this particular generation to highlight their specific relationship to, and experience of, HIV.

With the important focus on prevention of new HIV infection amongst adolescents and young people (e.g. PEPFAR et al., 2015), and the celebration of the success of reducing mother-to-child transmission (Fasakin et al., 2018; UNAIDS, 2019a), we risk eclipsing the generation who were born with HIV and who are surviving to adulthood. However, this generation of young people who were perinatally infected with HIV are a substantial population, and one, as evidenced throughout this thesis, that has particular experiences related to HIV that have changed over the course of their lives. This "biogeneration" will continue growing up, and their specific issues and needs will grow and develop with them. For example, we are already seeing some young people of this "biogeneration" navigating how to develop intimate relationships (Greenhalgh, Evangeli, Frize, Foster, & Fidler, 2016) and become parents themselves (Evangeli, Greenhalgh, Frize, Foster, & Fidler, 2014).

Applying the term "biogeneration" to these young people who were perinatally infected with HIV, encourages us to view this cohort as a generation who are intimately interlinked with their biosocial history, and who, as such, experience HIV in particular ways. It encourages us to follow this "biogeneration" as a cohort over time, as those perinatally infected with HIV grow from children, to adolescents, to young people and then adults. This can provide a more comprehensive understanding of their experiences and support needs than researching particular age brackets (for example 15-19-year olds), which individuals pass through as they grow. Further, applying the term "biogeneration" to young people perinatally infected with HIV reinforces the need for specific and tailored interventions to this particular population. Their particular experiences (for example, orphanhood) lead to particular needs (for example, support around processing grief and loss), which will develop and evolve as this "biogeneration" grows. I therefore recommend the application of Reynold Whyte's term, "biogeneration" (2014) to young people perinatally infected with HIV to acknowledge their particular experiences, to encourage continued focus on this cohort as it ages, and to continue to develop appropriate support interventions to care for their evolving needs.

Strengths and limitations

There are several strengths and limitations relating to the methods that were used for this research which are discussed in the section below.

Methodological strengths

One key strength was the "slow research" approach (Adams et al., 2014). Having been involved in the data collection in the qualitative research study in 2014-15, and choosing to re-recruit some of the young women who participated in that for the ethnographic study for this thesis, meant that I developed a long-term relationship with the young women and their families.

I followed their lives over four years, over a period when they underwent significant life transitions, including finishing school, starting new sexual relationships, going to college, and moving homes. This provided a level of insight into their lives that is unusual in research, which is normally less intensive or shorter-term (Adams et al., 2014). The "slow research" movement in global health emphasises the value of deliberately taking time for research and of pausing to produce deeper understanding, contrasting to the new normal of demands for speed and efficiency in research studies (Adams et al., 2014). In this thesis, having this longitudinal viewpoint enabled me to conduct analyses over time, as well as to develop close relationships with the young women and their families, discussed above. Previous research has documented how young people can sometimes speak normalised narratives that are deemed to be socially acceptable or expected, especially around ART adherence (Bernays et al., 2017). Building such long-term relationships helped to move beyond such dominant socially accepted narratives, with participants sharing stories that deviated from accepted 'good' behaviour, including adherence challenges, choices and decisions around sexual relationships, experiences with multiple sexual partners, and non-disclosure of their HIV status.

A further strength was the degree of flexibility that the participant observation method of the ethnography offered, which turned out to be very helpful and enabled observation of participants in a range of different settings and with a range of different friends and family. During data collection, the importance of spending time with participants at different times of day and different days of the week became clear, as different family members were at home in the evenings or on weekends, and participants' activities and behaviours changed accordingly. Participants frequently cancelled scheduled meet ups, or arrived late (sometimes several hours), and changed or disrupted plans. In other studies, in Zambia, wealthier individuals specified more clearly when they were available and not, compared to lower income individuals (Bond, personal communication). Arguably the young women's middle-income status empowered them to demand when they were able to

meet, and when not. The importance of remaining flexible became increasingly apparent, including being able to meet participants at very late notice, or reschedule to other times. It was fortunate that my circumstances enabled me to be flexible: I lived in the place of study, I didn't have rigid family or care commitments, and I was able to have a flexible working pattern that largely enabled me to meet the young women whenever suited them. During the study, several of the participants moved home to stay with other relatives, or moved to college. The flexible nature of the study allowed me to follow participants to other homes to observe changes in their lives, both within and outside Lusaka. I found that these home visits were often the most illuminating, as my understanding grew substantially from seeing the young women in the context of their own homes. This follows Fine's suggestion that participant observation is most effective when the researcher can observe participants interacting in spaces that facilitate the exploration of "the organised routines of behaviour" (Fine, 2003, p. 41). The flexible nature of the study also enabled me to tailor the participant observation to each participant, and to be sensitive to what was appropriate with each participant and their family. For example, some participants were comfortable with me joining them at their review at the health facility, while others were not. Some participants had more flexibility with time that they could meet up; others had less, particularly those who were working or studying at the time.

Generalisability of research

The limitation to this in-depth, flexible and intensive research is that I could only include a small number of participants. This meant that I could gather and understand only a limited range of experiences. The participants all had particular identities: they were all female, all aged 17-20 years, all middle-income, and all urban, living in Lusaka. In particular, no young men were included, so findings related to gender need to be interpreted in the context of having no data generated together with men for comparative purposes. The workshop with young women with unknown or negative HIV status attempted to provide some comparison with those not living with HIV,

although one workshop contrasted to a year of participant observation provided only a relatively rudimentary comparison. While such a small sample size in the ethnography enabled close relationships to be developed and in-depth data to be collected with each participant, these data generated were deeper rather than wider in nature and scope.

The study is therefore arguable limited in the degree to which the findings can be generalised beyond the particular group of middle-income young women living with HIV in Lusaka. In particular, I reflect upon the specificity of findings relating to the middle-income status of the young women. The intentional focus on middle-income young women filled a research gap, as there is very little research on this group (Long & Deane, 2015). However, this selection criterion, alongside the initial recruitment method of recruiting through health facilities, means that those who were not linked to or retained in care and those less financially stable were excluded from the study. Conducting the study only with middle income young women living with HIV made comparison to those in other income groups challenging within the study. However, comparisons can be made with existing literature. In other studies, poverty is documented to play a central role in many young people's lives and the ways in which they experience HIV (e.g. Pascoe et al., 2015). For young women in lower socioeconomic groups, experiences of food insecurity, transactional sex and older sexual partners are common (Pascoe et al., 2015). In the ethnographic study in this thesis, none of the young women were preoccupied by basic needs, such as finding shelter and food. Several of the young women were, however, concerned with securing the finances to attend college, attending which was a significant aspect of their aspirations:

> "*I'm want to go so badly, but I'm worried about where I'll get the funding*. *I feel bad speaking to mum about it, as she's got so many other worries, like for my step-siblings, and I don't want to burden her. I can really understand why some girls become prostitutes to pay for their school fees otherwise how else can they pay for it?*" (Rhoda, participant observation, 2018).

Rhoda later managed to apply for, and secure, a scholarship to study nursing at a college in Lusaka.

The findings in this thesis related to resilience and coping strategies to navigate the context of HIV stigma therefore need to be understood in the context of the young women's income level. As discussed in chapter 2, resilience and coping strategies emerge from the interaction of young people and their environment (Theron & Theron, 2010). The young women in this study had access to economic and social resources, which are not available to all young women living with HIV. These resources enabled them to easily travel to the clinic for doctors' appointments and peer support groups (through having money for transport), focus on other needs rather than basic needs of food and shelter, and have high aspirations such as going to college, that many were able to achieve. However, their economic resources also opened up other challenges, such as navigating treatment-taking in shared accommodation in boarding schools and colleges, which many of the young women found very challenging. These findings therefore support suggestions raised by Gillespie and colleagues that HIV interventions need to cut across socioeconomic groups, tailored to the specificities within different income groups (2007).

Despite these differences, I suggest that many of the findings in this thesis are relevant across income groups. Stigma is pervasive, although varying, across income groups (Corno & de Walque, 2013), and practicing secrecy to avoid unintentional disclosure and damaging their identity has been supported by other research with different groups of young people in other settings (Hardon & Posel, 2012; Toska et al., 2015). Previous research has shown notable, and unexpected, similarities in experiences among young people living with HIV across a range of diverse settings (Bernays et al., 2016). Further research comparing the experiences of young people from different socioeconomic groups would shed more light on the impact of socioeconomic status on HIV experience.

The fact that all the young women in the ethnographic study were middle income meant that the majority of data collection could take place in English, as they all spoke fluent English, which I view as a strength of the study. I could therefore build on the personal relationship that I had already developed with participants, without the need to have a research assistant or translator, as my Nyanja was not fluent enough to conduct data collection in. Previous research has demonstrated challenges of using translators in research, including negotiations of power and authority in the research process and ambiguities of translated language content (Berman & Tyyskä, 2011). In this thesis, building on this personal relationship was a key aspect to the research and was integral in enabling the generation of close and intimate data. I felt that having a translator would interfere with the close relationship with participants, and also the flexibility with which I could arrange and conduct participant observation sessions. However, it did mean that occasional conversations between family members and some nuances in communication were missed due to the language barrier.

Participation in research process

Another strength of the thesis was the active involvement of the young women in shaping the direction of research, particularly in the participatory workshops. This goes alongside a move to empower young people to meaningfully participate in, and contribute to research and programs (Larsson et al., 2018). This is in an era where the rights of young people are emphasised and demanded (Oliveras, Cluver, Bernays, & Armstrong, 2018). However, there is limited available documentation of youth participation; the evidence to date shows positive effects on program, self-efficacy and empowerment outcomes for young people (Melles & Ricker, 2018). I consider that this strengthened the study through ensuring a focus on the aspects of their lives, which the young women themselves felt were most significant. In the introductory workshop, I discussed the research objectives with the young women, and asked for their input into developing them. After a discussion of what aspects of their lives to focus on, Thandi said:

> "*I think that captures all the things that are important in my life: relationships, my family, studying, so I think those are the most important things to look at.*" (Thandi, participatory workshop, 2017).

In the closing workshop, I discussed the preliminary results around secrecy and silence as coping strategies to manage their identities, and facilitated a discussion and a 'card storm' exercise to work with the young women on analysis of this topic. This form of involvement I suggest relates to Larsson and colleagues categorisation of studies that involve young people in the decision-making process, where the participants contribute to the design, and their voices are taken seriously (2018).

In organising participant observation sessions, I tried to encourage the young women to determine as much as possible when and where we would meet. This had varied success: some participants were active in suggesting that I join them at church, or to show me around their college, or that they really wanted me to meet a particular friend who was very important in their lives. Others were more reluctant to dictate when and where we should meet. With the participants who fell into the latter group, I therefore had to be more proactive in arranging meeting up, which led to the research being more directed by me as the researcher than those particular young women as participants. Including participants in the design of the study, the production and analysis of data not only felt appropriate and ethical, but also contributed to the generation and interpretation of rich data.

The full scope of this participation was, however, limited. I had initially hoped to extend participation of the young women in the research beyond input into research design, participation in data collection and contribution to analysis, to their involvement in the presentation of results. In studies that Larsson and colleagues identified to have the greatest degree of involvement of young people, participants were included as co-designers throughout different stages of the research process, with shared power and responsibility (2018). In the ethnographic study for this thesis, I had hoped that it might be possible for a couple of the participants to present some of the findings at national or

international conferences. However, conversations with colleagues at Zambart, including a Zambian ethicist, highlighted major challenges with this that led to the decision that it would not be appropriate or ethical to do. Colleagues had previously experienced challenging unintended consequences of inviting members from community advisory boards to present at conferences. In particular, it had caused dissent amongst other members, who questioned the methods with which the member who were asked to present were selected, even though it was a random allocation. Since it would have been infeasible to arrange for all the participants in my ethnographic study to present, it created the challenge of how to ensure not to over privilege some participants in an uneven way, and I worried that there might be similar discontent with participants who were not selected. My attempt to create a more egalitarian relationship between researcher and participant through their involvement in dissemination thereby risked creating inequality among participants. Further, I worried about the implications of asking participants to be open about their HIV status in a public setting, especially given the findings in this thesis about the lengths the young women go to in order to protect their HIV status. I was uncertain about whether the young women would feel comfortable presenting the findings in this way, and I did not want them to feel pressured to do so by suggesting it as a possibility. I also worried about discussing it with participants as an option, when it was unconfirmed, and I worried about their disappointment if one of the many stages fell through. The many stages included: the decision over whether such participation was appropriate, selecting which participants might go, approval of a conference abstract, applications for funding and visas, and gaining approval from family members. I therefore decided to revise and reduce the ambition of the young women's involvement in the presentation of the results, to my presenting the main findings to them, and asking for their feedback and input to these through discussions and participatory methods in the closing workshop of the ethnography. However, I felt some disappointment that I was unable to facilitate the young women's participation throughout the research process, and it made me reflect on the limitations of participant involvement in research.

Documentation of data

Despite a balance of pros and cons, I believe my choice of how to document data collection through note-taking was a strength of the research. During ethnographic data collection I decided not use a voice recorder. This was for several reasons. Firstly, it was impractical to record conversations when multiple people were talking, and in different settings where the level of background noise would often have made it impossible. Secondly to transcribe hundreds of hours of participant observation transcriptions would have been time intensive. And thirdly, the presence of a voice recorder would likely have impacted the quality and intimacy of conversations, and possibly limited the amount or quality of information about their lives that participants revealed to me. Rutakumwa and colleagues have shown that in certain research situations, voice recorders are not appropriate, and that notes taken during the interview by well-trained interviewers and audio-recorded transcripts were comparable in the detail capture (2019).

Instead of using a voice recorder, I wrote notes as soon as possible after each session of participant observation, including writing down particularly pertinent quotes. This usually involved writing down brief notes immediately after the participant observation, to minimise recall bias. I did this while sitting in a café or in the car, or even during the participant observation sessions if I was left alone for a few minutes. I would then expand on these brief notes, usually later that day or the following day to write detailed notes, using the participant observation field notes template (Appendix 2.1) as a guide to ensure particular points are covered. I learned as I went along that it was important to stagger fieldwork sessions to ensure I had sufficient time to write up these notes in between meeting with each participant. This concurs with Rutakumwa and colleagues note on the importance of scheduling time for note taking when not using a voice recorder (2019). When I occasionally did not write notes soon after the participant observation session, I recognised that I was able to include less detail, as my memory wasn't sufficient. I feel this method of note writing satisfactorily captured the

majority of relevant conversations, interactions and details. However, particularly for quotes, while I aimed to capture the meaning and the manner in which they were said, and the words the participants used as much as possible, since these were not recorded or transcribed, they were not captured verbatim. Despite this, I consider the decision to not use a voice recorder for this ethnographic study as appropriate, and concur with Rutakumwa and colleagues that collecting data without a voice recorder can create a more open researcher-participant dynamic, and that effective note-taking can capture high quality and detailed data (2019). Given this, I agree that in some circumstances, "not recording is the best approach, not 'second best'" (Rutakumwa et al., 2019, p. 2).

Dissemination

The findings from this thesis have been disseminated to the research participants, clinic staff, colleagues at Zambart, LSHTM, other researchers and policy makers at international conferences, and to the public through presentations at schools.

Research participants: Findings were disseminated to research participants in the closing workshop of the ethnography. In this workshop, I presented findings around the restrictions the young women faced, the strategies that they practiced to manage these restrictions, the impact that these strategies had, as well as reflections on the collage method (see Appendix 2.3 for the workshop agenda). The participants discussed and commented on these findings as a group. They also contributed to analysis of the topics of coping strategies of secrecy and silence, after I presented preliminary findings on this topic. Input from the research participants on these preliminary findings was gathered through: i) a card storm activity around words they used to talk about HIV; ii) pair work about their strategies for managing disclosure; and iii) a group feedback discussion. This acted as a means of disseminating some of the findings, as well as engagement with participants in data analysis.

Colleagues at Zambart and health facility staff: I presented findings at a dissemination meeting held at Zambart, Lusaka in 2018, to colleagues at Zambart and staff from the health facilities, from where the participants were originally recruited. The presentation focused on the findings around the strategies that the young women adopted to manage their HIV identities, and feedback from this presentation was incorporated into the chapter on this topic (chapter 7). Appendix 3.1 includes the slides from this dissemination meeting.

Researchers – academic publications and presentations: Some of the papers in this thesis have already been published in peer-reviewed journals with international readership in the fields of the health of adolescents and young people, HIV and global health in developing countries. In addition to the papers contained within this thesis, I presented results from this thesis at the following national and international conferences in 2018-19 (posters and slide sets are included in the appendices). These presentations were subsequently written up to form the basis of the papers presented in the thesis (chapters 6, 4, 5, 7, and 8 respectively).

- Mackworth-Young C, Bond V, Wringe A. 2018. Sexual aspirations and fears for young women living with HIV: findings from ethnographic study in Zambia. Oral presentation at 'Evidence for Impact Symposium'. 20th-22nd March 2018. Lusaka, Zambia. (Appendix 3.2)

- Mackworth-Young C, Wringe A, Clay S, Chonta M, Chiiya C, Konayuma K, Sievwright K, Mbewe M, Mwale M, Stangl A, Bond V. Critical reflections on the use of repeated collages to understand the experiences of young women living with HIV in urban Zambia. Poster presentation at IAS. 23rd-27th July 2018. Amsterdam, Netherlands. (Appendix 3.3)

- Mackworth-Young C, Schneiders ML, Wringe A, Simwinga M, Bond, V. Ethics in Practice: Reflections from an ethnographic study among

young women living with HIV in Zambia. Oral presentation at 'Association for Social Sciences and Humanities in HIV (ASSHH) Conference'. 20th-23rd July 2018. Amsterdam, Netherlands. (Appendix 3.4)

- Mackworth-Young C, Bond V, Wringe A. Everyday 'lies', hiding and secrecy: Ethnographic study exploring strategies adopted by young women living with HIV in urban Zambia to protect their identity. Oral presentation at 'Association for Social Sciences and Humanities in HIV (ASSHH) Conference'. 20th-23rd July 2018. Amsterdam, Netherlands. (Similar slide set to Appendix 3.1)

- Mackworth-Young C, Bond V, Wringe A. Growing up with HIV: A temporal understanding of young women's experiences of living with HIV in Lusaka, Zambia. Poster presentation at 'AIDS Impact'. 29th-31st July 2019. London, United Kingdom. (Appendix 3.5)

Colleagues and fellow students at LSHTM: I presented findings from this thesis to colleagues at various LSHTM events. These included the following oral presentations:

- Reflections on using collages to understand experiences of adolescent girls living with HIV in Lusaka, Zambia. Presentation at Symposium on 'Adolescents and Young People Living with a Disability or Chronic Condition', London School of Hygiene and Tropical Medicine. 27th June 2017. London, UK. (Appendix 3.6)

- Secrets and "lies": Young women's everyday strategies to manage HIV. Presentation at 'Public Health Policy Faculty Research Afternoon', London School of Hygiene and Tropical Medicine. 13th June 2019. London, United Kingdom. (Similar slide set to Appendix 3.1)

- Growing up with HIV: A temporal understanding of young women's experiences of living with HIV in Lusaka, Zambia. Presentation at 'Research in Progress', London School of Hygiene and Tropical Medicine. 26th July 2019. London, United Kingdom. (Appendix 3.7)

Public engagement: I presented findings from this thesis in three schools, Lusaka International Community School in Lusaka, Zambia; School21 in London, UK; and St Paul's Girls School in London, UK. My partner works as a teacher, and his education networks led me to disseminating my experiences of doing this type of research to secondary school students in Zambia and London.

Conclusion

This thesis has provided applied, methodological and theoretical contributions to understanding the impact of HIV on the everyday lives of young women living with HIV. Through longitudinal ethnographic methods, an in-depth understanding of their everyday lives revealed the restrictions that they face within the social context of persistent stigma, the resilience that they demonstrated in the face of these restrictions, and how they navigated their identity and these constraints by using coping strategies and "bounded agency" (Evans, 2007). The thesis provides reflexive engagement with participatory methods with young women and ethics-in-practice of conducting the research.

Based on the findings in this PhD, I propose framing this group as a particular "biogeneration" (term adapted from Reynolds Whyte, 2014), whose lives and HIV infection are intimately entwined with their socio-historical context. My research questions prevalent discourses of normalisation of HIV by presenting how HIV led to secrecy, restrictions, more tightly bounded agency and the potential of negative impact to their identity. It also provides evidence on the resilience of young people living with HIV, including the strategies they employ to navigate HIV, offsetting a body of evidence that has historically focused on the challenges that HIV places on young people. In the context of anticipated and experienced stigma, secrecy and tight restrictions, I question prevalent public health narratives urging disclosure, and endorse support groups for young people living with HIV to provide critical safe spaces to share experiences, around HIV and beyond, openly with peers.

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Appendices

Appendix 1: Ethical procedures

1.1 Ethical approval certificates

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636

www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Miss Constance Mackworth-Young
LSHTM

13 April 2017

Dear Constance,

Study Title: Analysis of qualitative data on adolescent girls' experience living with HIV in Lusaka, Zambia

LSHTM Ethics Ref: 12101

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	CV_Constance Mackworth-Young	13/01/2017	1
Investigator CV	CV_Virginia Bond	13/01/2017	1
Protocol / Proposal	Protocol_Adolescent girls living with HIV_13012017_Version1	13/01/2017	1
Protocol / Proposal	Appendices_Adolescent girls living with HIV_13012017_Version1	13/01/2017	1
Local Approval	Letter_Ethical Clearance from Zambian Ethics Committee_Adolescent girls living with HIV_13012017_Version 1	13/01/2017	1
Local Approval	ICRW_IRB_Approval letter_14-0009	13/01/2017	1
Local Approval	Approval from Ministry CDMCH_Adolescent girls living with HIV_13012017_Version 1	13/01/2017	1
Covering Letter	Response letter to LSHTM ethics_Mackworth-Young_06042017	06/04/2017	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

Page 1 of 2

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
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www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Miss Constance Mackworth-Young
LSHTM

18 September 2017

Dear Constance,

Study Title: Social, sexual and medical transitions of young women living with HIV: ethnographic study

LSHTM Ethics Ref: 13875

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Information Sheet	Prior study in 2014-15_Info sheets and consent forms_25092014	25/09/2014	1
Investigator CV	CV_Constance Mackworth-Young_05052017	05/05/2017	1
Investigator CV	VirginiaBondShortCV_170613	13/06/2017	1
Information Sheet	Information sheet- ethnography	30/06/2017	1
Information Sheet	Information sheet - participatory workshops	30/06/2017	1
Information Sheet	Consent form - participants over 18 years	30/06/2017	1
Protocol / Proposal	Ethnography protocol_Final	30/06/2017	1
Information Sheet	Assent form - participants under 18 years	30/06/2017	1
Information Sheet	Consent form - parent or guardian	30/06/2017	1
Advertisements	Standard Operating Procedure on the recruitment process_15082017	15/08/2017	1
Information Sheet	Information Sheet Ethnography_15082017	15/08/2017	2
Information Sheet	Information Sheet Participatory Workshops_15082017	15/08/2017	2
Protocol / Proposal	Ethnography protocol_Submitted to LSHTM amendment_01092017	01/09/2017	2
Covering Letter	Response letter to LSHTM ethics_01092017	01/09/2017	1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

7th September, 2017.

Your Ref: 006-08-17.

Ms. Constance Mackworth-Young,
London School of Hygience & Tropical Medicine,
Keppel Street, London WC1E 7HT,
United Kingdom.

Dear Ms. Mackworth-Young,

RE: RESUBMITTED RESEARCH PROPOSAL: "SOCIAL, SEXUAL AND MEDICAL TRANSITIONS OF YOUNG WOMEN LIVING WITH HIV: ETHNOGRAPHIC STUDY" (REF. No. 006-08-17)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 4th September, 2017. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- Apply in writing to National Health Research Authority for permission before you embark on the study.
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

[redacted]

Dr. S. H Nzala PhD
VICE-CHAIRPERSON

Date of approval: 7th September, 2017. **Date of expiry**: 6th September, 2018.

THE NATIONAL HEALTH RESEARCH AUTHORITY
C/O Ministry of Health
Haile Selaisse Avenue,
Ndeke House
P.O. Box 30205
LUSAKA

MH/101/23/10/1

13 September 2017

Constance Mackworth-Young

London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT

United Kingdom

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Social, sexual, and medical transitions of young women living with HIV: ethnographic study."**

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

[redacted]

Sandra Chilengi-Sakala
For/Director
National Health Research Authority

All Correspondence should be addressed to the Provincial Medical Officer
Telephone: +260 211 256815
Telefax: +260 211 256814

In reply please quote:

File No. .....

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH

PROVINCIAL MEDICAL OFFICE
P. O. BOX 32573
LUSAKA

20th September, 2017.

Constance Mackworth – Young
Social Science Researcher, Zambart
PhD Candidate, London School
of Hygiene And Tropical Medicine

REF: REQUEST FOR AUTHORITY TO CONDUCT RESEARCH.

Reference is made to your letter dated 15th September, 2017 in which you are requesting for permission to conduct a research in Lusaka Province on the research entitled ***" Social, sexual and medicine transitions of young women living with HIV: ethnographic study".***

Lusaka Provincial Health Office is happy to inform you that permission has been granted for you to conduct a research in Lusaka Province, during the period you will be conducting your research there must be minimum interruption to health service delivery in the targeted health facilities. Besides, the final report of your research must also be shared with this office and the targeted district where the research will be done.

Be assured of our support as you carry out your research in the province.

Yours Faithfully,

[redacted]

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
HEALTH OFFICE, LUSAKA
0 SEP 2017
PROVINCIAL MEDICAL OFFICER
P.O. BOX 32573
LUSAKA

Dr. [redacted]
Ag/ Provincial Health Director
LUSAKA PROVINCE

Cc. District Health Directors – Lusaka Province

Physical Address: 3 Saise Road, Longacres, Lusaka, Zambia

P. O. Box 50827
Lusaka
Tel: +260-211-235554
Fax: +260-211- 236429

In reply please quote:

No:.....

REPUBLIC OF ZAMBIA

MINISTRY OF HEALTH
LUSAKA DISTRICT HEALTH OFFICE

26th September 2017

Constance Mackworth – Young (Ms)
London School of Hygiene and
Keppel Street, London WC1E 7HT
United Kingdom

Dear Ms. Mackworth-Young,

RE: AUTHORITY TO CONDUCT RESEARCH IN LUSAKA DISTRICT

Authority is hereby granted to conduct research on **"Social, sexual and medical transitions of young women living with HIV: Ethnographic study, Lusaka District".**

Kindly ensure that your findings are shared with the health facility and District Health Office and that the normal operations of the facility are not disturbed.

By copy of this letter, the In-Charges for Makeni, Chawama, Chilenje, Kamwala and Lilayi Health Facilities are kindly requested to facilitate accordingly.

Yours sincerely

[redacted]

Dr. C. Mbwili-Muleya
PRINCIPAL CLINICAL CARE OFFICER
For/DISTRICT HEALTH DIRECTOR

C.C: The Medical Superintendents/MO/In-Charges: Makeni, Chawama, Chilenje, Kamwala and Lilayi Health Facilities
C.C: Local PhD Supervisor: Dr. Virginia Bond, Zambart and London School of Hygiene and Tropical Medicine

1.2 Informed consent forms

INFORMATION SHEET FOR ETHNOGRAPHIC STUDY

You have been given this information sheet because you are being invited to take part in a research study. This information sheet describes the study and explains what will be involved if you decide to take part.

What is the purpose of this study?
This PhD study aims to understand the lives of a small number of young women aged 17-21 years in Lusaka. In particular it aims to understand how young women experience transitions throughout adolescence, including in terms of relationships with family, friends, teachers, healthcare workers, and sexual partners. This study will take place over 10 months from September 2017 to July 2018. Results from the study will be written up using pseudonyms in a PhD thesis and in papers in journals that will be publicly available.

Who is conducting this study?
My name is Constance Mackworth-Young. I am a researcher at the London School of Hygiene and Tropical Medicine. I will conduct the research with input from Dr Virginia Bond, Associate Professor, London School of Hygiene and Tropical Medicine. During my time in Zambia I am affiliated with Zambart. Dr Virginia Bond is Director and Head of Social Science at Zambart.

What is involved in participating?
I would like to spend an extended amount of time with you over about 10 months. I will join you in your daily activities and will participate in and observe these activities. This will include observations at home, the clinic, church, recreational spaces, educational institutions, and in your communities. I will conduct informal interviews with you, your family, friends, professionals and others who you interact with. You will also be asked to participate in a few activities, including writing a diary over two weeks, describing your activities and feelings during that time. The research will start with a workshop with all of the participants to discuss the project, to get input from participants and to create collages about yourself.

What are the risks in participating?
There is a risk that things that people outside the research may find out what we talk about and what you say and make assumptions about you which could be harmful to you. To keep this risk to a minimum, I will not disclose names, research notes, or any other information that may identify participants or their families beyond the research team. Research notes will be kept on a password-protected computer or in a locked drawer so that only the research team can see them. The results of this research may be published and full quotes from individuals may be used, but quotes will not be linked to named individuals. Instead pseudonyms will be used. However, if there is a serious health or welfare issue during the research, we are obliged to refer to

appropriate care. We will not disclose anything relating to you, without talking to you as the participant first.

What are the benefits and compensation to participating?
There is no direct benefit to participating. We will not provide money for participation in this research. We hope that this research will help support young women in the future as well as inform policy and expand programs to support young women in Zambia. Sometimes participants will be asked if they can travel within Lusaka for research purposes: you will be compensated for travel with a transport refund.

Do I have to participate?
Your participation in the research is voluntary. If you do not want to participate in the study, you may choose to leave the study at any time with no penalty and without giving a reason.

Who can I contact about the research?
If you have any questions about the research, please contact Constance Mackworth-Young on +260 964 303852 or Dr Virginia Bond at Zambart, Department of Medicine, Ridgeway Campus, P. O. Box 50697, Lusaka, +260 211 254 710. If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 211 256 067.

Thank you for considering taking part in this study and taking the time to read this information. If you are willing to participate in this study, please complete the consent form on the next page.

CONSENT FORM FOR PARTICIPANTS OVER 18 YEARS

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I understand that my participation is entirely voluntary.

I understand that my words may be quoted and my artwork may be reproduced anonymously in publications, reports and other research outputs.

I now consent voluntarily to be a participant in this project.

My signature below says that I am willing to participate in this research:

_____	_____	_____
Name of participant (printed)	Signature	Date
_____	_____	_____
Researcher (printed)	Signature	Date

ASSENT FORM FOR PARTICIPANTS UNDER 18 YEARS

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I understand that my participation is entirely voluntary.

I understand that my words may be quoted and my artwork may be reproduced anonymously in publications, reports and other research outputs.

I now consent voluntarily to be a participant in this project.

My signature below says that I am willing to participate in this research:

_____ _____

Name of participant (printed) Signature

_____

Age of participant

CONSENT FORM FOR PARENT/ GUARDIAN/ HEAD OF THE HOUSEHOLD

_____
Name of participant (printed)

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I understand that the participation of the young woman in my care is entirely voluntary.

I understand that my words and those of the young woman in my care may be quoted and artwork that the young woman in my care may create through the research may be reproduced anonymously in publications, reports and other research outputs.

I now consent voluntarily for the young woman in my care to be a participant in this project.

My signature below says that I am willing for the young woman in my care to participate in this research:

_____	_____	_____
Name of head of household	Signature	Date

_____	_____	_____
Researcher (printed)	Signature	Date

INFORMATION SHEET FOR PARTICIPATORY WORKSHOPS

You have been given this information sheet because you are being invited to take part in a research study. This information sheet describes the study and explains what will be involved if you decide to take part.

What is the purpose of this study?
This PhD study aims to understand the lives of young women in Lusaka aged 17-21 years. In particular it aims to understand how young women experience transitions throughout adolescence, including in terms of relationships with family, friends, teachers, healthcare workers, and sexual partners. This study will take place over 10 months from September 2017 to July 2018. Results from the study will be written up using pseudonyms in a PhD thesis and in papers in journals that will be publically available.

Who is conducting this study?
My name is Constance Mackworth-Young. I am a researcher at the London School of Hygiene and Tropical Medicine. I will conduct the research with input from Dr Virginia Bond, Associate Professor, London School of Hygiene and Tropical Medicine. During my time in Zambia I am affiliated with Zambart. Dr Virginia Bond is Director and Head of Social Science at Zambart.

What is involved in participating?
Participating involves attending two one-day workshops, held one month apart. These workshops will involve talking about your experiences of being a young woman in Lusaka, including some participatory activities.

What are the risks in participating?
There is a risk that things that people outside the research team and the workshop participants may find out what we talk about and what you say and make assumptions about you which could be harmful to you. To keep this risk to a minimum, I will not disclose names, research notes, or any other information that may identify participants or their families beyond the research team. Research notes will be kept on a password-protected computer or in a locked drawer so that only the research team can see them. The results of this research may be published and full quotes from individuals may be used, but quotes will not be linked to named individuals. Instead pseudonyms will be used. However, if there is a serious health or welfare issue during the research, we are obliged to refer to appropriate care. We will not disclose anything relating to you, without talking to you as the participant first.

What are the benefits and compensation to participating?
We will not provide money for participation in this research. You will be given a transport refund for attending the workshops. Some refreshments will be provided at the workshops

Do I have to participate?

Your participation in the research is voluntary. If you do not want to participate in the study, you may choose to leave the study at any time with no penalty and without giving a reason.

Who can I contact about the research?
If you have any questions about the research, please contact Constance Mackworth-Young on +260 964 303852 or Dr Virginia Bond at Zambart, Department of Medicine, Ridgeway Campus, P. O. Box 50697, Lusaka, +260 211 254 710. If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 211 256 067.

Thank you for considering taking part in this study and taking the time to read this information. If you are willing to participate in this study, please complete the consent form on the next page.

CONSENT FORM FOR PARTICIPANTS

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I understand that my participation is entirely voluntary.

I understand that my words may be quoted and my artwork may be reproduced anonymously in publications, reports and other research outputs.

I now consent voluntarily to be a participant in this project.

My signature below says that I am willing to participate in this research:

_____	_____	_____
Name of participant (printed)	Signature	Date

_____	_____	_____
Researcher (printed)	Signature	Date

1.3 Standard Operating Procedure on the recruitment process

Purposive sampling has been used to select young women living with HIV from middle-income backgrounds, who had participated in previous research in 2015 and with whom contact has been sustained over 2 years (through support groups and workshops). These young women will be asked to participate in the ethnographic study. All potential participants and their parents/ guardians know the researcher from the previous research conducted in 2015, and the researcher has retained their contact details (with their permission), including their telephone numbers stored using pseudonyms.

Once the young women living with HIV have been purposefully sampled, recruitment and informed consent/ assent will take place in the following way:

Step	Details
1. Call potential participants	Potential participants will be called to initially discuss the project. This conversation will include: 1. Asking what the potential participants are currently doing and where they are currently living (to check that they fulfil the recruitment criteria); 2. Briefly outlining the project as a further study with some of the participants from the previous research – all young women living with HIV – to understand more in-depth about their everyday lives; 3. Ask if they are interested in participating, and if so, whether I would be able to meet up with them and their families to discuss it further and to give more details.
2. Arrange time to meet	If potential participants would like to discuss further and are interested in participating, I will arrange a time where I can meet with them and their parent/ guardian, most likely at their home.
3. Give further details on the study	When I meet with them, I will discuss the study in greater detail. This will include all the details included on the information sheets plus: 1. The purpose of the study is to specifically understand the lives of young women living with HIV 2. The risks of participating also include unintentional disclosure of participant's HIV status, and the measures we will take to minimize this risk (outlined in the protocol) 3. Emphasizing that participation is entirely voluntary, and that they can end their participation at any time.

4. Read information sheets	After this discussion, if the young women and their parent/ guardian are happy for them to participate in the study, I will give them the relevant information sheets. The information sheets do not include any reference to HIV. This is to protect the HIV status of participants living with HIV in case a friend or family member who does not know the participant's HIV status sees the information sheet. I will explain that some of the detail is excluded from the information sheets to protect participants' HIV status, and so I have explained this verbally. They will be given an opportunity to ask any questions they may have.
5. Written informed consent	Once they have read the information sheet and been given the opportunity to ask questions, I will ask for written informed consent from their parents/ guardians. I am asking for parent/ guardian informed consent regardless of the age of the participant, due to the involvement of the parents/ guardians in the ethnography. This procedure complies with ethical guidelines for ethnographic research, where written informed consent is recommended to be sought from key gate holders (parents/ guardians/ head of household), and can also be sought from key participants (young women) (ASA, 2011). For participants over 18 years I will ask for their written informed consent. For participants under 18 years, I will ask for their written assent.

1.4 Protocol for disclosure and safety issues

Introduction

This document is to provide guidance for when potentially challenging ethical situations may arise during the course of the ethnographic research, including when to disclose information shared by the participant. The document identifies situations and gives a protocol to guide the researcher as to how act in each of these situations, while understanding that each case is unique and the response to each case may need to be adapted through judging what is most appropriate in that circumstance.

Sexual abuse

A participant may report past or on-going sexual abuse that she has experienced to the researcher. If a participant reports sexual abuse to the researcher, the researcher will initially ensure that the participant feels free to speak without judgement. The researcher will aim to be as supportive as possible, giving space for the participant to speak about the experience and her feelings in the way that she feels most comfortable.

If the sexual abuse is on-going or if it has not been reported, and if the perpetrator of the abuse is still alive, the researcher will talk to the participant about reporting the sexual abuse. The researcher will not disclose sexual abuse that the participant has told them about without discussing with the participant herself first. The researcher will also not disclose sexual abuse before talking to her supervisor, Virginia Bond, who has had experience in conducting research with children who have experienced sexual abuse in Zambia. The researcher will also discuss with Dr Musonda Simwinga, Zambart who has extensive research experience around research ethics in research in Zambia. If appropriate, the research could put the participant in touch with a counsellor, for instance at Young Women's Christian Association (YWCA) in Lusaka. If it is decided that reporting is necessary and if it is possible with the consent of the participant and/ or the participant's family, the sexual abuse will be reported to the police.

Domestic violence

Domestic violence may be witnessed by the researcher during observations, most likely in participants' homes, or reported to the researcher by the participant or their friends or family. If reported, the researcher will ensure that the participant feels free to speak about it without judgement, and will give them space to speak about it. If domestic violence is witnessed, the researcher will ensure her safety by leaving the room or the house quickly, and if she is staying in the participant's home, may leave, even if that cuts short the intended period of staying and observation.

If domestic violence is on-going and putting the participant or her family at risk, the researcher will talk to the participant about reporting domestic violence. The researcher will not disclose domestic violence that the participant has told them about without discussing with the participant herself first. The researcher will also not disclose sexual abuse before talking to her supervisor, Virginia Bond. If appropriate, the research could put the participant in touch with a counsellor, for instance at Young Women's Christian Association (YWCA) in Lusaka. If it is decided that reporting is necessary and if it is possible with the consent of the participant and/ or the participant's family, the domestic violence will be reported to the police.

Suicidal intentions

Participants may disclose suicidal intentions during the research. If so, the researcher will listen, try to be as understanding and sympathetic as possible, and help the participant to speak freely without judgement. Where possible, the researcher will offer support and advice. This may include that they speak to a particularly close friend or family member, or a counsellor they already know at the clinic. If appropriate, the researcher can offer to accompany them to do this. Advice may also include joining a support group run by their clinic. The researcher will assure the participant that they can feel free to talk to the researcher when they need/ want.

The researcher will report any disclosure of suicidal intentions to her supervisor, Virginia Bond. If the researcher and Virginia Bond judge the suicidal intentions spoken about to be at risk for the participant, then the researcher will first talk to the participant about the need to report this. The researcher will not disclose suicidal intentions that the participant has told them about without discussing with the participants themselves first. The researcher can offer to go together with the participant to talk to a counsellor, either at the clinic, or in a NGO, such as YWCA.

Disclosure of HIV status

A risk to participants is that participation in the research might lead to unintentional disclosure of their HIV status, which may lead to anticipated or experienced stigma. If the researcher suspects that a friend/ family member of a participant, who was not previously aware of the participant's HIV-status, suspects the participant's HIV status, the researcher would first talk to the participant about this, and ask her how she would best like to deal with the situation. The researcher will talk with Virginia Bond and Musonda Simwinga at Zambart. The researcher will make additional attempts to sensitively reaffirm with all contacts of the participant that the research is looking at the transitions of young women in Lusaka (without mentioning anything to do with HIV). If the participant talks to the researcher about anticipating or experiencing stigma, the researcher will take time to talk to her about this, and also suggest that she might talk to counsellors about this, and give her contact.

Non-adherence to ARVs

The researcher may find out that participants are not adhering to their treatment, either through observations, or if the participant speaks to the researcher about this. If this occurs, the researcher can find an appropriate time in which to speak to the participant about this, including to understand why she is not adhering, and to talk to her about it in a non-assuming, non-judgemental way. The researcher can provide encouragement to help her overcome some of the barriers that have stopped her taking treatment and to re-start taking treatment. If the participant is worried about admitting non-adherence either to her family or at the clinic, the researcher can offer to be present if she chooses to do this.

Illness and death

The participants themselves, or their family or friends, may experience serious illness or death during the period of the research. The researcher can assist participants to go to a health facility, but should not cover the costs of the medical care. The researcher can provide emotional support to the participant and their family, and can also refer participants and their families to counselling, for example with YWCA. In the case of the death of a participant or close family member, the researcher may attend the funeral only if appropriate and only if it would not cause suspicion around the HIV-status of the person who had died. If the researcher needs support relating to illness and death of participants, she can talk to her supervisor, Virginia Bond, or a trained counsellor who is known to her, Sue Clay.

If the researcher falls ill, she will take some time off fieldwork, and stay at home in Lusaka. If necessary, she will temporarily stop data collection when she is ill. Her medical care is covered by health insurance.

Harm to the researcher

The researcher may experience harm during the research. This may be emotional harm from hearing distressing stories or witnessing distressing events; or physical harm from being more vulnerable in the context of the research. If the researcher experiences harm during the research, the primary source of professional support is her supervisors, Virginia Bond and Alison Wringe. Additional support can be provided by Sue Clay, who is a trained counsellor in Lusaka, and by Musonda Simwinga, who can provide help and advice with culturally sensitive situations.

Appendix 2: Data collection tools

2.1 Participant observation field-notes template

Context

- Participant
- Location
- Date and time
- Who was present?
- How was the participant observation session arranged?

Session description

- What happened?
- Information gathered
- Key quotes
- Language used
- Description of the space where the PO took place

Relational description

- How did people interact to each other and to me?
- Questions raised by participants
- Interesting comments/discussion between people
- Body language of participants and those they interacted with

Reflections and interpretation

- Was anything striking/ different/ notable about the session?
- Any reason for concern (including ethics)?
- How did it compare to other days?
- How did it make me feel, what do I think about it?
- Areas to look into more deeply for future sessions
- Key ideas emerged/ developed from this session
- Personal thoughts/ reflections

2.2 Diary guidance

I am asking you to write in a diary every day for about a month weeks. I am providing you with a notebook/ diary and a pen. The purpose of using diaries in this study is to allow you space to talk about other aspects or things in your life that may not be talked about with me as the researcher face-to-face. It is also to understand what you do on a day-to-day basis, and also your general reflections and thoughts. The diary can give you room to choose what you want to write about and when you want to write.

If you are happy to do this, please write in the diary every day from today for a month. When you write in the diary, feel free to write about whatever you wish to write about. There is no constraint as to what you should/ shouldn't write about.

I am including some question guides in your diary that can help you think about what you might want to write about. You can follow these questions, but please don't feel restrained to just write about these topics.

- What did you do today?
- Where did you move today?
- Who did you see?
- What conversations did you have?
- How was your health today?
- How were you feeling today?
- Did anything unusual/ different happen?
- How does this day compare with other days?
- Any general thoughts or reflections
- Is there anything extra that you would want me to know about you or your life?

If it's ok with you I will ask to collect the diary after about a month. If you would like to keep the diary afterwards, please let me know, and I can return it to you.

2.3 Workshop agendas

Workshop agenda: Introductory workshop of ethnographic study

Time	Activity	Details
9am	Arrive	Sit in a circle
9.30-9.45	Start	Energiser – led by one of the participants
9.45-10.15	Round of how we are feeling	Open as a group, by saying - How we are feeling today - One thing that we would like to tell the group about us since we last met
10.15-10.45	Making collages	Introduction to collages - Remember the collages we made before? - Make another collage, this time that you feel represents you now. - Think about if you were to tell someone about yourself, what picture would you make?
10.45-11.00	Describe collages to the group	Tell us about your collage. - What does each picture/ visual/ words mean to you? - What do you think your collage says about you? - If you wanted to add something, but didn't, what would you have added?
11.00-11.15	Tea break	
11.15-11.30	Describe research study	Constance describes the research study - Purpose - What is involved in participating? - Risks and benefits - Importance of family and/ or friends being supportive and involved - More intensive than last research - Voluntary – can stop the research at any time - Focus on: 1. relationships with friends/ family/ boyfriends. 2. Transitions – changes over time from then to now and over the next few months. 3. How you think about your body, identity, and impact of ARVs. 4. How the context of where you live, the fact

		that you're living now with access to ARVs impacts your experiences Ask participants what they think about all of this, and about the focus areas. - Is there anything else I should pay attention to that's important in your lives? - Is there anything that you are afraid of in the research?
11.30-11.45	Story of what the research is	Break into two groups to discuss how participants think it would be best to present the research to other people if they ask about it. - If someone asks: "what is this research? Why is Constance with you?", how do you think it would be best for us to respond? - Can show that in a role-play. Or just describe what you think would be best to say.
11.45-12.00	Diaries	Ask how participants would most like to keep a diary for two weeks. - Some suggestions: write every day on WhatsApp, video diary, book written diary. - Discuss in two groups what you would most prefer to do.
12.00-12.15	Wrap up	One round with everyone - How did you feel about today? - One thing you're looking forward to about the research

Workshop agenda: closing workshop of ethnographic study

Time	Activity	Details
9am	Arrive	Sit in circle and chat about how everyone has been in the last couple of months.
9.30-9.45	Start	Energiser – led by one of the participants
9.45-10.15	Round of how we are feeling	Sit in a circle, and open by saying - How we are feeling today - One thing that we would like to tell the group about us since we last met
10.15-11.00	Feedback from participants on what it was like to participate in the research	Ask about their experiences of participating in the research. - How did you find it? - Which part of it did you particularly like? - Which part of the research did you find particularly challenging? - How do you think your family/ friends reacted to it?
11.00-11.30	Tea break	
11.30-11.40	Energiser	Led by one of the participants
11.40-12.30	Results from collage method	Constance to present results from collage method, including future aspirations and challenges Group feedback on these results
12.30-13.15	Lunch	Hungry Lion for everyone
13.15-14.15	Results around restrictions, coping strategies and secrecy	Constance to present preliminary results around restrictions, coping strategies and secrecy Discussion in pairs on the results Writing on cards other 'concealed language' Feedback all together
14.15-14.45	End of the research	How do you feel about the research coming to an end?
14.45-15.00	Closing energiser	Stick paper on everyone's backs. Each person writes one thing about that person that they value. Everyone writes, then we come back together, and we each read out our cards.
15.00-15.15	Closing	One round with everyone - How did you feel about today - One thing you will take away from being part of this research

Workshop agenda: workshop with young women with negative or unknown HIV status

Topics/ questions to explore

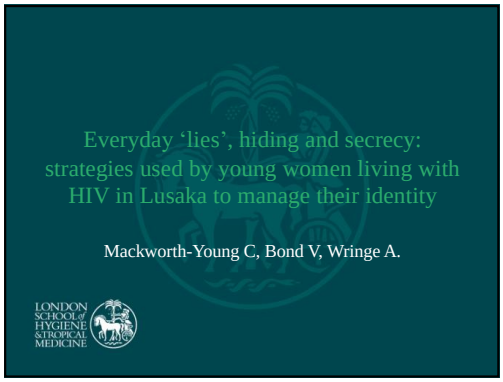
- Everyday activities
- What is important to them as young women in Lusaka? What do they have/ don't have/ would like to have? What do they do/ don't do/ would like to do?
- How has their lives changed over time? What do they aspire to in the future? What challenges do they face?
- What networks do they have? How do they view their relationships? What nice things/ challenges do they face in their relationships?
- How do they view their identity? Is there anything about their identity that they keep secret?
- How do they view people living with HIV? Do they have any friends or family living with HIV? How does that impact them or their views about those people?

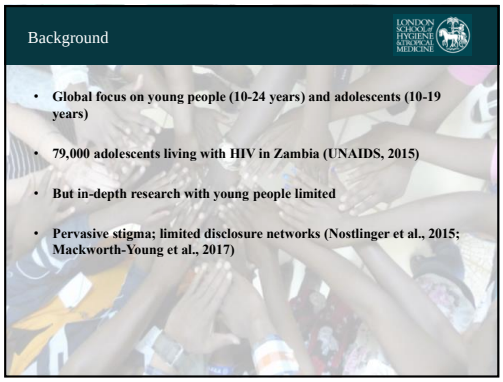
Time	Topic	Methodology
09.00-10.00	I**ntroductions**	Paired game- 'Walk around ' Intros of each other to the circle- name/ where from/ one of your wildest dreams
10.00-10.45	**Who am I?** What are some of the key events in my life? What is important to me? What do I want for the future?	Collage guided by the 3 questions Followed by a group sharing/ debrief
10.45-11.00	**Break**	
11.00-11.30	**Secrets**	Confidentiality game (holding secrets) In pairs:*? Are there some things about yourself, or some things you do, that you hide from others?* Brainstorm: Examples of things we sometimes hide
11.30-12.00	**Challenges**	Cardstorm- What are some of the challenges we face? Home/ School/ Friends/ Relationships/ Other
12.00-12.45	**Thoughts about HIV**	Brainstorm: *Has HIV touched your life in any way?* Stigma Case studies from the curriculum, in small groups. Extra questions
12.45-13.15	**Networks and relationships - who's in my world?**	Flipchart with 'Me' in the middle. Cards for different people, written by girls. Stick close or far from figure to show relationship. Debrief

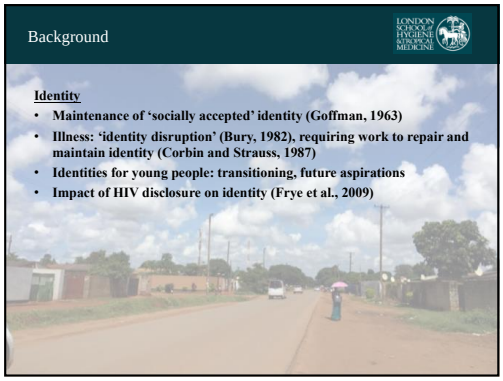
Appendix 3: Disseminated work

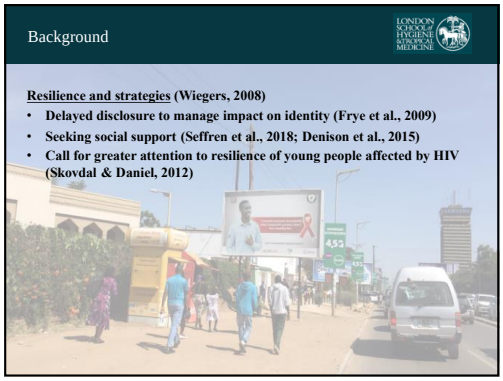
3.1 Dissemination meeting at Zambart, Lusaka, September 2018

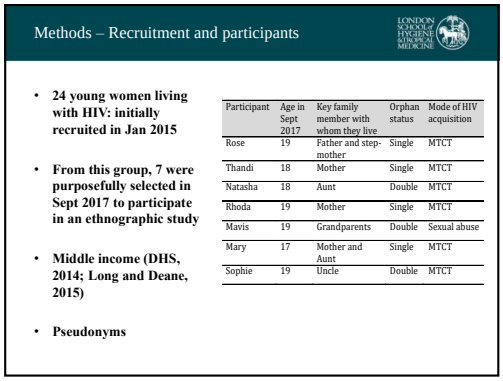
Everyday 'lies', hiding and secrecy: strategies used by young women living with HIV in Lusaka to manage their identity. Dissemination meeting at Zambart. 14th September 2018. Lusaka, Zambia



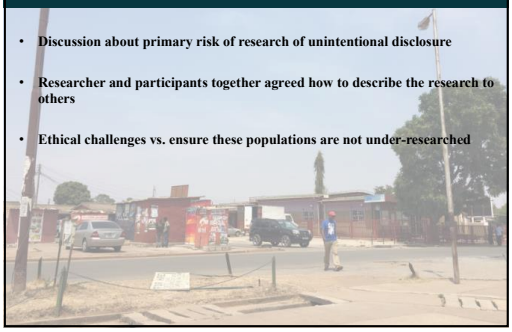








Ethical considerations



- **Discussion about primary risk of research of unintentional disclosure**
- **Researcher and participants together agreed how to describe the research to others**
- **Ethical challenges vs. ensure these populations are not under-researched**

Results – overview

Fear of unintentional disclosure

Strategies
- **"*I tell lies every single day*"**
- **Concealing ARVs**
- **Veiled language**

Impact of strategies: anxiety and guilt around 'lies'

Results – Fear of unintentional disclosure

- **Unintentional disclosure: feared**

"*the worst thing that could happen to me*" Mary

"*I just can't tell (my best friend). When I mentioned jokingly about HIV, she had a very bad reaction, so I just knew I couldn't tell her*" Mavis

- **Bad experiences of unintentional disclosure**

"*he made me feel like I was trash*" Rhoda

- **Wider intentional disclosure over time**

"I used to be that type of person who never wanted to tell anyone. I was so secret with my status. But now I've got that confidence" Sophie

Results - Strategy 1: "*telling lies*"

- **"*I tell lies every single day*"**
- **Presence at the clinic, how their parents died, what their ARVs are**
- **Cover-up stories when participants go to the clinic**

"*She kept on calling when I was at the clinic, asking where I was. So I just had to say that I was in town doing a few things. But then she wanted to join me in town, so I had to lie again.*" Mavis

Results – Strategy 2: concealing ARVs

- **ARVs: conspicuous sign of HIV status**
- **Challenge of limited privacy**

"*the biggest difficulty I have*" Thandi

- **Impact of ARVs being discovered**

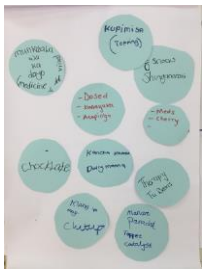
Results – Strategy 3: Veiled language

- **Veiled language, not mentioning HIV or ARVs**

"In my state"

"dosing"

"*she's like me*"



Results – Anxiety and guilt around 'lies'

- **Fear of discovery**

> *"The bad part is that I can't tell (my best friend). But I don't like it because there's no lie that can stay hidden forever. One day she is going to find out."* Mavis

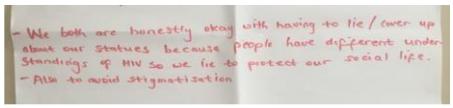
- **Guilt of telling lies**

> *"I still feel bad about lying to that woman. I always feel bad when I lie. It makes me feel so guilty inside. May God forgive me."* Rhoda

> *"Do you lie because of your status?"*
> *"Yes, a lot, all the time"*

Results – 'Lies' necessary

- **Lies are necessary**



- **Peace and freedom with those they have disclosed to**

> *"It's so nice to be with someone who knows. I don't know how to describe it; it's just so peaceful. She just understands; I don't need to explain or tell stories."* Natasha

Discussion – key findings (i)

Limitations

Small and specific group of young women LWH

Pragmatic strategies

- **Necessary in environments with limited privacy (Mutwa et al., 2013) and high mobility – resilience in challenging circumstances**
- **Challenges disclosing conflicts with global drive for disclosure**
- **Personal impact of these strategies: psychological, anxiety, guilt**

Discussion – key findings (ii)

Managing identity

- **Unintentional disclosure – led to 'spoiled identity' (Goffman, 1963)**
- **Managing identity by choosing who to disclose to (Bond, 2010)**
- **Strategies made their lives *appear* 'normal', but require multiple, everyday adaptions to their behaviour**

Thanks:

Participants and their families for giving their time and sharing their lives

Colleagues at Zambart for support

Supervisors: Dr Virginia Bond and Dr Alison Wringe

Funding: ESRC

Health facilities: Chawama and Pediatric Center for Excellence, UTH

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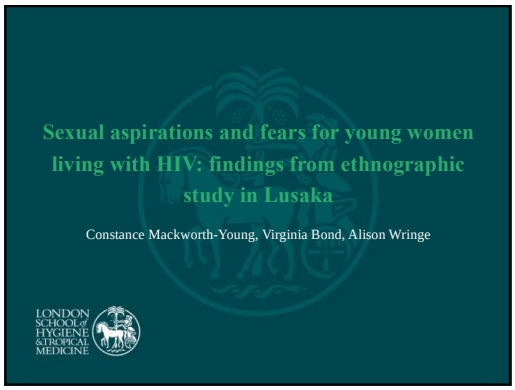
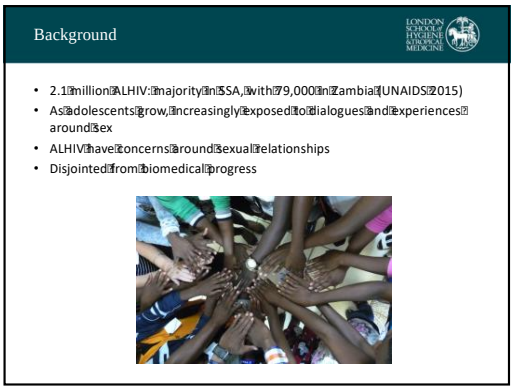
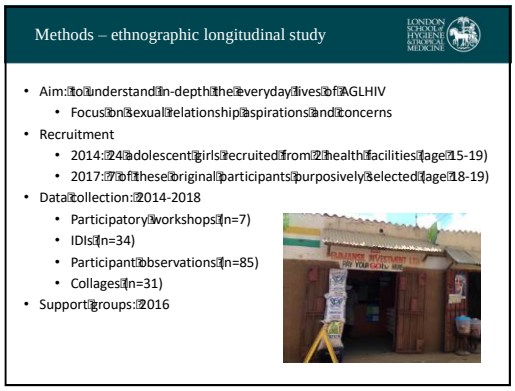
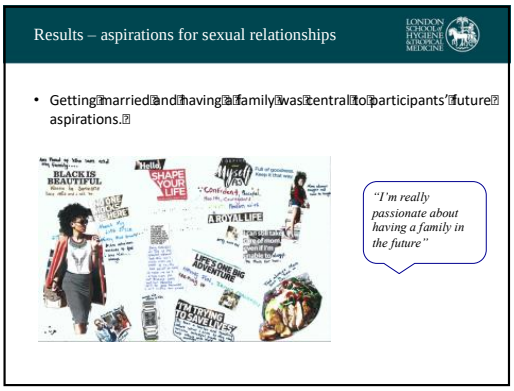
3.2 Evidence for Impact Symposium, Lusaka, March 2018 – oral presentation

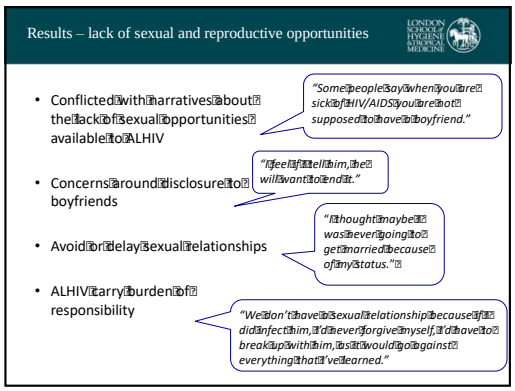
Mackworth-Young C, Bond V, Wringe A. 2018. Sexual aspirations and fears for young women living with HIV: findings from ethnographic study in Zambia. Oral presentation at 'Evidence for Impact Symposium'. 20th-22nd March 2018. Lusaka, Zambia.

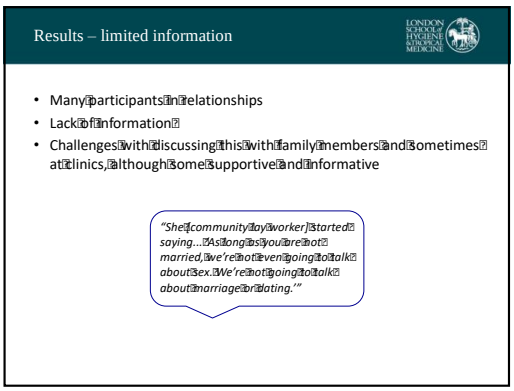












Results – value of open discussions in support groups

- Support groups = valued opportunities to discuss how to safely navigate sexual relationships.
- Peer educators want to discuss options of safe sex and condom use as well as abstinence
- Help with disclosure to partners can lead to support from partners
- Support and information enabling transition over time

"I enjoy peer education, but it's difficult telling people one thing, abstinence, but then if you're having sex yourself it's quite contradictory. It's important to also teach options of condoms and safe sex."

"Since she knows my status, he now comes with me to my review"

"I now have so much confidence"

Discussion

- Conflicting narratives between sexual and reproductive aspirations and perceived reality of a future living with HIV
- Opportunity to use the focus on adolescent-friendly programs and support groups for ALHIV to ensure inclusion of discussions on relationships
- Curriculum for support groups piloted, including session on relationships
- Opportunity to provide more information through CSE curriculum in schools
- Importance of providing correct and supportive information that provides a range of options

Thanks to:

All the participants for their time and openness in participating in the studies

Funders: ESRC and MAC AIDS Foundation

Collaborators: Zambart; Anne Stangl, ICRW; Chipo Chiiya, Mutale Chonta, Sue Clay, 3Cs Regional Consultants

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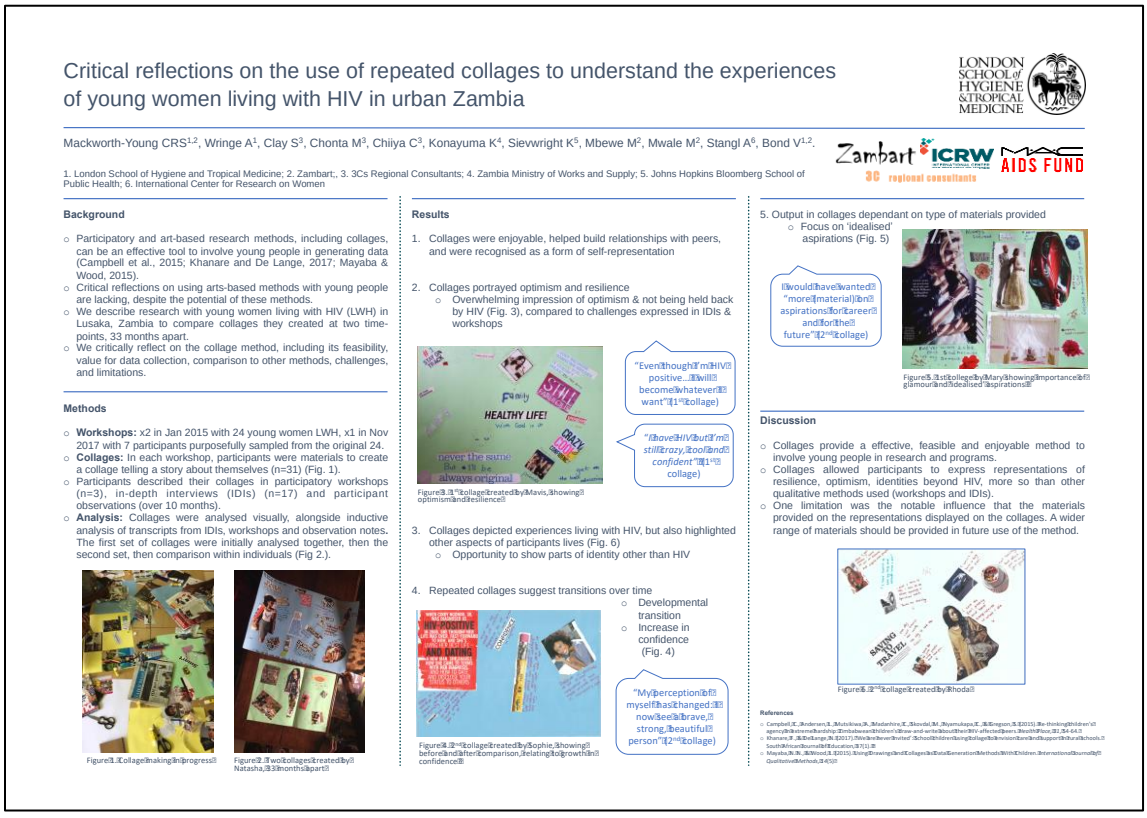
3.3 International AIDS Society Conference, Amsterdam, July 2018 – poster presentation

Mackworth-Young C, Wringe A, Clay S, Chonta M, Chiiya C, Konayuma K, Sievwright K, Mbewe M, Mwale M, Stangl A, Bond V. Critical reflections on the use of repeated collages to understand the experiences of young women living with HIV in urban Zambia. Poster presentation at IAS. 23rd-27th July 2018. Amsterdam, Netherlands.



Critical reflections on the use of repeated collages to understand the experiences of young women living with HIV in urban Zambia

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Mackworth-Young CRS[1,2], Wringe A[1], Clay S[3], Chonta M[3], Chiiya C[3], Konayuma K[4], Sievwright K[5], Mbewe M[2], Mwale M[2], Stangl A[6], Bond V[1,2].

Zambart ICRW AIDS FUND 3C regional consultants

1. London School of Hygiene and Tropical Medicine; 2. Zambart;, 3. 3Cs Regional Consultants; 4. Zambia Ministry of Works and Supply; 5. Johns Hopkins Bloomberg School of Public Health; 6. International Center for Research on Women

Background

- Participatory and art-based research methods, including collages, can be an effective tool to involve young people in generating data (Campbell et al., 2015; Khanare and De Lange, 2017; Mayaba & Wood, 2015).
- Critical reflections on using arts-based methods with young people are lacking, despite the potential of these methods.
- We describe research with young women living with HIV (LWH) in Lusaka, Zambia to compare collages they created at two time-points, 33 months apart.
- We critically reflect on the collage method, including its feasibility, value for data collection, comparison to other methods, challenges, and limitations.

Methods

- **Workshops:** x2 in Jan 2015 with 24 young women LWH, x1 in Nov 2017 with 7 participants purposefully sampled from the original 24.
- **Collages:** In each workshop, participants were materials to create a collage telling a story about themselves (n=31) (Fig. 1).
- Participants described their collages in participatory workshops (n=3), in-depth interviews (IDIs) (n=17) and participant observations (over 10 months).
- **Analysis:** Collages were analysed visually, alongside inductive analysis of transcripts from IDIs, workshops and observation notes. The first set of collages were initially analysed together, then the second set, then comparison within individuals (Fig 2.).

Figure 1. Collage making in progress

Figure 2. Two collages created by Natasha, 33 months apart

Results

1. Collages were enjoyable, helped build relationships with peers, and were recognised as a form of self-representation
2. Collages portrayed optimism and resilience
   - Overwhelming impression of optimism & not being held back by HIV (Fig. 3), compared to challenges expressed in IDIs & workshops

"Even though I'm HIV positive...I will become whatever I want" (1st collage)

"I have HIV but I'm still crazy, cool and confident" (1st collage)

Figure 3. 1st collage created by Mavis, showing optimism and resilience

3. Collages depicted experiences living with HIV, but also highlighted other aspects of participants lives (Fig. 6)
   - Opportunity to show parts of identity other than HIV
4. Repeated collages suggest transitions over time
   - Developmental transition
   - Increase in confidence (Fig. 4)

"My perception of myself has changed: I now see I'm brave, strong, beautiful person" (2nd collage)

Figure 4. 2nd collage created by Sophie, showing before and after comparison, relating to growth in confidence

5. Output in collages dependant on type of materials provided
   - Focus on 'idealised' aspirations (Fig. 5)

"I would have wanted more [material] in my aspirations for career and for the future" (2nd collage)

Figure 5. 1st collage by Mary, showing importance of glamour and 'idealised' aspirations

Discussion

- Collages provide a effective, feasible and enjoyable method to involve young people in research and programs.
- Collages allowed participants to express representations of resilience, optimism, identities beyond HIV, more so than other qualitative methods used (workshops and IDIs).
- One limitation was the notable influence that the materials provided on the representations displayed on the collages. A wider range of materials should be provided in future use of the method.

Figure 6. 2nd collage created by Rhoda

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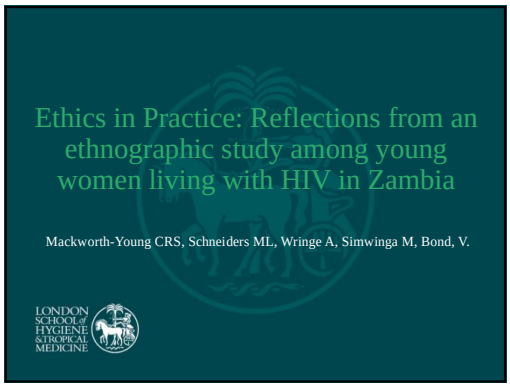
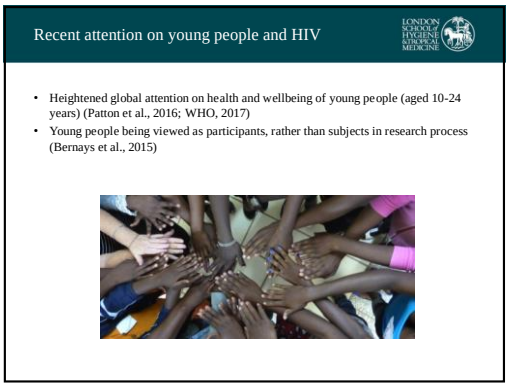
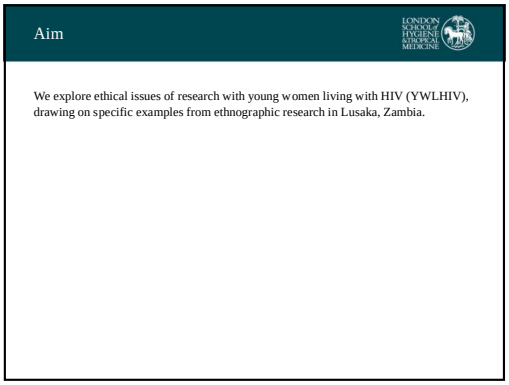
- Khanare, F. P., & De Lange, N. (2017). Why Are They Involved? School Children's Learning Challenges Revisited and Support Structures in Rural Schools in South Africa. Journal of Education, 0(71), 0.
- Mayaba, N. N., & Wood, L. A. (2015). Using Drawings and Collages as Data Generation Methods With Children. International Journal of Qualitative Methods, 14(5).

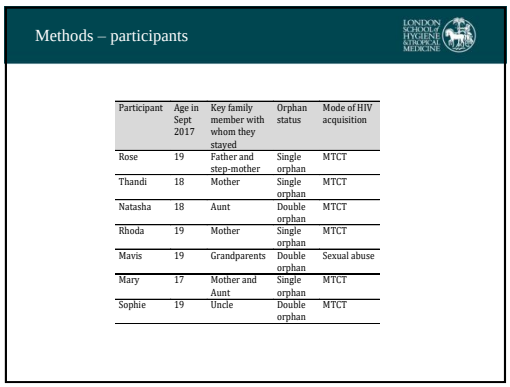
3.4 ASSHH Conference, Amsterdam, July 2018 – oral presentation

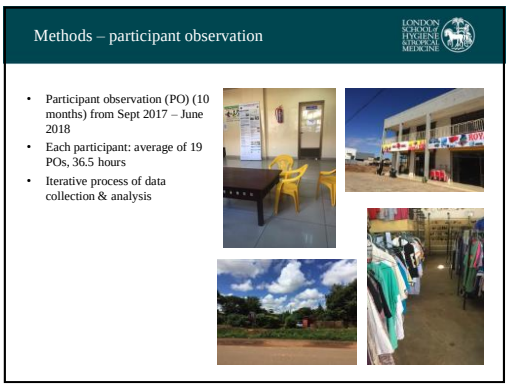
Mackworth-Young C, Schneiders ML, Wringe A, Simwinga M, Bond, V. Ethics in Practice: Reflections from an ethnographic study among young women living with HIV in Zambia. Oral presentation at 'Association for Social Sciences and Humanities in HIV (ASSHH) Conference'. 20th-23rd July 2018. Amsterdam, Netherlands.











Methods – data analysis

- Data collection: also workshops, diaries and collages
- Ethical issues emerged inductively as a key focus area.
- Iterative and continuous reflection on ethical issues
- Thematic analysis of ethical issues

Results overview

- Benefits of research to participants
- Researcher-participant relationships
- Confidentiality vs. ownership of data
- Telling 'white lies'
- Obligations post-research

Benefits of research

- Initially questioned what the benefits of the research were to participants
- Material benefits
- But main benefit of research highlighted by participants were non-material: relationship with researcher

"It was so nice for me to have someone I could feel I could tell everything to, and that I knew would always listen. I didn't know I had so much going on in my life until I had the chance to talk to you and tell you everything about it." Thandi, PO notes

Researcher-participant relationships

- Participants sought researcher's advice and input outside the remits of the research
- Advice sought about boyfriends
- Researcher asked to assist in family disputes

"I haven't spoken to anyone else about this. Just in the diary and to you." Mary, PO notes

"I have a favour to ask you. Could you possibly call my sister and tell her that we met, you met with me, and that you saw where I am staying, that I am staying with a friend, and that I am living somewhere that's nice and safe. Will you tell her that, because she trusts you, and it'll sound better coming from you than from me." Mavis, PO notes

Confidentiality vs. ownership of data

"I really want to keep the diary. It's been the only place I can openly speak about all the difficulties these last few weeks." Natasha, PO notes

"I want to show it (the collage) to my friend. I just disclosed to her, and I want her to understand what I've been going through." Sophie, PO notes

"I think it's best if you keep it [the collage]. I don't have anywhere safe for it, and I worry if my roommates found it that they would ask a lot of questions." Mary, PO notes

- Choice in hands of participant, rather than researcher
- Balance of autonomy vs. potential harm

Telling 'white lies'

- Researcher participated in 'white lies' that participants told to hide their HIV status.
- Researcher introduced as "*friend*", "*researcher*", "*someone I met through the support groups*" to protect participants' confidentiality
- Researcher hid participants' HIV status when directly questioned about it

"this research does not focus on anything like that (HIV) but it's more broadly trying to understand about how young people live their lives" Researcher, Mavis, PO notes

Obligations post-research

- Ending with a workshop with all participants together.
- Challenges in ending a close and long-term relationship
- Continued contact with participants?

> "*Who will I just be able to talk to about anything when you've gone?*" Thandi, PO notes

Discussion

Key findings

- Role of researcher and relationship between researcher and participants is complex, especially in ethnography
- Ethical challenges of confidentiality vs. truth and autonomy
- How to ensure protection from harm while truly participatory and empowering and not excluded from research

Conclusions

- Importance of active critical reflection on ethics throughout research process
- Ethical Principles essential, but also importance of flexibility and adaptation

With thanks to:

The participants for their time and openly sharing their stories

Collaborators from Zambart, 3Cs Regional Consultants and ICRW

Funding from ESRC

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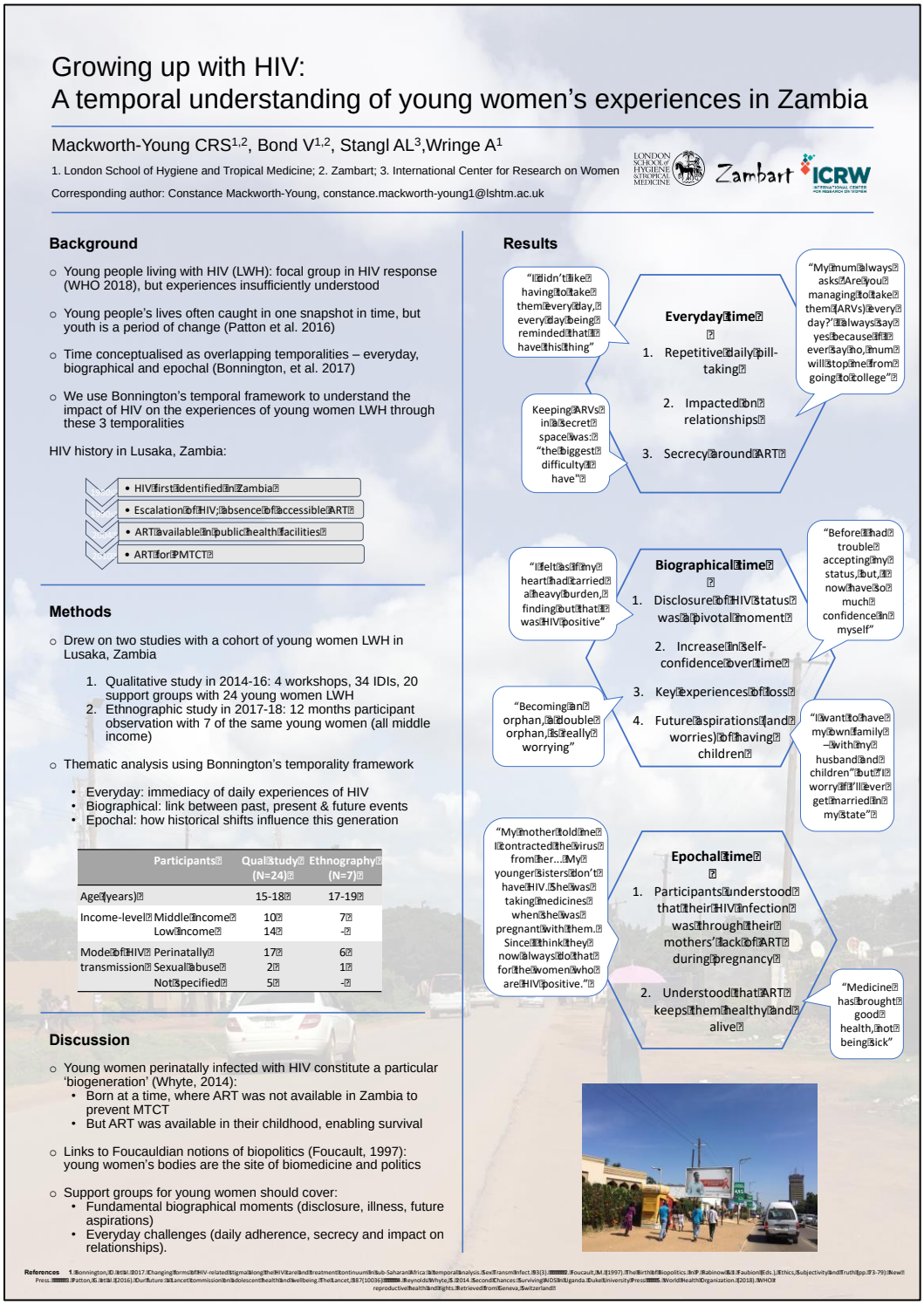
I have no conflict of interests to declare

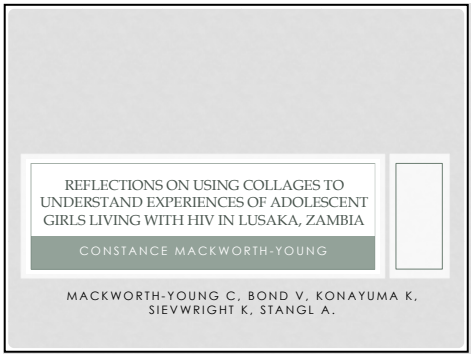
3.5 AIDS Impact, London, July 2019 – poster presentation

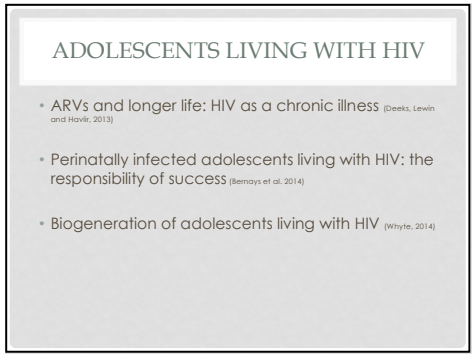
Mackworth-Young C, Bond V, Wringe A. Growing up with HIV: A temporal understanding of young women's experiences of living with HIV in Lusaka, Zambia. Poster presentation at 'AIDS Impact'. 29th-31st July 2019. London, United Kingdom.

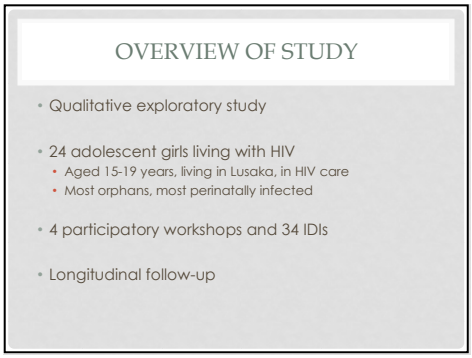


3.6 LSHTM, June 2017 – oral presentation at 'Symposium on Adolescents and Young People Living with a Disability or Chronic Condition'

Reflections on using collages to understand experiences of adolescent girls living with HIV in Lusaka, Zambia. Presentation at Symposium on 'Adolescents and Young People Living with a Disability or Chronic Condition', London School of Hygiene and Tropical Medicine. 27th June 2017. London, UK.







GLAMOUR AND BODY

"I don't want to ever lose my body or become less healthy."

"When I finish school, if I look like this there will be no one who will know that I am on treatment"

TRAUMA AND GRIEF

"Just because someone breaks you, it doesn't mean it's the end."

FAMILY

"I'm positive, but my family is still with me and I can go to them for support"

"Like for example here, I can be HIV positive, but I've got a family. My status doesn't mean that I shouldn't have a family and stuff"

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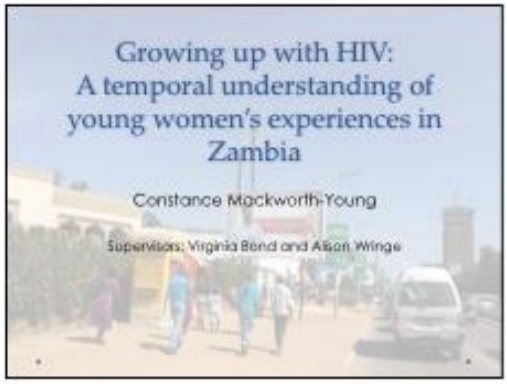
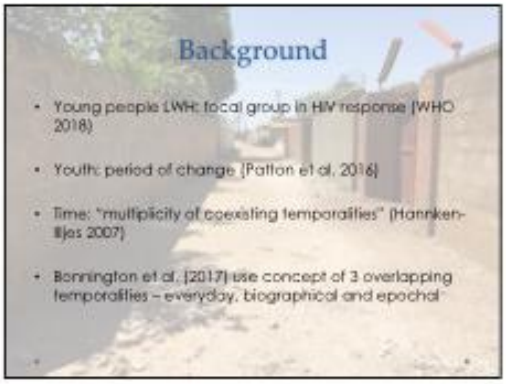
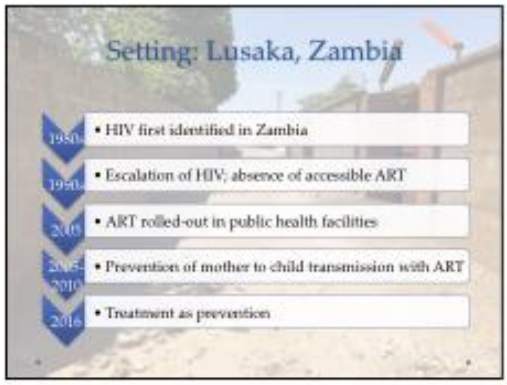
With thanks to:
All the participants
The study team
Funders: Economic and Social Research Council and MAC AIDS Fund

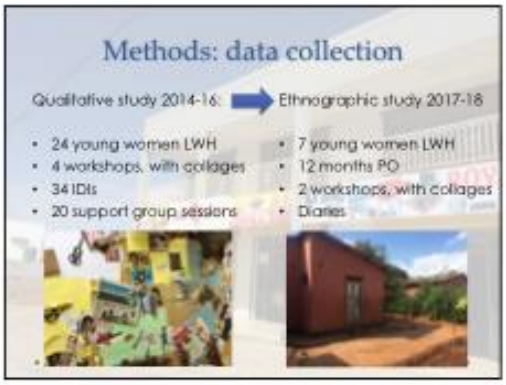
3.7 LSHTM, July 2019 – oral presentation at 'Research in Progress'

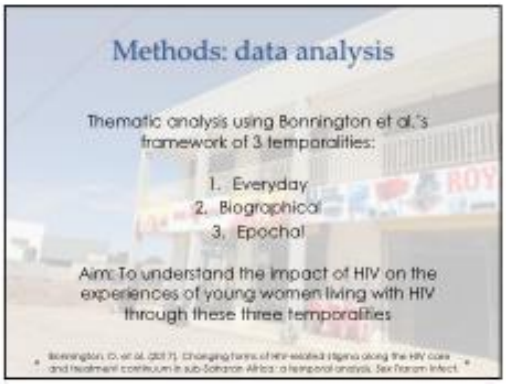
Growing up with HIV: A temporal understanding of young women's experiences of living with HIV in Lusaka, Zambia. Presentation at 'Research in Progress', London School of Hygiene and Tropical Medicine. 26th July 2019. London, United Kingdom.











Everyday time

"I didn't like having to take them every day, every day being reminded that I have this thing"

Repetitive daily pill-taking

Keeping ARVs in a secret space was: "the biggest difficulty I have"

Secrecy around ART

Biographical time

"I felt as if my heart had carried a heavy burden, finding out that I was HIV positive"

"Before I had trouble accepting my status, but, I now have so much confidence in myself"

Disclosure of HIV status

Increase in self-confidence

Experiences of loss

Future aspirations (and worries) of having children

"Becoming an orphan, a double orphan, is really worrying"

"I want to have my own family – with my husband and children" but "I worry if I'll ever get married in my state"

Epochal time

"My mother told me I contracted the virus from her... My younger sisters don't have HIV. She was taking medicines when she was pregnant with them. Since I think they now always do that for the women who are HIV positive."

"Medicine has brought good health, not being sick"

Discussion

Young women living with HIV constitute a particular 'biogeneration' (Whyte, 2014)

Links to Foucauldian notions of biopolitics (Foucault, 1997)

Support groups for young women should cover:

- Everyday challenges
- Fundamental biographical moments eg. loss
- Future aspirations for families

Thanks to:

Participants and their families for giving their time and sharing their stories

Supervisors: Dr Virginia Bond and Dr Alison Wringe

Colleagues at Zambart

Funding: ESRC